Parenting Under Pressure: The Experiences of Parents/Guardians of Autistic Children in Kerala, India

Sidharth Shankar

Submitted in accordance with
the requirements for the degree of PhD

The University of Leeds
School of Sociology and Social Policy
2022

Author’s Declaration

The candidate confirms that the work submitted is their own and that appropriate credit has been given where reference has been made to the work of others.

ACKNOWLEDGEMENTS

I owe genuine gratitude to many people whose advice and support was fundamental in completing my thesis. Firstly, I thank God for the blessings and for giving me a sense of purpose and direction. My utmost respect and appreciation go to Dr. Sharon Elley and Dr. Alison Sheldon, my supervisors at the University of Leeds. Thank you, Dr. Elley and Dr. Sheldon, for entrusting me with opportunities to better myself as a researcher and for providing the necessary feedback and inspiration to push myself further. I thank my first-year viva examiners, Dr. Lisa Buckner and Dr. Daniel Edmiston for their beneficial comments. I am also grateful to Dr. Miro Griffiths and Dr. Roxana Barbulescu for their prompt supervisory support and valuable feedback. I must express my heartfelt thanks to all the participants in my research for their time and input, which helped me develop this thesis. In particular, I reserve my deep gratitude to the parents and guardians of autistic children who spoke about their life experiences openly and treated me with trust and warmth.

Many thanks to the various organizations and individuals who believed in the relevance of my project and enabled my access to potential participants. Specifically, I must thank Mr. Madhu Pookkad, Mr. Prakashan Pookkad, Mrs. Mothi Habeeb, principal of ‘Rotary School for Special Children’, Mr. Vijayaraghavan, the honorary director of ‘Centre for Autism and other Disabilities Rehabilitation Research and Education’ (CADRRE), the staff at CADRRE, Dr. Chitra S. Nair, Mr. Mansoor, principal of ‘Asha-Kiran School for the Differently Abled’, and Mrs. Annie at ‘Sathram Autism Resource Centre’ for their sincere assistance.

To my father, G. Shankar- your guidance and conviction that I could undertake a Ph.D., even when I had doubts myself, and your financial support and emotional support have been crucial in helping me finish this doctoral thesis. Thank you acha (dad) for the timely talks and added motivation. To my mother, Sugatha Shankar- your unwavering emotional support, financial support, and tremendous love and affection has played a significant role. I thank you amma (mom) for your guidance and warmth. Thanks to my dear wife, Aishwarya- your trust, belief, and unwavering practical and emotional support has been immense, and I am ever so grateful. Thank you Aishu, for the valuable mind-mapping sessions as well. Thanks

to Aishwarya’s parents for their genuine thoughts, prayers, and emotional support. Thank you to my friends and colleagues for your loyal friendship and valuable feedback. I would like to dedicate this thesis to my Aishu (wife), my Acha (dad), and my Amma (mom) who have lived through this experience with me, never doubted my commitment, and provided constant practical, emotional and intellectual support. Lots of love….

Abstract

This Ph.D. thesis focuses on the first-hand, ground-level experiences of parents and guardians of autistic children in the State of Kerala, India. It explores the barriers faced by parents/guardians in relation to social interactions, raising an autistic child, and accessing services. Thirty-two semi-structured face-to-face interviews were conducted with parents/guardians of children (across the ‘autism spectrum’) aged ten and below, over a six-month period. All the interviews were completed before the onset of the coronavirus pandemic in India. Those who participated in the project identified with diverse socio-demographic backgrounds. The perceptions of parents/guardians enabled a comprehensive analysis of parenting experiences and the factors responsible for creating disabling barriers and disparities in terms of privilege.

Using the social relational model of disability as a tool, this thesis extended family debates and makes an original contribution by arguing that along with their autistic children, parents/guardians are disabled due to barriers arising from unequal social interactions which undermine their psycho-emotional well-being. This dissertation finds that the ‘impairment effects’ associated with the autistic child can create some restrictions in daily caregiving responsibilities. However, impairments do not constitute disability and are not the primary barriers in parenting. In order to understand the complex experiences of parents/guardians, this project has employed an intersectional approach to analyse the influence of factors including gender roles, access to resources, and caste/tribe status on parental perceptions of barriers and privilege. These concepts are rarely applied in the Indian sociological literature to comprehend the experiences of parenting autistic children, and so will provide a fresh addition to Indian sociology. Thus, by linking broad literature from disability studies and sociology with the generated data from the fieldwork that was conducted, this thesis contributes to Indian sociological literature by producing a qualitative, sociological study on the experiences of parenting autistic children in India.

TABLE OF CONTENTS

LIST OF ABBREVIATIONS

H	**Hindu**
M	**Muslim**
C	**Christian**
SC	**Scheduled Castes**
ST	**Scheduled Tribes**
OBC	**Other ‘Backward’ Classes**
GC	**General Caste**
WHO	**World Health Organization**
ICIDH	**The International Classification of Impairments, Disabilities, and Handicaps**
ICF	**The International Classification of Functioning**
UPIAS	**Union of the Physically Impaired Against Segregation**
UT	**Union Territory**
GNI	**Gross National Income**
HPI	**Human Poverty Index**
GDI	**Gender Development Index**
UN	**United Nations**
RCI	**Rehabilitation Council of India**

PWD	**Persons with Disabilities**
UNCRPD	**United Nations Convention on the Rights of Persons with Disabilities**
RPWD	**Rights of Persons with Disabilities**
CADRRE	**Centre for Autism and other Disabilities Rehabilitation Research and Education**
PDS	**Public Distribution System**
ABA	**Applied Behavioural Analysis**
MBBS	**Medicinae Baccalaureus Medicine Chirurgiae/Bachelor of Medicine**
MBA	**Master’s in Business Administration**
AYUSH	**Ayurveda, Yoga, Unani, Siddha, Homeopathy**
DSM-V	**Diagnostic and Statistical Manual of Mental Disorders**
ASD	**Autism Spectrum Disorder**
LAMIC	**Low and Middle Income Countries**
NFB	**National Federation of the Blind**
DRM	**Disability Rights Movement**
DRG	**Disability Rights Group**
IYDP	**International Year of Disabled Persons**

CHAPTER 1: INTRODUCTION TO THE THESIS

This thesis draws attention to the raw experiences, inequitable access to services, the disparity in privileges, and the exclusionary practices encountered by parents/guardians of autistic children in contemporary Indian society. It assesses the influence of factors embedded in the social fabric which may create barriers for some parents/guardians, while privileging others, and identifies the social interventions that need to be implemented in order to address their needs. Some parents/guardians of autistic children continue to be 'othered' and face oppressive barriers due to their close association with their children. The ideal hopes of parents/guardians pertain to acquiring resources that can increase the inclusive opportunities for their children. However, the passage is not always smooth, and they stumble upon different roadblocks. This thesis, therefore, aims to question the complex diversity of experiences among parents/guardians which creates disparities or differing circumstances for them. The perceptions of parents/guardians are crucial because they determine the well-being of the family and its survival.

The thesis entails a detailed exploration of parents/guardians' access to services/resources, the impact of daily social interactions on their psycho-emotional well-being, their experiences of parenting autistic children in a social environment, and the factors which create barriers for them. By incorporating socio-cultural factors and respecting the contextual situation, this thesis offers a nuanced analysis of parenting and autism in India. I intend to be reflexive and critique the different debates on autism, disability, and parenting, while connecting them to the empirical data that has been generated. I hope to contribute meaningfully to the existing sociological discourses on parental experiences and autism in the family by using the social relational model of disability and linking parents'/guardians' experiences of psycho-emotional disablism to Goffman's concept of stigmatising attitudes towards people (arising from social interactions) who are considered as the 'other', thereby bringing to light the 'disabling' barriers faced by parents and guardians in India.

Once the reasons for unequal experiences of privilege and marginalisation are explored and the recommended social interventions are implemented, they will enhance opportunities to understand the complex family experiences and enable parents/guardians' direct access to support mechanisms, thereby mitigating ‘disabling’ barriers. This thesis thus offers a contribution to wider debates about the social interactions of the family, the impact of individualised perceptions of autism, the pressures of parenting an autistic child, the uneven distribution of information and services, mutual interdependence, and the value of inclusion. To design and implement contextually appropriate interventions, the voices of people (including parents/guardians and especially mothers of autistic children) facing barriers must be heard. The researcher facilitates an improved understanding of their diverse social experiences through mutual collaboration. This study contributes to wider disability politics by placing emphasis on the voices of parents/guardians of autistic children, some of whom face oppression and experience social barriers. It is significant for autistic communities because the focus is placed on the pressures of parenting which primarily arise from unequal social interactions. Stresses stemming from impairment effects are also detailed, but these are determined to cause some restrictions, rather than being a central factor in creating disabling barriers. This thesis generates a theoretically rich and in-depth understanding of family experiences and the implementation of inclusive social interventions.

Chapter one introduces the reader to the thesis by providing the background for the study. In this chapter, I explain my personal motivation for undertaking a research study on the topic of parents/guardians of autistic children. The objectives of the thesis will be discussed and the chapter comprises a section which enhances the reader’s familiarisation with autism in India. An outline of the following chapters and an overview of what they entail will be included in this chapter. Finally, this chapter will address the use of certain terminology relevant to this thesis. The next section will begin with the background to the thesis.

Background of the Study

According to the World Health Organization (hereafter WHO), there are one billion disabled people across the globe, who form the world’s largest minority (WHO, 2020). Disability is recognized as an indicator of discrimination alongside other social factors including gender, race, class, and caste (Vaidya, 2016a). Vic Finkelstein (1981) draws attention to the historical notions of disability; according to him, disabled people have historically been associated with terms such as ‘unfortunate’ and ‘tragic’ (Swain et al., 2014, p. 6). Over the years, these prevalent notions have faced criticism and disabled people have called for political emancipation and inclusion. However, the individualised perceptions of disability (due to medical and scientific expansion), with a focus on impairments and clinical interventions for cure, have continued to persist (Barnes & Mercer, 2005). The over-emphasis of such perceptions is a major contributory factor to the continued discrimination and barriers experienced by disabled people and their families.

Erving Goffman (1963, p.3) identifies and explains the concept of stigma (based on micro-level interactions; explored further in chapter two) which occurs when an individual is 'reduced from a whole, usual person to a discounted one' in the minds of others during social interactions. According to Goffman (1963), stigma refers to the relationship between an attribute of an individual and the stereotype attached to it. A person may possess a stigma or an 'undesired differentness' which makes them 'not quite human' (Goffman, 1963, p. 5). Therefore, society may impose different types of discrimination against the person. Society constructs the individual's inferiority and the danger they represent for possessing an attribute which is considered to stand outside the social norm (Goffman, 1963). Disabled individuals are subjected to different types of discrimination because they are adjudged to possess attributes which differ from the social norm (Ali et al., 2012). Nevertheless, it is not only people with impairments who are disabled; their family members are also disabled (please refer to chapter two for more details) and endure barriers due to their connections with the individuals with impairments. Family members may be held accountable for the occurrence of an 'impairment', which in turn may subject them to the blame and abuse of others (Ali et al., 2012). Afia Ali and colleagues (2012) draw attention specifically to mothers who are blamed for the child's impairment, or any characteristics displayed by the child in public, which may fall outside the perceived socio-cultural norm. Some parents/guardians often internalise such perceptions from social interactions and experience the undermining of their psycho-emotional well-being, resulting in psycho-emotional 'disablism'.

Autistic individuals and their families have endured similar experiences. Leo Kanner has been credited with first describing the term 'autism' in 1943, followed by Hans Asperger in 1944 (Jaarsma & Welin, 2011). In the early 1990s, the eminent psychologist Lorna Wing (who was also the mother of an autistic individual) placed autism on a ‘spectrum’ and positioned Kanner’s understanding at the ‘severe’ end of the spectrum, and ‘Asperger syndrome’ at the ‘milder’ end (Runswick-Cole, 2014). Simon Baron-Cohen (2015), citing Steve Silberman (2015), draws attention to Asperger’s work with autistic children (across the ‘spectrum’), five years before Kanner’s concept became widely known. Although Silberman’s book (2015) credited Kanner with making positive contributions, which included helping Jewish refugees escape to the USA from the Holocaust, he (Kanner) infamously attributed a child’s autism to the ‘coldness’ of their parents, specifically pointing fingers at mothers (these notions were also promoted by Bruno Bettelheim). This is a major factor which has subjected some mothers of autistic children to unequal social interactions, blame and shame, thereby causing deleterious effects on the family. Sidney Kinnear and colleagues (2015) too, highlight a previous study by David Farrugia (2009) who mentioned the negative impacts of stereotypes associated with autism and parenting; the notion of ‘cold parents’ and the perceived hereditary aspect of autism increases the chances of discriminatory practices/attitudes toward parents/guardians. Some parents/guardians of autistic children can be associated with the term, ‘discreditable’- the child’s characteristics, which may generate discriminatory remarks/reactions, are not immediately visible (Gray, 2002). Rather, when people view a specific ‘behavioural pattern’ which may fall outside the norm, some are likely to place the blame on the parent/guardian. Thus, this thesis analyses the diverse experiences of parents/guardians, some of which may ‘disable’ them and create stressful barriers for them.

I took a special interest in the subject of autism because of its presence in my extended family. My father’s first cousin (who is an aunt of mine) is the mother of three autistic individuals, all three of them clinically diagnosed and categorized across the different ranges of the autism spectrum. After the diagnosis of the first child, my aunt and her husband's decision to try for more children had been questioned and ridiculed by some family members. The doctors had even ‘warned’ them about the likelihood of autism in the next child. As a child, I barely paid attention to such reactions toward them, because I did not have either the academic knowledge or the critical acumen to probe it any further. However, with time, education, and exposure to autistic individuals and their families, I began questioning the reasons for my aunt and her family's limited participation in social/family activities and their eventual disappearance from family functions. Currently, as an adult researcher, with an understanding rooted in disability studies and sociology, I can connect their contextual situation to the 'othering' practices experienced by some parents/guardians of autistic children. I can critically analyse better, the exclusionary attitudes which come to light when there is an occurrence of autism in the family, and the internalisation of shame (from social interactions), blame, and pressures experienced by some parents/guardians which undermine their psycho-emotional well-being, leading to their 'disablement'. The collective, interdependent nature of the family system is then shattered, and parents/guardians are devoid of the support they need. Thus, this thesis intends to explore and unravel parenting experiences of raising autistic children. It enhances an understanding of the challenges endured by parents/guardians in everyday life, with a view to identifying possible micro, meso and macro-level social interventions to reduce or eliminate social barriers. The next section will provide an overview of autism in India (for an in-depth analysis of perceptions of autism in Indian families, please refer to chapter three), and offer a summary of existing/prevalent autism-related research studies. It will identify the research gap and argue for the need to develop a fresh approach to sociological research on parenting autistic children in India.

An overview of autism in India

The epidemiological data on autism prevalence is limited in 'low-and middle-income countries' including India. Chetna Duggal and colleagues (2019) found autism estimates ranging from 0.15% to 1.2 % of the Indian population (the total population of India stood at 1.38 billion as of 2020), while other studies draw attention to an estimate of over 2 million autistic individuals in the country (Johansson, 2015; Singh et al., 2019). The varying accounts of existing statistics are attributed to different factors like certain limitations in diagnostic tools (to incorporate contextual or socio-cultural aspects), the uncoordinated transmission of awareness/information, and some cultural factors. Cultural beliefs such as 'boys speak later than girls', and 'bad blood' karma (parents/guardians may conceal the occurrence of autism in the family due to the perceived fear that a prospective groom or bride for the child's sibling(s) may shy away from an alliance or marriage) continue to persist. These factors influence some parents'/guardians' decision in hiding their children's diagnosis to prevent the 'devaluation' of family genes (Desai et al., 2012; Sarrett, 2015). A figure of 8 to 10 million autistic individuals in India was quoted at the South Asian Autistic Network Meeting in Delhi in 2015 (Vaidya, 2016a). Most existing autism research within the Indian literature resides primarily in clinical studies, with an overwhelming focus on diagnosis and clinical interventions (Daley, 2004; Gupta & Singhal, 2005; Kishore & Basu, 2011; Desai et al., 2012; Bashir et al., 2014; George & Sakeer, 2015; Gaur & Pandey, 2016; Das et al., 2017; Panjrath & Mishra, 2018). While these studies are important, a robust sociological study focusing on the influence of socio-cultural factors on the experiences of parents/guardians can enhance understanding of their social interactions, psycho-emotional well-being, daily caregiving roles and access to services.

Irrespective of considerable social progress over the years, sociodemographic factors including gender roles, access to resources, and identification with a particular caste/tribe may create both privilege and barriers. Therefore, drawing attention to the influence of these factors on parents'/guardians' experiences can enable a deeper analysis of the relationships within the family, and uncover levels of accessibility, the awareness of autism, and the social interactions impacting the well-being of the family. This research recognizes the existence of sociological studies in India, some of which aptly analyse the influence of certain socio-demographic factors on disability and the family, particularly in Northern India. For instance, in their respective studies, Nilika Mehrotra (2008) and Anita Ghai (2015c), have highlighted the importance of gender, access to economic resources, and identification with a caste/tribe, along with familial networks, as fundamental to the well-being of disabled members in the family system.

The aforementioned factors are all interlinked and can reinforce each other to create complex experiences. For instance, the identification with a caste/tribe may generate either privilege or regulation of economic and social life in India, especially for women. Existing research has found that the access to economic rights and social participation become more constricted in the lower half of the hierarchical ladders of the caste system and determine the opportunities to acquire resources such as land, labour, capital, credit, and education, among others

(Newman & Thorat, 2007). Nilika Mehrotra (2008) shared her concern for women in India (irrespective of caste/tribe status), who are accustomed to take their health less seriously. In particular, economic hardships experienced by some women, who are classified as 'scheduled castes' or Dalits (traditionally, they are among the most disadvantaged groups in India- in terms of education and socio-economic background) , work against their survival (Mehrotra, 2008). Disabled women in some families are married off to a disabled man, a widower, or to someone who cannot find a partner/spouse for different reasons including illiteracy, low income, and caste endogamy (Mehrotra, 2008). Zuleyha Cidav and colleagues (2012) call attention to the influence of gender roles by insisting that mothers of autistic children are less likely to work, or work fewer hours per week and earn substantially less (economically) when compared to the fathers. Thus, it is imperative to analyse the significance of social factors including gender, access to resources and caste/tribe status on the experiences of parents/guardians of autistic children.

This research on parental/guardian experiences in India is different because it recognizes that barriers not only affect individuals with impairments, but also their family members, including parents/guardians who are 'disabled' by the barriers in society (Benson & Keyes, 2014). The study will use Carol Thomas's (1999; 2004a; 2004b; 2004c) social relational model of disability (explained further in chapter two) to primarily assess the effect of unequal social interactions (which undermine the psycho-emotional well-being of parents/guardians) and 'impairment effects' (the direct effects of an impairment/restrictions caused by an impairment in the social environment). It will also link Erving Goffman's (1963) understanding of discriminatory attitudes (arising from micro-level interactions), toward parents/guardians due to their association with an autistic child and how such reactions can 'disable' the parents and adversely impact the family. An intersectional analysis is used to reveal the different levels of perceptions of parents/guardians from various socio-demographic backgrounds. Thus, this thesis adds a fresh dimension to sociological studies in India by highlighting the impact of gendered divisions in caregiving positions, unequal social interactions which undermine the psycho-emotional well-being of parents/guardians, and their experiences of raising an autistic child, inequitable access to resources, living conditions, and social mobility. Sociological research utilising the aforementioned tools has rarely been used in Indian sociological studies and therefore, this research project is timely as it addresses the sociological gap in knowledge and explores the social realities of parents/guardians. The next section provides detailed outlines for the rest of the chapters that are included in this thesis.

OUTLINE OF THE THESIS

Chapter two begins with a critical analysis of disability rights; specifically, the history of disability rights and legislations pertaining to enhancing the inclusion and participation of disabled people will be explored in this chapter. The chapter entails a detailed analysis of the United Nations Convention on the Rights of Persons with Disabilities (hereafter, UN CRPD) and its importance for disabled people and their self-advocacy efforts. The chapter also highlights the drawbacks of the UN CRPD and explains how it can help parents/guardians in eliminating barriers. Moreover, an explanation of a framework which entails and recognizes socio-cultural/contextual issues is also given. The chapter then moves onto an exploration of the prominent disability models that were developed in the United Kingdom. Specifically, the individual model will be explored first, after which the chapter will present a detailed understanding of the social model of disability. The discourses pertaining to these contrasting models are explained in depth. Then, the social relational model of disability is explained in this chapter. I explain my reasons for choosing the social relational model of disability as a tool to best understand parents'/guardians' experiences in this thesis. The chapter assesses the concept of stigma and links the social relational model with Erving Goffman's understanding of stigma, which is primarily based on micro-level interactions. These interactions may subject some parents/guardians (due to their close association with autistic children who are considered to possess attributes which deviate from the social norm) to negative reactions. Some parents/guardians may internalize the blame and shame of raising an autistic child and experience the undermining of their psycho-emotional well-being. Donna Reeve (2004) cites Carol Thomas (2007, p.73), who extends the social model to explore the social relational 'kernel' which highlights disability as the 'imposition of social restrictions on people with impairments and the socially engendered undermining of their psycho-emotional well-being'. It includes restrictions which determine what disabled people 'can do and what they can be' (p. 73). Thomas (2004a) also calls attention to the ‘impairment effects’ or the implications of impairments in a social world that is non-accommodative of people with impairments. The chapter then provides the reasons for using an intersectional framework to analyse the perceptions of parents/guardians at the intersection of socio-demographic factors. At its most basic, intersectionality is defined as a concept when different axes of power and social identities intersect with each other and are mutually constitutive- they reproduce and reinforce each other to create unequal experiences of oppression and privilege (Mukhopadhyay, 2015). The analysis of parents’ experiences of raising autistic children can foreground the complex range of perceptions.

Chapter three begins by familiarising the reader with a general understanding of the Indian geographical location, culture and economy. The chapter draws attention to disability in India; more specifically, important statistical information and the prevalent attitudes towards disability and disabled people are explored. The chapter entails an overview of the disability rights movement in India and the efforts of disabled people which led to the recognition (by the government of India) for the need to pass a comprehensive disability legislation. The chapter offers a detailed account of disability policies, disability legislation and related information which seeks to enhance the understanding of the reader. The perceptions of autism in India and the socio-cultural attitudes toward autistic individuals and their families are examined in this chapter. The chapter discusses the State of Kerala and the reasons why it was chosen as the site to conduct field work. The chapter also provides a historical and contemporary analysis in relation to the status of women in Kerala. Thus, chapter three offers an analysis of the culture in India, perceptions of autism and a broad socio-cultural context of Kerala.

The fourth chapter discusses the methodology and the related tools that were used to conduct the fieldwork for this thesis. The overarching research question and sub-questions are listed in this chapter. The chapter draws particular attention to the aim of the thesis and the epistemological and ontological basis of the thesis. The chapter addresses the reasoning behind its qualitative approach, and specifically draws attention to the need to understand people and their social lives. This approach is undertaken to fulfil the objectives of the thesis. The use of a semi-structured interview schedule and its benefits for this thesis are detailed and validated in the chapter. The reasons for choosing parents/guardians as the sample population for this study are then addressed. A purposive sampling method was used to recruit participants who were best suited to fulfil the objectives of this thesis. After sampling, the process of participant recruitment is explained step-by-step. Then, details of the fieldwork are provided in chart format to enhance the reader's understanding. The process of interviewing and the strategies that were used to ensure a smooth interview process are discussed in detail. Ethical issues encountered during fieldwork and the subsequent interventions which were implemented to overcome them are detailed in this chapter. Informed consent and confidentiality of the participants are also discussed. The chapter explains how manual coding and analysis were conducted after gathering/generating data from the fieldwork. Doing so facilitated an in-depth understanding of the factors which influenced the experiences of parents/guardians. The chapter finally discusses the strengths and limitations of this thesis. Reflexivity will be used to explain my experiences as a researcher and the challenges I faced during fieldwork.

Chapter five, which is the first empirical chapter, offers a detailed analysis of the roles occupied by parents/guardians. The chapter uses the empirical data generated from the interviews to provide an analysis of the diverse experiences of privilege and the barriers faced by parents/guardians of autistic children. The role of mothers and the pressures experienced by them when raising an autistic child are discussed. Using the social relational model of disability, the chapter explores the impact of unequal social interactions which undermine the psycho-emotional well-being of mothers and 'impairment effects' which create some restrictions for them. The chapter analyses the experiences of a grandmother, who is the primary caregiver/guardian for an autistic child. It details the impact of unequal social interactions on the mother of the child who internalized the shame of raising an autistic child. These factors have adversely affected the grandmother and her role in the child's life. The chapter moves on to explore the pressures faced by some mothers in employment and mothers with limited informal support systems. The chapter draws attention to spousal support and its impact on parenting. The chapter provides an understanding of the complex experiences of parents/guardians by exploring the impact of social interactions, stresses from raising an autistic child and the influence of cultural factors and gendered divisions of roles. The experiences of some fathers of autistic children, which is limited in sociological research, are discussed in the section. The majority of the fathers who had participated were involved in caregiving duties. The chapter thus offers an understanding of the experiences/perceptions of fathers, and the stresses they may endure during social interactions and when raising an autistic child. The limited involvement of the father of an autistic child is detailed in the chapter and the reasons for his limited involvement are explored.

The concept of stigma and its impact on the experiences/perceptions of parents/guardians are explored in chapter six. Some parents/guardians are impacted when they internalize the negative reactions towards the family. This may arise from the direct discrimination experienced by parents/guardians. Parents/guardians are also affected when they fear possible discrimination and negative reactions of others. Thus, this chapter explains ‘enacted’ stigma and ‘felt’ stigma endured by both mothers and fathers. Some parents/guardians may be blamed due to their impairment. For instance, the responses and reactions of a father with a speech impairment is explored in this chapter. The chapter also provides an analysis of the experiences of some parents/guardians who actively resist the negative reactions of others to protect their family. These parents/guardians may not only protect the child, but also the spouse against harsh reactions. The chapter discusses the experiences of some parents/guardians who imbibe low opinions of their children and consider them (the children) to be inferior. These perceptions may already add to the low self-esteem and low self-confidence held by some parents/guardians.

Chapter seven places emphasis on the influence of the health care system in maintaining and transmitting the individualised perceptions of autism which may impact adversely on the psycho-emotional well-being of some parents/guardians, thereby creating psycho-emotional disablism. The chapter discusses the link between the medical system and colonial rule in India, and specifically focuses on the impact of medical expansion in Kerala. The chapter gives attention to some parents’/guardians’ aspirations for their child to attain the standards of ‘normalcy’. When some parents/guardians perceive that the child may not progress to their desired level, which is close to ‘normalcy’, they endure disabling barriers from internalizing the shame of raising an autistic child. In an intense academic environment, like in India, comparisons may arise and the chapter offers a discussion regarding its impact on the perceptions of some parents/guardians. Self-reliance and independence are other concepts explored in this chapter; for instance, some parents/guardians value the concept of being independent and may associate dependency with inferiority. Thus, this chapter explains the impact of individualised notions on parenting autistic children.

The concluding chapter eight summarises the thesis, highlights the main discussion points, and provides an analysis/discussion on the complex experiences/perceptions of parents/guardians. The gaps are addressed/identified and micro, meso and macro-level recommendations are provided. These suggestions are made to benefit autistic individuals and their families. They are devised to ensure that significant contributions can be made to policy developments which seek to protect the interests of parents/guardians of autistic children (specifically mothers), thereby reducing the disabling barriers faced by them. The government of Kerala has traditionally initiated some important social justice initiatives (explained in chapter three) and implementing some recommendations can generate additional changes which facilitate the elimination of barriers faced by parents/guardians and their children.

TERMINOLOGY

I am aware of the different ways of addressing people with impairments, however, for this particular research, I use the term ‘disabled people’ when referring to people with impairments who are ‘disabled’ by social barriers (Clark & Marsh, 2002). Nick Watson (2012) cites the work of Carol Thomas who argued that impairments may create some restrictions of activity. However, these restrictions are not ‘disability’, rather, they are ‘impairment effects’ or the restrictions associated with an impairment (Watson, 2012). Disability, according to Thomas (1999) is social in origin. Thomas’s concept is the most useful one for this thesis; while disability refers to the social restrictions imposed on people with impairments, some may also face restrictions from an impairment. However, impairments do not cause disability.

In this thesis, I use the words, ‘autistic children’ or ‘autistic people/individuals’. Neuro-diversity, a movement developed by autistic individuals (clinically diagnosed with ‘high-functioning’ autism), is now primarily associated with the social change and citizenship rights of individuals with neurological or neuro-developmental diagnoses (Jaarsma & Welin, 2011). At its most basic, neurodiversity proponents consider ‘atypical’ development as ‘normal’ human variation. For instance, autism may be viewed as a neurological difference or variation associated with an individual and the occurrence of an impairment may not be recognized. Some ‘neurodiversity’ proponents draw attention to the term ‘autistic individuals’ rather than ‘individuals with autism’, as autism is an inseparable part of their identity (Runswick-Cole, 2014). It is argued that ‘person-first’ language separates a person from their impairment and focuses on the ‘lack of’, rather than what the individual is capable of doing in reality. Runswick-Cole (2014) further recognizes that person-first language tries to ‘normalize’ the concept by talking about people first without drawing attention to their differences that should be respected or valued. This thesis recognizes that value must be placed on the differences of individuals. However, impairments (associated with autism) which creates some restrictions for autistic individuals and their families are also recognized. Therefore, for the purpose of this study, autism will not be considered merely to be a neurological variation.

The terms ‘Other Backward Classes’ (OBC), ‘Scheduled Caste’ (SC) and ‘Scheduled Tribe’ (ST) and ‘General Caste’ (GC) are used to denote the main different caste/tribe groups, identified by the Constitution of India (The government of India, 2020, p. 25). The caste system traditionally refers to a hierarchical ladder which entails a hierarchy of social roles that remain fixed for life.

Caste is derived from the Portuguese word, ‘casta’ which means breed or race. In India, there are four varnas in the Hindu system of caste: the Brahmins or priests and doctors, Kshatriyas or warriors, Vaishyas or merchants and businessmen, and Shudras or labourers/ lower castes (Chauhan, 2008; Vaid, 2014). The first three varnas were traditionally considered as ritually ‘purer’ than the Shudras. Those who do not form part of the varnas were referred to as the ‘untouchables’ who were placed outside the hierarchical system (Vaid, 2014). The ‘untouchables’ are formed by a collection of sub-castes or ‘jatis’ and they were traditionally restricted from performing ritual activities and interacting with members of a ‘higher’ caste. The contemporary division of castes is complex due to the presence of thousands of jatis across each varna.

The Indian Constitution recognizes the following groups for its affirmative action or reservation policies. The ‘Scheduled Castes’ or SCs (which includes those formerly referred to as the ‘untouchables’), the ‘Scheduled Tribes’ or STs (who are geographically isolated) and the ‘Other Backward Classes’ (Vaid, 2014). These groups have experienced historical marginalization and disadvantage in relation to access to resources and opportunities. The SCs, STs and OBCs have access to governmental provisions in education and employment (Vaid, 2014). Reservations have been criticised by some for solidifying caste identity, while others have placed emphasis on the need for the same to overcome oppression and discrimination. There are also the ‘general castes’ and the term ‘forward caste’ has been used to represent them (Spears, 2016). ‘General caste’ is a term which is used to refer to ‘forward caste’ in the context of reservation. The ‘Forward’ caste or ‘General’ caste have traditionally experienced a higher status in Indian society than those who identify with the other castes/tribes (Sankaran et. al, 2017). Divya Vaid (2014) highlights that a universal acceptance of any one hierarchy does not exist across a region or the country. There are dominant castes across a local area/region. In addition, caste exists in other major religions in India including among Muslims and Christians (Vaid, 2014).

For this study, individuals who identify with ‘Other Backward Classes’ (OBC), ‘Scheduled Caste’ (SC) and ‘Scheduled Tribe’ (ST) are are classified as ‘backward’ (based on the government of India classification), while those who identify with the ‘general caste’ (GC) are categorized as ‘forward’ (Chauhan, 2008). However, this study recognizes that while some people who identify with the OBCs may have adequate access to economic resources, they are categorized as socially and educationally ‘backward’ (Chauhan, 2008). Those who identify with the SCs and STs are considered to be the lowest in the hierarchy and some remain restricted in terms of access to resources due to their occupational and geographic situation (Chauhan, 2008).

The term ‘developing country’ has been used to refer to a group of nations characterised by limited social development and economic measures (Khokhar & Serajuddin, 2015). The World Bank had previously used the term (for convenience in publications) to primarily refer to ‘low- and middle-income countries’. The classification of countries as ‘developed’ and ‘developing’ was based on the annual threshold level of Gross National Income (GNI) per-capita (Khokhar & Serajuddin, 2015). The usage of the term has drawn criticism as it could be interpreted as judging the development status of any nation. Emma Stone (1999) too, discusses the problematic use of the term ‘developing nations’. This can indicate a ‘ladder of development’, with some Western nations being placed on the top half of the ladder, while the rest of the world placed below them. It can suggest that those at the base of the ladder are well behind their ‘Western’ counterparts (Stone, 1999). In addition, there is a need for countries to be classified more accurately. It can be difficult to classify some low- and middle-income countries as ‘developing nations’ because of the significant differences in their GNI per capita (Khokhar & Serajuddin, 2015).

The Sustainable Development Goals (SDGs) focus on goals for the world, recognize that inequality persists and therefore place emphasis on the need for goals to be achieved by everyone. In comparison, the Millennium Development Goals (MDG) framework separated the world into ‘developing’ and ‘developed’ categories, with specific targets for each classification (Khokhar & Serajuddin, 2015). In this thesis, Stone’s terms such as ‘majority world’ (‘the Third World nations’) and ‘minority world’ (‘Industrialised West’) are used. For instance, when referring to the Indian context, I use the term, ‘majority world’. It is also argued that using the term ‘majority world’ can help reduce perceptions of geographical notions about wealth and power (Stone, 1999).

Patriarchy, according to Holly M. Hapke (2013, p.12), is ‘a set of social arrangements that privilege men, in which men as a group dominate women as a group, structurally and ideologically’. The term ‘classic patriarchy’ refers to a type of patriarchy in which men assert their dominance over women and children. Women's subordination is primarily manifested through gendered roles, and women are tasked with the responsibility of child rearing (Hapke, 2013). Hapke (2013) also explains domestic patriarchy, in which women are primarily restricted to the home, performing domestic chores, and are excluded from the public sphere. I use Holly M. Hapke’s understanding of patriarchy in my thesis.

CHAPTER 2: DISABILITY RIGHTS, MODELS OF DISABILITY, STIGMA AND THE FAMILY

INTRODUCTION

The term ‘disability’ entails varying debates about how it should be understood. History has witnessed the association of disabled people with terms such as ‘unfortunate’, ‘oppressed’, ‘useless’, ‘tragic’ and ‘incapable’ of economic contribution and social participation (Hunt & Finkelstein, 2014, p.3). Jayne Clapton and Jennifer Fitzgerald (1997) draw attention to earlier beliefs pertaining to disability where ‘bodily differences’ were deemed to be the consequence of evil spirits, the devil, witchcraft or God's displeasure. Scott Eaton (2020) insists that disability was included in the category of ‘deformity’ and ‘monstrosity’ in the ‘early modern period’. Peter Coleridge (1993) points to the understanding of disability as a punishment for ‘previous-life-misdeeds’ in most religions and cultures. He draws attention to the link between impairment and ‘possession by demons’ in Christianity and opines that such beliefs are widespread across the world. Anita Ghai (2015a) too, highlights the perceptions of disability across the world; the presence of malevolent spirits and sorcerers are associated with causing ‘sickness’ and disability. Chomba Munyi (2012) adds that the prevalent attitudes towards disabled individuals are determined by the fear of sickness and the desire to avoid ‘evil’.

Disabled people have actively resisted discrimination and were instrumental in taking the initiative (by themselves) to draw attention to their equal rights in terms of participation and access to resources. The motto of ‘Nothing about us, without us’, developed and embraced by some disabled people, influenced the disability rights movement in countries like the United Kingdom by enhancing notions of self-advocacy, citizenship rights and participation. The negative attitudes towards disabled individuals primarily stem from the lack of broad contextual understanding of impairments. The medical and scientific expansion is mainly responsible for the long-established focus on bodily impairments and medical interventions (Barnes & Mercer, 2005). Disabled people were subjected to institutionalization due to the widespread negative perceptions that they possessed ‘serious functional limitations’ (Finkelstein, 1991). However, the latter part of the 20th century (1970s onwards) witnessed a shift in the understanding of disability.

The focus turned to liberation from oppression, the empowerment of disabled people, and accepting the value of differences among people (Hughes & Paterson, 1997). Thus, the 20th century witnessed two influential, yet contrasting models, which challenged one another to shape the disability discourse, particularly in the United Kingdom. The individual model, which focused on the functional 'incapacity' of people and solutions in medical interventions was ingrained in society. This was later challenged by the social model, where the emphasis lies upon proactive social change due to the inadequate accommodations for disabled people in society (Barnes, et al., 1999). The aforementioned models will be discussed in detail in this chapter.

The term, 'stigma', developed by the Greeks, initially referred to 'bodily signs' which served as 'markers of unusualness' in a person, and was often associated with the moral status of the particular individual (Goffman, 1963). In the present day, the term (at its most basic) is applied to denote that a person is a 'disgrace'. An individual's social identity is formed when engaging in social participation. Their attributes and/or characteristics may then be converted into normative expectations. The social environment determines the characteristics of an individual; the characteristics attributed to a specific individual is their 'virtual' social identity, while those possessed by an individual in actuality refer to their 'actual' social identity (Goffman, 1963). Social interactions can determine whether an individual is adjudged to possess an 'undesirable' attribute which makes them different from others. The attitudes of individuals in society towards the person with the perceived 'undesirable' characteristics can generate 'internalised oppression'. The stigmatised individual may perceive their attribute(s) as 'defiling', and imbibe these perceptions, making them feel that they fall short of normative expectations (Goffman, 1963). Individuals in society imbibe social norms early in life; the meaning of being a member in society and not being one are recognized. Violation of social norms and the stigmatization experienced by individuals considered to veer away from such norms form a major part of Goffman's work (Birenbaum, 1992). The diagnosis of an impairment adversely impacts on some parents/guardians who are considered as the 'carriers' of 'courtesy stigma' (explored in detail later on in this chapter). However, the experience of stigma may vary depending on the type of impairment. For instance, the presence of a cognitive impairment may be more stressful for some parents/guardians in comparison to the presence of chronic illness (Birenbaum, 1992).

By focusing on the social relations which can create psycho-emotional disablism from unequal interactions, this chapter provides the researcher's understanding of disability, and the way disability is used in the thesis to understand the experiences of parents/guardians. The chapter also links disability and stigma and explains the influence of stigmatising reactions on autistic individuals and their families. I begin the chapter with a section which discusses the concept of disability rights, before moving on to the models of disability.

DISABILITY RIGHTS

According to the WHO (2011), 15% of the world's population or one billion individuals live with one form of impairment or another (Krahn, 2021). The majority of known individuals living with impairments belong to low- and middle-income (LMIC) countries. The aforementioned statistics are subject to increase; demographic shifts can result in a larger number of elderly people who may be more likely to experience the occurrence of an impairment (Krahn, 2021). Disability has primarily been considered as a clinical issue in the public setting; clinical professionals were deemed to be the experts and were tasked with the responsibility of working in the field of disability and finding cures or solutions to rectify the same (Aluas et al., 2012).

Disabled individuals have traditionally been viewed as 'deviant' and 'dependent' in some minority and majority world nations, including the United Kingdom. They were primarily portrayed in a negative light and any exclusionary practices against disabled individuals were considered to be the outcome of their individual limitations or impairments (Skarstad, 2018). Therefore, over the course of history, disabled individuals have been treated as subjects of charity. Their rights to equal social participation continue to be discounted by some in society (Harpur, 2012). However, collective mobilization by some disabled people to tackle social barriers and social injustices began in the 1960s and 1970s (including in the United Kingdom). The prevalent perception of the white, middle-class, male 'able' body and its correlation with 'normalcy' was challenged. They (disabled people) also called attention to the inappropriateness of scientific knowledge about sickness and diseases in the context of disabilities (Sabatello, 2014).

Disabled individuals have faced different types of oppression and discrimination; for instance, they have been excluded due to the practice of eugenics and institutionalization. In contemporary times, some disabled people face exclusion in relation to employment, education and social participation. Therefore, they may not be able to exercise their rights or have their rights valued in some instances. Human rights are universal when they are enjoyed by all individuals irrespective of socio-economic status, geography, disability, race or religion, among others (Bickenbach & Bickenbach, 2009). To acquire and exercise basic human rights, an individual is not required to pass an eligibility test; rather, their human qualities are considered to be enough.

Lucy Series (2020) states that the concept of 'human rights' emerged after the Second World War. The notion of human rights was incorporated in the Universal Declaration of Human Rights (hereafter, UDHR) and adopted by the United Nations in 1948. Disabled people and the barriers they faced continued to be ignored in the international arena. Series (2020) draws attention to Article Two of the UDHR to accentuate the 'invisibility' of disabled people; while the provision of the Article calls for the protection of minorities who undergo oppressive treatment, it does not explicitly mention disabled people. The European Commission of Human Rights (ECHR), 1955, a special body of the council of Europe authorized by the European Convention of Human Rights, failed to bar forced sterilisation, which resulted in the continued involuntary sterilisation of disabled people in some European countries (Series, 2020).

The shift towards recognizing disabled people as rights bearers began in the 1960s and 1970s. According to Series (2020), the UN adopted rights-based declarations (which utilized the individual model definition of disability) in 1971 (rights of the 'mentally retarded') and 1975 (rights of 'disabled persons'). The first rights-based International Act was passed with the 1975 Declaration on the Rights of Disabled Persons (Sabatello, 2014). The UN also declared 1981 as the 'International Year of Disabled Persons'; in the same year, plans were made to create global reports on disabled people and their lived experiences (Series, 2020). The UN Decade of Disabled Persons was marked from the year 1983 (Sabatello, 2014). Resulting from the UN Decade of Disabled Persons, the Standard Rules on the Equalization of Opportunities for Persons with Disabilities was adopted by the UN in 1993 (Standard Rules, n.d.). The UN Standard Rules focused on the commitment of governments to attain and enhance equalization of opportunities disabled people. The UN then adopted the 'MI principles' in 1991, which sought to protect individuals with mental illness (Series, 2020). The institutionalisation of disabled people faced an angry backlash; disability rights activists resisted and opposed their confinement to institutions. They strived for citizenship rights and improved access to social participation by highlighting the daily discrimination they faced. The disability rights movement (primarily led by individuals with impairments) was fundamental in promoting self-advocacy and the same was reflected in their motto, 'Nothing about us, without us' (Sabatello, 2014).

The first Asian and the Pacific Decade of Disabled Persons (1993 to 2002) intended to enhance awareness on the importance of devising legislation, policies and programmes that address the barriers faced by disabled people (History, n.d.). The second Asian and Pacific Decade of Disabled Persons (2003 to 2012) placed emphasis on rights-based approach to disability, reflected in legislation and policies in the region. The third and current Asian and the Pacific Decade of Disabled Persons (2013 to 2022) highlights the importance of generating data which measures the participation of disabled people in development opportunities locally and across borders (History, n.d.).

When the UN was in the process of developing binding conventions which focused on the issues of specific populations, including women (1979) and children (1989), there were calls for a disability convention. The Vienna Declaration (1993) was important for disability rights as it centred on important aspects such as interdependence, economic development, indivisibility, human rights and democracy, among others (Sabatello, 2014). International disability organizations then came together in Beijing, China, to devise strategies which could enhance the rights of disabled people and improve their access to equal participation in society. A committee was established by the UN in 2001 to assess proposals for a convention on disability and a convention was adopted by the UN on the 13th of December, 2006 (Series, 2020). Although, efforts were being made to enhance access toward social participation and eliminate discrimination or social barriers, discrimination on the basis of disability was not recognized by the European Court of Human Rights until 2009 (Series, 2020).

The UN CRPD came into force in 2008 and it offers recommendations and directions on interventions which can aid disabled people in exercising their rights (Harpur, 2012). For instance, Article One highlights an important goal of the UN CRPD which calls for the promotion, protection and access to equal human rights for all disabled people. Some rights like the right to equality, right to life and right to non-discrimination are well-established in the UN CRPD (Harpur, 2012). These rights are ensured and solidified by the UN CRPD by including rights to access buildings, public transport, rights to participate in social functions, rights to healthcare and social protection, among others. The UN CRPD also includes provisions related to implementation and monitoring schemes. Thus, the UN CRPD sought to achieve human rights for disabled people on an equal basis with non-disabled people.

The prevalent discussions on the rights of disabled people are recognized as important in the disability sector. However, these (discussions) are also considered to primarily make sense in some minority world nations or nations in the industrialised West, including the UK (Grugel & Piper, 2009). The principles of human rights developed in some minority world nations are sometimes determined to explain and give an answer to global discourses and situations pertaining to disabled people. A primary challenge arises when trying to understand and decide on what constitutes human rights; some individuals in minority world nations may possess an ingrained belief that human rights form the basic principles of a ‘developed society’ (Grugel & Piper, 2009). Developmental agendas tend to focus on macro level issues and follow the notion that ‘development’ will result in social costs; the growth of institutions was emphasised, but the role of development in relation to outcomes for the individual was not considered (Grugel & Piper, 2009). Therefore, over the years, there has been limited discussions between human rights consultants/specialists and international developmental organizations, including disability organizations. The UN CRPD has also had its share of criticisms; for instance, the lack of clarity in the UN CRPD as to who should be included under its protection is one key issue which continues to face criticism (Sabatello, 2014). It does not include a definition of disability or of ‘persons with disabilities’. The UN

CRPD highlights the need for social accommodation, but has misgivings about the practicality of the role of governments in tackling injustice experienced by disabled people. Criticism has also been levelled at the UN CRPD’s concept and applicability of ‘mainstreaming’ disability (Sabatello, 2014). Article Three of the UN CRPD places emphasis on dignity, respect for differences and individual autonomy; nonetheless, a society’s willingness to move ahead with the aforementioned concepts remains unclear (Sabatello, 2014).

Thus, the rights of disabled people continue to meet challenges and remain excluded from the agenda of some international development organizations. Structural discrimination and the prevalence of individualised notions of disability have created barriers and have hindered the equal social participation of disabled people. The human rights approach must recognize and include the interdependence between disabled individuals and their families to implement legislation which can enable their access to equal participation in social activities (Sabatello, 2014). The rights of parents/guardians are also important because of their association with disabled people. Parents/guardians too, face exclusionary practices and oppression, which may disable the family. For instance, barriers may arise during unequal social interactions; the psycho-emotional well-being of some parents/guardians of disabled individuals may be adversely affected when subjected to negative reactions. These barriers can negatively impact on their right to participate equally in social activities and access opportunities for their children. The UN CRPD recognizes the importance of the parents/guardians when it highlights the obligation of the society and state to offer protection to disabled individuals and their families to enjoy equal rights (Sabatello, 2014). However, concrete measures must be implemented to ensure that parents/guardians can access resources/services to support their children and improve their own well-being. Monitoring measures must also be taken as detailed in the UN CRPD, so that countries can follow suit and bring about an effective solution for parents/guardians which reduces social barriers and enhances their participation in social activities.

Disability has been sometimes associated with the image of wheelchairs and guide dogs, but these associations are not universal. For instance, disability can be different in cultures outside of minority world nations (Sabatello, 2014). In some cultures in India, disability can be attributed to the sins committed by individuals in their previous lives. The concept of ‘Karma’ (explored later in detail) is prevalent in some countries, including India; a person has impairments because of the sins committed in a previous life. According to Susan Reynolds Whyte and Benedicte Ingstad (1995), cultural differences in relation to disability permeate contextual-specific social and political relationships. Therefore, notions developed in some minority world nations may not be applicable in other contexts. To ensure change which can directly benefit disabled people and their parents/guardians, disability policies which seek to enhance human rights must be culturally sensitive, transparent and systematic (and ought to include monitoring processes). Disability is a concept which must be assessed and understood in geopolitical terms; for instance, there is the need to analyse historical and cultural meanings of disability in different contexts (Meekosha, 2011). Some limitations in the concept of disability in minority world nations must be acknowledged, recognized, and addressed. The knowledge of traditional/indigenous researchers must be recognized and not merely dismissed (Meekosha, 2011). Legislations which seek to enhance equal rights should incorporate traditional knowledge and socio-cultural factors to make it more clear, concrete and operational. Then these (legislations) can produce effective change according to the specific situational context. Parents/guardians need access to equal rights to participate in social activities and ensure opportunities for their children. The next section will offer a detailed analysis of the individual model of disability, which is a concept that has factored into disabled peoples' initiatives to fight for their rights.

MODELS OF DISABILITY

Individual Model of Disability

Colin Barnes (2019) suggests that perceptions of ‘impairments’ vary according to time and social context. In many cultures across the world, impairments have been (and still are) associated with sins committed in previous lives (also referred to as ‘bad karma’), evil, demons and witchcraft, which has resulted in the social exclusion of disabled people (Coleridge, 1993; Barnes, et al., 1999). Over the years, non-disabled people have engaged in charitable acts as an obligation to perform one's religious duty, which has reinforced relationships of superiority and inferiority (Hammell, 2006). In some ‘minority’ world nations like the United Kingdom, ‘disability’ was traditionally associated with an inherent individual ‘problem’. Inclusion within the community existed before the industrial revolution; however, disabled people were still subjected to experiences of oppression and discrimination (Barnes, 2019). Although the focus on ‘dependence’ and ‘independence’ has existed for many years prior to the industrial phase in the United Kingdom, industrialization gave rise to the dominant concept of ‘dependency’ which was considered ‘problematic in ways it had not been before’ (Goble, 2014, p. 32). Industrialisation, changes in work patterns, urbanization, and prevalent doctrines like medicalisation and eugenics were factors which created prejudices (Barnes, 2019). The influence of such beliefs led to further exclusionary practices, including the marginalization of disabled people from mainstream socio-economic activities. Barnes (2019) draws attention to Talcott Parsons’s (1951) assessment of the medical profession and its role; ‘good health’ is linked to ‘normalcy’ or being ‘normal’, while ‘sickness’ or ‘impairment’ is equated with social deviance. Therefore, clinical professionals are required to eliminate ‘deficits’ or impairments and bring back people as close to ‘normalcy’ as possible (Barnes, 2019). This notion has had a significant influence on the ‘management’ of disability over the years.

During the industrial period, capitalistic market forces played a role in the shift from a subsistence-based economy to a need for fast paced production, which excluded disabled people based on the perceptions that they are not ‘fit enough’ to handle complex machinery and contribute to society. In the 19th and the 20th centuries, an ‘able body’ was a necessity for workforce inclusion; in the 21st century, an ‘able mind’ was also added (Barnes, 2000). This shift paved the way for society to be established under the ideals of independence, competition and maximization of profit (Barnes et al., 1999). The pervasiveness of such ideals led to the institutionalization of disabled people and their subjection to interventions and treatments for ‘cure’, without the adequate consideration of their social experiences or need for social accommodations (Oliver, 1990). The concepts of individuality, dependence and independence differ across cultures; in some South Asian cultures (for instance, some cultures in India), decisions regarding interventions/treatments are resolved by the mutual collaboration among immediate and extended family members (Lang, 2001). Regardless of socio-cultural variations, the individual model of disability, which focuses on individual impairments and ‘normalizing’ the body with ‘corrective intervention’, has remained prevalent across the world (Beauchamp-Pryor, 2011).

The individual model has dominated understanding of disability in academia, particularly in medical and therapeutic literature (Priestley, 2010). The model assumes that individuals with impairments are unable to participate in social activities and will therefore encounter challenges adjusting to the social norm based on their body’s individual ‘limitations’ (Krcek, 2013). The surrounding social environment and cultural factors are considered to be ‘neutral’, and the overarching focus pertains to the ‘normalization’ of disabled people (Marks, 1997). Mike Oliver (1996b) identifies two central tenets of the individual model of disability: 1. The model situates the ‘problem’ within the individual and 2. The ‘problem’ is caused by the functional ‘limitations’ associated with an impairment. Thus, the individual model is also known as the ‘personal tragedy model of disability’.

According to the individual model, the term disability is associated with an inherent ‘defect’ which resides within the individual. The body is deemed ‘abnormal’ and is a target for clinical intervention, cure, and rehabilitation (Retief & Letšosa, 2018). The negative connotations placed on the concept of disability have resulted in some questionable interventions (for instance, euthanasia) carried out on disabled individuals. Some individualised terms which create negative opinions of disabled people are highlighted by Marno Retief and Rantoa Letšosa (2018); they include ‘invalid’, ‘cripple’, ‘handicapped’ and ‘retarded’. These views continue to reinforce the dualism which considers non-disabled people as ‘superior’ to disabled people (Retief & Letšosa, 2018). The increasing criticisms of the individual model resulted in the multiple incarnations of the WHO’s ‘The International Classification of Impairments, Disabilities and Handicaps’ (hereafter, ICIDH) system (which arose from the individual model; the most recent incarnation being the ‘International Classification of Functioning, Disability and Health’ (or the ICF) which attempts to deconstruct disability by acknowledging the interaction of people with their environments, recognizing impairments as ‘problems’ in bodily function, difficulties in engaging in social activities and problems in functioning at the social level (Hammell, 2006).

The medical response to an impairment may be appropriate (at times), but the same is not applicable to the social phenomenon of ‘disability’. Therefore, primarily viewing disability as ‘shortcomings’ or ‘limitations’ to be ‘cured’ can restrict understanding and pose barriers to individuals (Hammell, 2006). The authority for determining ‘treatment and cure’ is often placed on the ‘expert’ medical professionals, some of whom may reduce the decision-making capacity of disabled individuals. Colin Barnes and Geof Mercer (2010) draw attention to the traditional notion of the individual model which identifies clinical intervention and rehabilitation as solutions to ‘illness’ and disability. The social environment and its related barriers are not taken into consideration and this may affect policy reforms aimed at enhancing and securing the citizenship rights of disabled individuals. Barnes and Mercer (2010) cite Vic Finkelstein (1993a, 1993b) who points out that disabled individuals are expected to conform to social norms with the guidance of clinical professionals. Dimitris Anastasiou and James Kauffman (2013) assert the importance of individualised services by placing emphasis on individual differences which can enable access to services. They, however, recognize a contradiction that can occur when differences are emphasized; when individual differences are highlighted, it may result in unjustified discrimination. However, if they are not recognized, there is the danger of neglecting human needs, again potentially resulting in discrimination. In addition, the individual model remains linked to the economy, as it can determine a person’s eligibility for public assistance (Beauchamp-Pryor, 2011).

An overwhelming focus on the individualised understandings of disability can generate consequences which may undermine the lives of disabled people and their parents/guardians. In society, doctors are accorded the role of ‘experts’ and they possess the power to make fundamental decisions regarding the lives of disabled people (Oliver, 1996b, p.36). The individual model can create perceptions of all disabled people wanting to be ‘normalised’, without due consideration of their actual feelings and social experiences (Swain & French, 2000). The model adopts the notion of ‘normality’ and thus seeks to restore disabled people to ‘normality’ or ‘as close to ‘normality’ as possible’ (Oliver, 1996b, p. 36). The dominance of an individualised understanding of disability has witnessed the development of other clinical professions including physiotherapy, occupational therapy and speech therapy, all aimed at the restoration of disabled people toward ‘normality’ (Oliver, 1996b). The individualised notion of disability and impairment has also permeated the policies, practices and interventions in a ‘minority world’ nation like the United Kingdom. For instance, the screening, detection and abortion of ‘impaired’ foetuses may not be questioned due to the prevailing view of disability as a ‘tragedy’ that should be avoided (Swain & French, 2000). Mothers of disabled individuals are put through immense pressure to undergo screening and terminate pregnancies if an impairment is detected. Thus, the problems endured by disabled people are linked primarily to their impairment, instead of the limited accommodations, accessibility and acceptance in society (Swain & French, 2000). Disabled people therefore face expectations to become independent, normal and adjust to the norms in society (Swain & French, 2000).

Basing the understanding of disability primarily on inherent/personal ‘limitations’ which need to be rectified can ignore social barriers that may hamper the full participation and inclusion of disabled people and their families. Social experiences are important and the next section explores the origins of the social model of disability, its impact on the lives of disabled people, and how it has mobilised the disabled people’s movement (specifically in the United Kingdom).

The Social Model of Disability

Paul Hunt and Vic Finkelstein, were among the frontrunners who saw the need for a comprehensive strategy to address the oppression and discrimination faced by disabled people. Their efforts led to the establishment of The Union of the Physically Impaired Against Segregation (hereafter, UPIAS) in 1972, with the first task involving the deconstruction of the meaning of disability by separating impairment and disability- impairment refers to the loss of limb or alteration of physical, physiological and cognitive ability, while disability alludes to the oppression that is imposed on top of the impairments by a social organization which primarily caters to the needs of non-disabled people (UPIAS, 1976). Thus, social modelists like Hunt and Finkelstein helped to reformulate the concept of disability. Disability is a social construct; rather than an inherent, individual ‘limitation’, disability is created by the interaction of the biological (impairment) and the social (environment) which leads to certain restrictions for people with impairments

(Travis, 2014). As the term ‘disability’ began to be increasingly associated with forms of social oppression, it was developed into a tool and termed ‘the social model of disability’, by Mike Oliver in 1983 (Oliver & Barnes, 2010). Rhidian Hughes (2010) draws attention to Mike Oliver’s (1983) point which emphasises the need to focus on the physical and social environments that create barriers for disabled people. The social model of disability can be separated into 5 different components: 1. There is a clear distinction between impairment and disability- impairment refers to the functional ‘limitations’ of the individual (physical, mental or sensory impairment), while disability pertains to the reduced opportunities resulting from insufficient social accommodations to participate in social activities. 2. Impairment denotes physical, mental and cognitive functional ‘limitations’, whereas disability focuses on the social organization. 3. Disability is the result of social barriers, and not impairments. 4. Disability is created by capitalistic oppression which marginalizes people with impairments, and 5. Disability is not synonymous with personal ‘tragedy’ (Anastasiou & Kauffman, 2013).

The social model of disability is representative of the activism undertaken by disabled people themselves, which has in turn influenced disability politics, for instance in the United Kingdom (Terzi, 2004). The model enhanced the collaboration of diverse actors within disability politics, and laid the foundation for policy amendments and disability rights (Thomas, 1999). According to the social model, disability is created by social and economic structures; the primary aim pertains to addressing the issues of oppression and discrimination created by systemic or institutional exclusion and cultural attitudes rooted in social practices (Terzi, 2004). The social model challenges the individual model of disability by drawing attention to the marginalisation, oppression and the ‘disabling’ barriers produced by the socio-cultural institutions.

Liz Crow (1996) insists that changes in society are necessary to eliminate social barriers and disadvantages experienced by disabled people. These changes can bring about opportunities which seek to prevent prejudice and discrimination. The ‘disablement’ of an individual with an impairment shares no correlation with the body; rather, disability creates the social barriers and restrictions imposed on disabled people (Terzi, 2004). The social model is a tool which can help to analyse prevalent negative attitudes, limited access to services and support systems. The core tenet of the model suggests that it is barriers in society (rather than impairments) which 'disabled' people need to be eradicated (Hughes, 2010). The social model thus draws attention to the limitations in social accommodations for people with impairments and challenges the concepts of dominance and subordinance present in the social fabric, which privileges non-disabled people over disabled people (Lang, 2001). Vic Finkelstein, one of the proponents of the social model, argued for social accommodations and changes in the attitudes of people in the community toward disability (Anastasiou & Kauffman, 2013). The social model has contributed to the field of disability studies by enhancing the educational perspectives on inclusion.

The importance of the social model of disability cannot be understated. However, the model has faced criticism. Mike Oliver (1996a) recognizes drawbacks, albeit with the intention of arguing against them. In the social model, the dualism/separation of impairment and disability excludes the difficulties which may arise from the impairment itself, while highlighting social restrictions as the sole cause of 'disabling' individuals (Oliver, 1996a). Other drawbacks include the following: The social model may depict disabled individuals as a homogenous group, without giving consideration to the oppression faced by individuals with different types of impairments (Oliver, 1996a). Carol Thomas (1999) too, elaborates on the aforementioned point by explaining that the principles of the social model may neglect or underrepresent the needs/experiences of disabled people with certain impairments, like learning disability and autism. When the primary focus pertains to understanding and eliminating social barriers, cultural and experiential dimensions of disability can be ignored (Thomas, 1999). Thomas (1999) goes on to state her concern that the effect of impairments in the lives of some disabled people may be disregarded. Impairments may create restrictions for some disabled people. Finally, she calls attention to the insufficient consideration given to the experiences of disabled people who are influenced by socio-demographic factors like race, class and gender. Thomas (1999) highlights another argument against the social model which highlights that the tenets of the social model are primarily designed by heterosexual, Caucasian males.

The discussions which draw attention to the gaps in the social model need to be addressed. However, the importance of the social model cannot be understated. Oliver (2013), for instance, stresses its importance by insisting that the tenets of the social model have enabled disabled people to confront the dominant individual model of disability. The social model has also proved vital in developing a ‘collective disability consciousness’ which has helped to strengthen the disabled people’s movement (Oliver, 2013). Terzi (2004) cites Oliver who insists that while the social model enables an understanding of the social world it does not, however, explain the root causes of disability and social barriers. Oliver (1996a) also maintains that the social model is predominantly about the collective experiences of ‘disablement’. Thus, the social model is a tool that has been politicized to understand the social barriers faced by disabled people. Crow (1996) emphasises the need to capture the wholesale experience of disability and impairment. According to her, disability and impairment can only be fully comprehended by analysing their interactions with each other.

Among the models of disability used to understand the experiences of autistic individuals and their families, the social model is deemed to be a suitable tool. Anastasiou and Kauffman (2013), however, argue that while the social model shifts focus away from the impairments of autistic individuals, it does not provide insight into the ‘severely’ restricted communication and interaction patterns among some autistic individuals. Dan Goodley (2001) too, indicates that the tenets of the social model primarily cater to the needs of people with physical impairments, ‘While the social model of disability isn’t written exclusively for people with physical impairments, it may seem that way’ (p. 212). The understanding of disability provided by the tenets of the social model has been instrumental in politicizing disability and enhancing the rights of disabled people and their families by increasing their access to social participation, employment and education, among others. This thesis seeks to understand the impact of unequal social interactions in undermining the psycho-emotional well-being of disabled people and their parents/guardians. In addition, it looks at the pressures experienced by parents/guardians when raising an autistic child. My understanding of disability, therefore, resides in the social relational kernel which analyses social interactions between disabled and non-disabled people, some of which may undermine the psycho-emotional well-being of disabled individuals. Thus, the social relational model of disability will be explored next.

Social Relational Model of Disability

Carol Thomas (1999) identifies disability as a form of social oppression imposed by a contemporary social organization on people with impairments, which create barriers for them. According to Thomas (1999), disability is based on unequal social interactions and/or relationships. Donna Reeve (2004) too, calls attention to Thomas's social relational model which understands disability as the imposition of social restrictions on people with impairments and the socially engendered undermining of their psycho-emotional well-being. The barriers faced by disabled people determine what they can do and what they can be. Reeve (2004) identifies different agents of barriers including family members, friends and anyone who may be in contact with a disabled person. Disability is not a static concept; rather, it has historical and spatial specificity and there is the need to analyse the different forms of 'disablism' or exclusionary practices in particular contexts (Thomas, 1999). Thomas (1999) draws attention to 'impairment effects' which may be ignored by some social modelists. She insists that some restrictions are caused by physical, sensory and cognitive impairments and these impairments directly impact disabled people in their daily lives. Impairment effects are created when there is an interaction between biological and social processes and named through cultural factors. Some socially imposed restrictions affect the psychological and emotional pathways, creating psycho-emotional 'disablism'. The interaction between disability and impairment shapes the lives of disabled people.

The social relational model looks at the concept of power domination over people with impairments by those who are socially constructed as the 'non-impaired' or the 'normal'. The social relational model explores how social relationships (on a micro and macro-scale) generate two distinct groups, one where the non-disabled individuals possess significant power, and the other which sees disabled people being marked out as inferior due to their differences (Thomas, 2004c). The lives of disabled people are restricted by the actions, institutions, and social structures constructed by the non-disabled people, which reduce them (disabled individuals) to the position of 'lesser citizenship'. Thus, the social relational model stresses that disability is defined by the lived experience of the body and it is created on the basis of unequal social relationships which undermine the psycho-emotional wellbeing of people with impairments, and that disabling restrictions are imposed through social interactions (Cologon, 2016). Disability occurs through ‘barriers to doing’ (socially imposed environmental/economic barriers), ‘barriers to being’ (hurtful words, comments, or actions at an individual/institutional level which can affect an individual’s self-esteem, resulting in ‘psycho-emotional disablism’) and ‘impairment effects’, which are the physical, sensory, intellectual and emotional impacts of ‘impairments’ on an individual’s functioning in the social world (Cologon, 2016).

Thomas (2004b) maintains the importance of understanding the relationship between disablism (a term that is used to grasp the types of social exclusions faced by people with impairments) and impairment. While, the effects of an impairment may have an immediate impact on daily life, the ‘centrality’ of disablism is prioritised (Thomas, 2014, p.14). Thomas (2004a) points to the interaction between impairment effects and disablism with the social reality that in turn creates them both and gives meaning to them. She asserts the need for a ‘social model of impairment’ where the medical professionals should not be given full responsibility over the concept of impairment, nor solely associate a biological difference with a socio-cultural construct. A framework that recognizes the ‘social dimensions of the biological’ and the ‘biological dimensions of the social’ is required to understand disability (Thomas, 2014, p.14). This approach can turn attention to social interactions (between disabled and non-disabled people) and its impact on familial relationships, community-based interactions, and in encounters with health, welfare and education services. It draws attention to power, the decisions made and the meanings of social interactions in close networks of relationships. The ‘disabling’ barriers arise from such interactions and have an impact on some disabled individuals' sense of self, identity, self-esteem, and existential security (Thomas, 2004a).

Thomas (1999) explains that ‘psycho-emotional pathways’ must be explored to enhance the understanding of disability. Social barriers are both external (for instance barriers which restrict access to employability) and internal (barriers which affect the inner mind). The negative attitudes, cultural representations and images can generate ‘internalised oppression’ among some disabled people; they imbibe and accept others’ attitudes toward them. When these reactions are internalised during social interactions, disabled people tend to feel worthless, doubt themselves, feel hopeless and hurt, and they become the ‘slave of their archetypes’ (Thomas, 1999). The psycho-emotional restrictions are thus social in origin, triggered by and sustained through social interactions. Stereotypes and colloquial language (for example, ‘out of your mind’, ‘idiot’, ‘lame’) reinforce notions of disabled people as ‘lesser humans’ (Thomas, 1999). While some people may fight against negative reactions, others may imbibe the oppression and comply with assuming the ‘disabled role’ in society. Psycho-emotional disablism also interacts with systemic oppression; for instance, disabled people face restrictions in terms of employment opportunities. Those who internalise the discrimination may not apply for jobs, believing that they do not have a chance. The psycho-emotional ‘disablism’ experienced by disabled people is part and parcel of disablism, and should not be placed in the realm of ‘personal’ or ‘private’ trouble (Thomas, 1999).

This research adopts elements from Thomas’s social relational model of disability. This thesis is based on my understanding of disability, and it analyses the psycho-emotional barriers which arise primarily from unequal micro-level social interactions between disabled and non-disabled people. These social interactions can undermine the psycho-emotional well-being of disabled people and their parents/guardians, who are themselves consequently disabled. Aside from unequal social interactions, parents/guardians are also impacted by some impairments associated with autism; for instance, some parents/guardians may face restrictions from raising an autistic child on a daily basis. These restrictions may arise from the child’s impairments. In some socio-cultural contexts, a child with a speech impairment (who may face restrictions in communicating their needs and may ‘lash out’ from frustration) and their parents/guardians may be subjected to negative reactions from the family and society. Micro-level social relationships are the first part of social interactions and they determine the disabling impacts on disabled people and their families. Once the negative attitudes/reactions from interactions are internalised, it can lead to deleterious consequences, thereby disabling individuals from what they can be and what they can do. Therefore, this thesis adopts the social relational model to understand micro-level experiences of parents/guardians which can create disabling barriers for them. It also recognizes that parents/guardians may be impacted by restrictions arising from the child’s impairment. The efforts taken by parents/guardians to resist experiences of stigmatization and enhance participation of their children in social activities will also be explored in the empirical chapters. As the project primarily focuses on the impact of negative micro-level experiences, there is a need to link the concepts of stigma and disability. The next section thus entails an exploration of stigma and examines how it ties to the social relational model of disability, which is used as the primary tool to derive parent/guardian experiences for this thesis.

STIGMA: AN INTRODUCTION

Erving Goffman's (1963) work is credited with generating the contemporary discourses on stigma and it has led to the proliferation of research in the field (Major & O' Brien, 2005). According to Goffman (1963), stigma refers to the negative judgements that damage an individual's identity or trait(s), in particular where the identity or trait(s) falls outside the social norm. Graham Scambler (2020) draws attention to Goffman's division of stigma into three different types: 1. Physical 'deformities' or physical impairment, 2. 'Blemishes in individual character' or cognitive impairment (including 'mental disorder' and autism), and 3. 'Tribal stigma', which is associated with race and culture, and passed on from one generation to another. Goffman (1963, p.3) asserts that stigma occurs when an individual is considered to possess an attribute which makes them 'less desirable' and therefore, the particular individual is reduced from a 'whole person' to a 'discounted one'. However, not all 'undesirable' characteristics are deemed to be problematic, only those that do not conform to the stereotype of 'what an individual should be in society' (Goffman, 1963, p. 3). These stereotypes lay the foundation for excluding some people from society (Major & O' Brien, 2005).

Sara Green and colleagues (2005) draw attention to stigma as a concept that is not merely a trait of an individual, but lies in the interactions between the stigmatised person and those who analyse the 'negative differences' of the person. Thomas LeBel (2008) cites Leary and Schreindorfer (1998, p. 20) who place emphasis on the perceived violation of social norms as a factor which stigmatises and excludes individuals. Farrugia (2009) highlights the different types of stigma (based on social interactions) as described by Goffman (1963). 'Enacted stigma' refers to the overt discrimination against stigmatised individuals and their families, while 'felt stigma' is the fear of possible overt discrimination, thereby generating feelings of shame and embarrassment (Farrugia, 2009). Scambler (2020) calls attention to ‘project stigma’, which refers to the active resistance of stigmatised individuals against experiences of discrimination, oppression, blame and shame. The concept of ‘territorial stigma’ has also been identified by Scambler (2020). Territorial stigma refers to places which are marked by shame- those who enter such places are blamed and shamed for creating their own distressing situation; for instance, parents taking their child to an organization which provides autism-related services. LeBel (2008) also draws attention to the division of stigma by Falk (2001) into: 1. ‘existential stigma’ or stigma that is out of the concerned individual’s control (for instance, stigma created by impairment, ‘mental illness’ and old age) and 2. ‘achieved stigma’ where a person is stigmatised due to their ‘conduct’ (prisoners, homeless individuals). Although most research primarily focuses on one stigma at a given time (Lebel (2008), some individuals identify with different stigmatised groups. Scambler (2009) states that the concept of ‘normal’ cannot exist without the notion of ‘abnormality’ and therefore, the ‘stigmatised’ and the ‘non-stigmatised’ are products of the same norm.

Although influential, Goffman’s understanding of stigma has invited criticism; Farrugia (2009) has highlighted the ‘structural power relationships’, alongside stigma based on micro-level interactions. Mark Hatzenbuehler and Bruce Link (2014) insist that stigma-related research has primarily focused on micro-level individual perceptions and interactions. They stress the need for more research on structural stigma which analyses cultural norms and institutional policies that may restrict opportunities and access to resources. Scambler (2020) too, points to the need to understand stigma along micro, meso and macro level processes/interactions. Stigma can be conceptualised in terms of ‘power and domination’ to enable an understanding of ‘the structures, mechanisms, and justifications of power to function’ (Tyler & Slater, 2018, p. 732). Thus, stigmatisation is a form of government which generates and reproduces inequalities. The discrimination experienced by stigmatised individuals (including disabled people and their families) is not only based on individual interactions, but also on the structural or institutional barriers in the social environment (Scambler, 2020). Social, political and economic power are employed to create the experiences of stigma at the intersection of culture, power and difference. Consequently, this will lead to systemic exclusion; for instance, appropriate legislations or actions may not be approved or implemented by the government due to perceptions that disabled people are stigmatised because of their inherent ‘limitations’ (Scambler, 2020). Thus, stigma refers to the social processes which reproduces structural power relationships and thereby excludes stigmatised individuals from the social world.

Irrespective of the criticisms, Goffman is crucial in reconstructing disability by basing the concept (disability) on social prejudice, rather than on individual impairments (Susman, 1994). This study utilizes Goffman’s concept of stigma primarily generated from micro-level social interactions to understand the stigmatising experiences that ‘disable’ the parents/guardians. Therefore, the next section focuses on the influence of stigma on disability and the family. It links the concept of stigma and the social relational model of disability which can enhance the understanding of disabling barriers experienced by the family.

Disability, family and the impact of stigma

Parents/guardians confront a life-changing situation when there is an occurrence of impairment in the family. Some adjust emotionally and intellectually to a child’s clinical diagnosis and seek to better understand the support systems in place for them (Russell, 2003). Parents/guardians may undergo stresses relating to the care-giving needs of their child, and also face stigmatising experiences which can undermine their psycho-emotional well-being. Some parents/guardians endure low feelings of well-being in comparison to parents/guardians of non-disabled children (Sloper & Beresford, 2006). In addition to some restrictions which may arise from impairments associated with the child, social barriers, unmet service needs, limited formal and informal social support systems all factor into their experiences. The involvement of parents/guardians in employment can restrict their interaction with the child. Financial constraints may also arise when parents face difficulties in juggling both caregiving obligations and employment duties (Sloper & Beresford, 2006).

In the family, the lives of non-disabled siblings may also be affected; some non-disabled siblings may experience difficulty when experiencing dual realities (Stalker & Connors, 2004). For instance, on the one hand, they experience a world based on standards of ‘normalcy’, where some may show intolerance towards disabilities and differences. At home (in some instances), impairments may be accepted and necessary accommodations may be provided for the disabled child (Stalker & Connors, 2004). Some non-disabled siblings may continue to remain active (in adult life) in the lives of their disabled sibling due to a close bond shared between siblings and a sense of obligation on the side of the non-disabled sibling (Dew et al., 2013). Some non-disabled siblings may experience reduced attention from parents/guardians. Parents/guardians may be busy taking the disabled child for therapy and other related services. This may create resentment among some non-disabled siblings towards their disabled siblings and the parents/guardians (Guse & Harvey, 2010). Some may face restrictions upon participation in certain social activities deemed by parents/guardians to be unsuitable for the family. Non-disabled siblings may also be affected by stigmatising reactions toward them due to their association with the disabled sibling.

In Indian society, sibling relationship is associated with the cultural image of an 'ideal social bond' (Vaidya, 2016a, p. 114). In some instances, an older sibling may be placed with the responsibility of taking care of the younger one until parents return home. Non-disabled siblings may notice that their disabled sibling is 'different' during social interactions with others (Vaidya, 2016a). When parents focus on meeting the needs of the disabled sibling, non-disabled siblings may feel jealous. In other instances, they may feel a sense of protectiveness toward the disabled sibling. Sisters were primarily given the onus of caregiving responsibilities while brothers had to 'think' about the prospect of future responsibilities (Vaidya, 2016a). The shame of being associated with a disabled sibling prevented some from opening up about their lives to peers. Guidance from a clinical professional could only be sought by those who had access to adequate resources. In some cultures in India, where arranged marriages continue to form a big part of the norm, an alliance between two families can be adversely affected when the non-disabled sibling and/or parents/guardians are associated with the disabled sibling. Some people may subject them to stigmatising reactions by drawing attention to the 'bad blood' of the family and parental incompetence (explained in further detail later on). Thus, family members (especially parents/guardians) are affected by their association with the disabled child or member.

Mavis Dako-Gyeke (2018) calls attention to the concept of 'courtesy stigma' or the experiences of stigma by an individual due to their interlinks with a stigmatised individual. Stigmatising reactions are directed not only towards disabled individuals, but also towards anyone who is closely associated with the individual (Werner & Shulman, 2014). For instance, family members, especially parents/guardians, endure stigmatising reactions due to their close relations with the stigmatised individuals (Dako-Gyeke, 2018). Family members are subjected to the negative attitudes and responses of people in society (Werner & Schulman, 2014). Parents/guardians are affected by stigma due to their interpersonal links with the disabled individual and it often leads to a 'spoiled social identity' (Farrugia, 2009). Ara Francis (2012) refers to the works of Scambler and Hopkins (1986), Gray (2002) and Green and colleagues (2005), all of whom place emphasis on the 'felt' (perceptions of possible discrimination they may endure) and 'enacted' (the direct discrimination faced by parents/guardians in social interaction) stigma faced by parents/guardians of disabled children.

Clinical facilities and biomedical knowledge provide tools to measure the development of a child based on the social norm. A child is measured in different stages and this has created the dichotomy of the 'normal' and 'deviant' child (Priestley, 2010). 'Normalcy' has resulted in standardized timetables and sequences which are used to compare children and assess their growth/development. Rigorous assessments and evaluations have generated discourses on child health; a child's 'failure to thrive' or a 'delay' is considered as the primary basis for identifying clinical interventions (Priestley, 2010, p. 65). Disabled children are exposed to assessments which may deem them to be inferior and imperfect against 'normative yardsticks'. They are then targeted by clinical interventions, interventions for cure and institutions. In Indian society, where academic and professional achievement continues to hold prime importance, the competence of parents/guardians is questioned. Parents/guardians face blame and shame when their children do not fall within the 'normative yardstick'. Mothers in particular experience disabling barriers arising from unequal social interactions which undermine their psycho-emotional well-being. The onus of caregiving responsibility is placed on mothers and they are subjected to negative reactions from their own family members (including husbands) when the child's development does not follow the normative standards set by society.

Parents/guardians of disabled children may experience courtesy stigma as a result of the child’s impairment, which may lead to parents/guardians avoiding social interaction (Song et al., 2018). Research has found that parents/guardians of disabled children experience increased discrimination and its subsequent consequences including mental health problems, depression, lower psycho-emotional well-being and daily mood problems, when compared to parents/guardians of non-disabled children (Song et al., 2018). Parents/guardians of autistic children too, face stigmatising reactions; Kevin Chan and Donald Leung (2020) highlight the blame faced by some parents/guardians of autistic children who are held responsible for their child’s autism diagnosis. Hereditary transmission of autism and ‘bad’ parenting (for not controlling or disciplining their children) are factors which are attributed to parents/guardians. These negative reactions can affect the psycho-emotional well-being of parents/guardians. Alexie Hays and Maria Butauski (2017) too, add that parents/guardians of autistic children face complex experiences of stigma due to the ‘invisibility’ of autistic characteristics among some individuals. Goffman (1963, p. 17) brings attention to ‘discredited’ and ‘discreditable’ stigma; when the stigma is visible, it is referred to as discredited stigma. Stigma is termed discreditable when it is inconspicuous or not visible- some people may be able to pass as ‘normal’. Some parents/guardians of autistic children may fall under those who are categorized as ‘discreditable’ due to the lack of physical manifestations of autism among some individuals. Thus, stigma is an influential factor with regards to disability and parental experiences.

There are various factors which affect the daily living experiences of disabled children and their parents/guardians. These factors can influence the intensity or type of stigma faced by them. Factors like social background, poverty, and access to resources affect the lives of disabled children and the family. For instance, some disabled children and their parents/guardians can be adversely affected if they live in areas characterised by social deprivation (Watson, 2012). Access to diagnosis may not be straightforward and the lack of adequate access to resources can increase structural barriers/stigma faced by them. Impairments may also influence the social participation of children and families; some impairments may create restrictions and in some social functions, social accommodations may not be available (Watson, 2012).

This study utilises Erving Goffman's concept of stigma and locates disability at the micro-level social interactions between disabled and non-disabled people. The notion of 'courtesy stigma' and parents'/guardians' links to a disabled child can expose them to stigmatising reactions of society which may arise from daily social interactions. These reactions can be debilitating and 'disabling', thereby creating barriers in their social lives. Parents'/Guardians' daily interactions and the internalisation of perceived and direct discrimination by them are explored to understand the social barriers they face. This goes in line with the elements of the social relational model of disability which associates disability with unequal micro-level social interactions which may undermine the psycho-emotional well-being of parents/guardians and generate 'psycho-emotional disablism'. The 'discreditable' attribute attached to some autistic individuals may subject the parents/guardians to negative reactions from the public, as when a child displays certain characteristics associated with autism. Parents/guardians are disabled by certain interactions with family and society, where they are held responsible for the child's impairment. This thesis recognizes the fact that parents/guardians are also likely to face pressures in relation to daily caregiving; for instance, some restrictions which may arise from the impairments associated with autism can be stressful for parents/guardians. The challenges pertaining to the lack of acceptance of autism and the limited accommodations/support systems for some parents/guardians can lead to reduced social participation of the family in social activities. The internalisation of negative reactions can create deleterious social barriers for the family, and they are further explored in the empirical sections. The next section provides a critique of intersectionality and its utility for this thesis.

INTERSECTIONAL ANALYSIS

This study uses an intersectional framework to understand the experiences and perceptions of parents/guardians of autistic children, located at the intersection of social factors like gender, access to resources and caste/tribe identity. The term intersectionality was used and solidified by Kimberle Crenshaw in the 1970s, to draw attention to the interplay or intersection of race and gender, on the experiences of 'black' or minority women in relation to employment and violence (Björnsdóttir & Traustadóttir, 2010). Intersectionality originated from 'black' feminist traditions and 'Third World' liberation movements, even though much credit has been placed upon the field of gender studies in the ‘Global North’ (Salem, 2016). Floya Anthias (2012) mentions that intersectionality does not refer to one particular approach; rather, it focuses on a range of approaches which seek to understand the boundaries and social hierarchies in life. Alongside Crenshaw, Patricia Hill Collins is also recognized for her contribution to intersectionality. Together with Crenshaw, Hill Collins was responsible for providing the impetus to the concept of intersectionality by emphasizing its political standpoint. For instance, Hill Collins uses the ‘matrix of domination’ which highlights the interlocking oppressions across social, economic and political arenas, which reinforce each other to bring about injustice (Anthias, 2012). In addition, she linked the concept to gender, race and class. This played a pivotal role in drawing attention to the discrimination endured by ‘racialised’ women who are subjected to intersectional ‘invisibility’.

Crenshaw sought to understand the power dynamics that marginalized the rights of African-American women (Alexander-Floyd, 2012). She used intersectionality to challenge the law’s alleged colour-blindness and neutrality (Nash, 2008). A legal scholar by profession, Crenshaw, via legal discourses, called attention to the experiences of ‘multiply marginalized’ women which took precedence over a ‘single-axis’ framework that analysed race and gender separately (Anthias, 2012). By rejecting a single axis framework, the concept is aimed at understanding how race and gender (for example) can intersect and reinforce privilege and discrimination (Nash, 2008). Thus, the intersectional analysis brings forward the experiences of individuals who may face different types of marginalization and whose interests have been largely ignored by feminist and anti-racist movements.

Anthias (2012) underlines the forms of intersectionality deconstructed by Crenshaw: 1. Structural intersectionality, which refers to the embedded inequalities that determine ‘black’ women’s experiences of racism and sexism- for instance, when they are subjected to domestic abuse, only the issue of physical ‘abuse’ is addressed (Anthias, 2012). However, there is a need to understand how the cycle of abuse can be eliminated by tackling poverty and unemployment, among other factors. 2. Political intersectionality, that is evidenced by the persistence of anti-racist and feminist groups to fight racism or sexism using a single-axis approach, without considering the interplay of racism and sexism in the lives of ‘black’ women, and 3. Representational intersectionality, when representations are meant to highlight the characteristics of an entire group of individuals (Anthias, 2012).

An intersectional framework enhances an understanding of the different ways in which multiple identities combine to create unique barriers, and how people may be discriminated against as a combination of their identification with different social factors (Stienstra, 2012, p. 458). People who face experiences at the intersection of multiple identities can be relegated or constructed as ‘nobodies’ and ‘non-citizens’ by the social establishments designed to protect and empower them (Erevelles & Minear, 2011). Thus, intersectionality is used to analyse and understand not only a multitude of oppressions, but also the ‘multiplicative relationships among them as well’ (Strand, 2017). Each form of oppression intensifies the other, and affects the cumulative experience of a group. However, feminist scholars (including Deborah King) have maintained that oppression is not additive, but intersecting and it can be referred to as ‘multiple’ jeopardy.

Intersectionality is concerned with the questions of power and inequities (including disparity in terms of privileges) faced by people. The concept is based on five tenets: 1. Intersectionality holds a commitment towards social justice 2. It recognizes that privilege and marginalization can exist and co-exist within, among and between groups 3. Intersectionality entails an understanding of social identity categories and power systems which shift over time 4. It involves a dedication to anti-essentialism and variation within categories and 5. Intersectionality is based on an investment in the multiplicative nature of identities (Strand, 2017). The intersectional framework has the potential to analyse micro, meso and macro-level experiences at the intersections of varied social factors, thereby bringing forth the individual experiences and systemic oppression endured by people. A singular identity may pay attention to only one factor as the base of all experiences- it is expected to explain all the life experiences of one group. Therefore, intersectionality is a feasible analytical framework which assesses experiences across multiple differences. So, rather than looking at gender, access to resources and caste as individual or separate components, intersectionality analyses how the aforementioned factors work together to produce privilege and oppression (Erevelles & Minear, 2011).

Nikol Alexander-Floyd (2012) insists that intersectionality has become a buzzword devoid of much substance or history. Crenshaw had mentioned her use of the term ‘intersectionality’ as a metaphor and had expressed her surprise at how the concept had become a ‘buzzword’ (Salem, 2016). It is argued that intersectionality is now primarily associated with diversity, rather than with the radical erasure of inequalities (Anthias, 2012). According to Alexander-Floyd (2012), Crenshaw’s work can be utilised as an ‘ideograph’- a method that analyses broader notions of oppression and power which constrains the lives of ‘black’ women. The dynamics of power, social structure, class and political economy have been ignored in some studies (Anthias, 2012). Therefore, there is a need to analyse the dynamics of inequality and violence through the institutions where power and economic interests are exercised, and not solely at the intersections of gender, race and other social factors (Anthias, 2012).

Although there are doubts about the methodology that can be used to understand the complex experiences of individuals who face multiple marginalization, Jennifer Nash (2008) draws attention to Leslie McCall’s intersectional methodological framework which can be divided into the following: 1. Anti-categorical approach- this approach rejects categories and stresses that categories like race and gender are too complex to provide an understanding of lived experiences, 2. The intra-categorical approach seeks to describe the lived experiences of ‘multiply marginalized’ individuals within groups, and 3. The inter-categorical approach examines the differences among social groups across multiple conflicting dimensions (Nash, 2008). Crenshaw had also identified further issues stemming from the ‘universalizing tendency’ and the ‘bait and switch’ strategy of intersectionality (Anthias, 2012). The universalizing tendency occurs when it is understood that a problem goes beyond ‘black’ or multiply marginalized women and encompasses the plight of ‘all women’. This notion ultimately highlights the plight of white women and not ‘black’ women. The ‘bait and switch’ outlook occurs when the focus is on the issues of black women, albeit to only make visible the problems faced by white women (Anthias, 2012). Thus, a conception of identity that recognizes the ways by which power and inferiority work in intersecting ways to create an individual’s experiential social reality is crucial (Nash, 2008). While intersectionality aims at describing the multiple marginalization and privilege faced by individuals, it ignores detailed explanation of the ways in which privilege and oppression intersect and reinforce each other to create complex experiences. By embracing privilege and oppression as complex and simultaneous, the intersectionality concept can enhance the understanding of both identity and oppression (Nash, 2008).

Disability is an under-explored category in intersectional studies, and the experiences of disabled people and their parents/guardians can be understood by using intersectionality which can highlight their experiences of privilege and marginalization (Strand, 2017). Thus, analysing disability using an intersectional framework can enable understandings of complexities in the experiences of people and accomplish the task of mediating multiple differences. Additionally, Saxe (2017) insists that an intersectional approach can help to analyse the experiences across the autism spectrum at the intersection of multiple different identities. Although still an emerging notion, situating autism at the intersection of different identities can help to challenge the individual model approach and highlight the social structures that perpetuate inequality (Saxe, 2017). Thus, this study entails an intersectional analysis which focuses on the experiences of privilege and marginalization faced by parents/guardians. It explores why some parents/guardians may have more privilege, while others face a cycle of disabling barriers.

SUMMARY

This chapter began by providing detailed discussions on the history of global disability rights, the individual model and the social model of disability. The disability rights movement was fundamental in enhancing self-advocacy among disabled people and in improving their access to social activities. Disabled people actively developed and implemented the CRPD, which was adopted by the UN. The tenets of the CRPD were based on the motto: ‘Nothing about us, without us’. The section then explained the two differing models which dominated disability discourses in the United Kingdom in the 1970s. The individual model focuses on inherent impairments and biological ‘limitations’ of individuals, while the social model highlights the need for social accommodations and the elimination of social barriers. I elaborate on my understanding of disability which is based on the social relational model of disability. Disability is created during unequal social interactions which undermine the psycho-emotional well-being of disabled individuals and their parents/guardians, resulting in psycho-emotional disablism. The restrictions caused by impairment effects are discussed; however, it is acknowledged that disability is social in origin. Erving Goffman’s concept of stigmatising reactions arising from social interactions is linked to the social relational model to explain the ‘disabling’ barriers faced by parents/guardians of autistic children. Parents are affected by ‘courtesy stigma’, and subjected to stigmatising reactions, which in turn increases their proneness to internalised oppression. When they imbibe the negative reactions of others, parents’/guardians’ psycho-emotional well-being is adversely affected, leading to potential dire consequences. Thus, this thesis is an exploration of the pressures experienced by parents/guardians of autistic children, the barriers they face, and the inequitable access to resources. The next chapter looks at India, Indian culture and perceptions of disability and autism in India.

CHAPTER 3: INDIA AND KERALA CONTEXT

INTRODUCTION

This chapter explores the history, culture and economy in India. Statistical information pertaining to the number of states, total population, literacy rates, prevalent religions and GDP are provided. Geographical divisions are detailed and the cultural history is explained. The aforementioned information is provided to enhance the reader's understanding of the Indian context and the influences of socio-cultural factors on parental experiences of raising an autistic child in India. India is a country with varied socio-cultural influences across the different states and an overview is provided to better understand the complexity of experiences of parents/guardians. The chapter delves into disability in India, the socio-cultural notions of disability and existing perceptions. The diversity of socio-cultural factors can enhance the nuanced analysis of parental experiences in a multicultural society. The chapter provides a detailed overview of the disability rights movement in India and then gives a detailed assessment of disability legislation that seeks to protect the rights of disabled people. The information regarding the existing legislations highlights the Indian government's efforts in recognizing disability rights, while also pointing to the need for additional policies that can address the direct needs of parents/guardians. The concept of autism is primarily rooted in clinical understanding; however, some parents/guardians access alternative modes of interventions with the hope of eliminating characteristics pertaining to autism. The socio-cultural perceptions of parents/guardians in existing literature are highlighted to enhance the understanding of the reader. Finally, the chapter underlines the reasons for the study to be centred on the State of Kerala. Irrespective of social development initiatives that have occurred in Kerala, gendered divisions of labour and patriarchal notions of family roles (among other factors) have influenced the lives of parents/guardians. An exploration of the reasons for choosing the State of Kerala as a field study is necessary to understand the validity of this thesis. Thus, this chapter intends to familiarise the reader with disability and autism in India and explains the reasons for basing the research for this thesis in Kerala.

INDIA: GENERAL INFORMATION, CULTURE AND ECONOMY

India became an independent nation on the midnight of August 15, 1947. It is the seventh largest country in the world, covering an area of 32,87,263 sq. km (12,69,346 sq. mi). The Indian peninsula is separated from mainland Asia by the Himalayas; it is surrounded by the Bay of Bengal in the East, the Arabian Sea in the West, and the Indian Ocean to the South. India is neighboured by countries such as Afghanistan and Pakistan to the North-West, China, Bhutan and Nepal to the North, and Myanmar and Bangladesh to the East. Sri Lanka is separated from India by a narrow channel formed by Palk Strait and the Gulf of Mannar. The country is divided into four regions: the great mountain zone, plains of the Ganga and the Indus, the desert region, and the southern peninsula (National Portal of India, n.d.). India, being a union of states, is a sovereign, secular, democratic republic with a parliamentary system of government, where the President is the constitutional head of executive of the union. Each state has a nominal head or a governor as well as a chief minister, along with a council of ministers elected by the government. Altogether, there are twenty-nine states and seven union territories (UT) in the country, with each State/UT having its own unique demography, history, culture, dress, festivals and language, among others. These factors make India, socially and culturally, one of the most diverse countries in the world.

Rana Haq and colleagues (2020) observe that the 1950 Indian Constitution placed emphasis on being a secular nation based on equality for all. They argue discrimination/oppression based on caste was abolished and reservations in education and employment were formalized. However, some minorities continued to face discrimination and violence in their daily lives. Communal divide between Hindus (the largest majority) and Muslims (the largest minority) have resulted in violence and displacement of many. In addition, discrimination against marginalized groups including SCs, STs, and Muslim women have increased. The introduction of the Citizenship Amendment Act (CAA) and the National Register of Citizens (NRC) have resulted in protests and violence. For instance, Muslims who remained in India after its partition in 1947, are at risk due to these regulations which require them to prove their citizenship or face extradition. Furthermore, the resentment of minorities like Muslims has witnessed an increase in fake news published in some right-wing websites which draw attention to a ‘Muslim takeover’ in India by 2050. These historical and contemporary factors make India an intriguing setting to explore the experiences of parents/guardians coming from varied backgrounds in relation to privilege and marginalization.

Partha Majumder & Analabha Basu (2014) add that the Indian population belong to a diverse set of cultures and language groups. The Constitution of India has identified twenty-two different languages, of which Hindi is recognized as the official language. India is also characterised by different cuisines and festivals celebrated across the nation. People dress in varied styles and follow different religions (National Portal of India, n.d.). Doranne Jacobson (2004) calls attention to the hierarchical nature of Indian society; individuals are ranked according to their qualities. The notions of equality are not present in the daily lives of some people, even though India is the largest democracy in the world. Social hierarchy is based on caste/tribe groups and also organised in terms of wealth and power (Jacobson, 2004). Hierarchy can exist within a family environment as well; in some families, men assume the role of the ‘head’ of the family- any decision(s) may be carried out only after conferring with them. Arpita Khare (2011) highlights social acceptability as a crucial component in Indian society. The individual achievements of people are viewed in terms of the family and social achievements. Thus, the individual and society are interlinked- the individual’s identity cannot be separated from the group (Khare, 2011). Indian society is primarily based on social interdependence; for instance, there is emotional interdependence between family members and people are involved with each other. Some young individuals are dependent on their parents to find them a suitable bride or husband. The joint family system is common and remains a significant social force, even in current times, when nuclear families are also on the rise (Jacobson, 2004).

The population of India, based on the 2011 Census (the last available one), stood at 1.21 billion (according to Agarwal (2020), the figure is estimated to reach 1.36 billion in 2021), where 623.7 million are males and 586.4 million are females. The disparity in the sex ratio can be attributed to diverse socio-economic, cultural and historical factors; for instance, an increasing number of girl children experience discrimination more than boy children and some parents may opt for selective abortion (Saikia et al., 2021). The Pre-Conception and Prenatal Diagnostic

Techniques Act, 1994 was implemented to ban the use of prenatal diagnostic techniques for selective abortions; however, the Act is considered to be ineffective. While the government implemented legislation which stabilised the sex ratio from 2007 to 2012, it has decreased significantly since 2013 (Saikia et al., 2021). The Census revealed Hinduism as the majority religion accounting for 79.8% of the total population, with Islam coming second at 14.3%, followed by Christians, Sikhs, Buddhists, Jains, and others (National Portal of India, n.d.). According to the World Bank Data (2019), India's gross national income (GNI) per capita stands at 6,950 US dollars, compared to the United Kingdom's GNI per capita at 44,090 US dollars. India's gross domestic product is 2.651 trillion dollars, compared to the United Kingdom's which stands at 2.638 dollars. The multi-dimensional view of poverty focuses attention on multiple deprivation faced by people, rather than basing it on calories or income. According to Drèze and Sen (2002), human poverty is much more than income or access to material benefits (Akire & Seth, 2008). The UNDP 'Human Development Reports' (2020) cites a multi-dimensional poverty index (MPI) score for India at 0.123%, which is ranked 62nd among 107 countries including Sri Lanka, China, and Pakistan (NITI Aayog, 2020). According to the UNDP 'Human Development Reports' (2020), the gender development index (GDI), based on the ratio of female (0.573) to male (0.699) human development index (HDI) stands at 0.82, which shows unequal development indicators for females when compared to males (if the development indicators pointed toward equality, the number would stand at 1.0). While the diversity and richness of the cultures in India are to be celebrated, it makes for an intriguing analysis of the experiences of inequality and deprivation in a multicultural society. For instance, what does it mean for women and motherhood in India? What are the experiences of women in a particular State? What are the experiences of mothers from different social backgrounds in relation to raising an autistic child? Thus, there is much scope for the exploration of the privileges and inequalities instilled in the social structure. The next section includes an exploration of disability as perceived in Indian society.

DISABILITY IN INDIA

The 2011 Census indicates that 26.8 million people in India have one kind of impairment or another. This accounts for 2.1% of the total population in the country. Dilshad Ariz (2018) draws attention to contrasting disability statistics in

India; although the Census (2011) gives a figure close to 26.8 million disabled people in the country, a report by the World Bank cites the actual figure at 55 to 90 million, which is 5 to 8% of the population. Vaidya (2016a) too, highlights the number of disabled individuals in the country based on the Census (2011); however, this statistic is primarily based on a framework which includes only a few impairment categories (excluding autism). Vaidya (2016a) draws attention to Ghai, who states that there are 70 million disabled individuals in India. Among the total number of disabled people in India (based on 2011 Census statistics), 12.6 million are males and 9.3 million are females (Ghai, 2015a; Bhattashali et al., 2018). The variation in the prevalence data can be attributed to different factors. One such factor may be the government structure; according to Rebecca Dickinson (2018), there is no single governmental ministry which oversees the direct needs of disabled people. The responsibility for health, education, governmental benefits, and wellness is dispersed across departments without a unified approach to understanding or meeting the needs of disabled people.

Cultural factors too, play a significant role and there is a tendency among some to hide the occurrence of an impairment within the family system. Maya Kalyanpur and I. P. Gowramma (2007) recognize certain cultural factors; for instance, family members may decide to wait to disclose the impairment in the family or seek diagnosis. The presence of an impairment in the family can mark them out as different and create barriers in relation to social interactions. Although clinical diagnosis can reduce potential negative reactions and blame subjected towards the parents, it can also ‘damage’ the notion of a ‘healthy lineage’, thereby producing ‘bad blood stigma’. Jennifer Sarrett (2015) places emphasis on the notion of ‘bad blood’ stigma; in a family where there are two children and one sibling has an impairment, the marriage prospects of the non-disabled sibling may be adversely affected due to the occurrence of an impairment. Sarret (2015a) goes on to explain that an increasing number of mothers are subjected to blame due to their daily involvement with the child. ‘Mercy killing’ and abandonment are still rampant in some regions in India and they are increasingly likely to happen to female disabled children (Dickinson, 2018). This may also be a factor in creating a disparity in sex-ratios between males and females. These socio-cultural factors can restrict parents/guardians from obtaining a diagnosis for the child and in turn affect government statistical surveys and access to government provisions.

There are other socio-cultural notions which affect disabled people and their families. The concept of ‘karma’ remains prevalent; an individual is born with an impairment due to sins committed in their previous life. Social accommodations may not be provided/implemented due to beliefs that there is ‘nothing to be done’ to enhance their lives (Gupta & Singhal, 2004; Dhar, 2009). Charitable acts like provision of food, money, and clothes offer a route toward ‘dharmic’/sacred duty for non-disabled people as a way of attaining ultimate liberation (Singh & Ghai, 2009). Ghai (2015a), cites Indian history and mythology which has considered disabled people as not ‘fully human’ (p. 29). In Indian mythology, flaws are associated with impairments of certain characters; for instance, in Hindu mythology Dhritarashtra, a king is denied the throne due to a visual impairment. Shakuni, another character, is primarily associated with an orthopaedic impairment and Manthara, a ‘dwarf’ woman, is considered as someone with an ‘evil intent’ (Addlakha, 2016, p. 45). Some current attitudes toward disabled people may reflect the historical oppression/discrimination they have faced. These attitudes highlight a limited understanding of the multidimensionality of disability experiences. Vanessa Singh and Anita Ghai (2009) underline the negative implications of holding a heroic opinion of some disabled people due to their participation in activities, which are otherwise perceived to be impossible for them. Their efforts are considered to be ‘valiant’ in overcoming their ‘deficits’ and ‘shortcomings’. Goffman (1963) insists that ‘success stories’ help to penetrate areas of ‘normal’ acceptance (p. 37) for disabled people who are perceived to possess ‘undesirable’ characteristics. I argue that the stance of Singh and Ghai (2009) remains valid, even in contemporary times; the perceptions of disabled people as heroic can be associated with power relations which give non-disabled people a medium through which an impairment can be invalidated and at the same time, sustain its own authenticity (Loja et al., 2013). Some studies analyse the implications of gender with disability, in particular the experiences of disabled women in the Indian context. Ghai (2002) for instance, is an important disability studies academic who has explored disability and gender-based discrimination by analysing the interlinks between gender and impairment, and its ‘disabling’ impact on women’s lives.

Coping mechanisms are prevalent in the literature; Gupta & Singhal, (2004) draw attention to the use of cognitive illusions, problem-focused coping, and positive reappraisal as ways by which Indian families cope during stressful situations when assisting their child or family member with an impairment. Family members (including parents/guardians and siblings) may experience disabling barriers without coping mechanisms. It can impact on daily living experiences, care and interpersonal relationships. The unequal distribution of support systems can exacerbate stresses, affecting the family’s psycho-emotional well-being and determining the perceptions of parents (Gupta & Singhal, 2004). Diagnostic labels may generate negative connotations and social barriers for not only those with an impairment, but also their family members (especially parents/guardians), who are held responsible for the impairment. This can affect the siblings as well, thereby contributing to the instability of the family system (Dhar, 2009). Thus, the raw experiences of parents/guardians can enable an understanding of how they are disabled as the primary guardian(s) of children with impairments. Analysing these experiences can enhance understanding of complex parental perceptions in India and contribute to the development of more sociologically-informed interventions at the policy level, which may be limited due to the primary focus on individual limitations (Richard, 2014).

This thesis recognizes that the concept of disability varies depending on the context. James Staples (2020) has outlined some sociocultural factors that are prevalent in India which may have an influence on how individuals perceive disability. In some instances, a disabled individual may be viewed as ‘undesirable’, while in others, the individual may be valued. Access to disability-related services may vary depending on the situation; for instance, in India, some disabled individuals may endure barriers like high costs of services, unavailability of services and the negative attitudes of some clinical professionals toward those from a lower-socio-economic background. Poverty is a factor that may result in the occurrence of an impairment and restrict access to services/resources. The occurrence of an impairment is more likely for individuals living below the poverty line. Some disabled children from impoverished backgrounds may not have access to education, even though there are calls for ‘integrated’ school settings. In Indian academia, disability studies have not obtained institutional backing in India-disability has traditionally been viewed as ‘uncontroversial’ in comparison to other markers of oppression like caste and gendered division of roles (Staples, 2020, p. 31). Disability legislation like the Rights of Persons with Disabilities Act, 2016, which makes reference to the UN CRPD 2006, reflect models developed in the industrialised West, including the UK. Some disability rights organizations in India are criticised for highlighting barriers primarily faced by middle-class men. However, disabled people in India are not homogenous and endure barriers in relation to their caste and their socio-economic background among others. Additionally, interdependence is a value that exists among some families in India and in some instances, disability may be considered to be a familial concern. Therefore, this thesis adopts an approach which recognizes socio-cultural and contextual factors when applying the social relational model to understand the varied experiences of parents/guardians of autistic children. The disability rights movement in India and its impact on disabled people is explained next in this chapter.

Disability Rights in India

During the period of colonisation in India, disability was not considered to be an identifier of discrimination or oppression. After gaining Independence in 1947, the ‘National Council for Handicapped Welfare’ was established to concentrate on planning and implementing disability legislation across the nation (Mehrotra, 2011). The 1949 Indian Constitution (15.2) also applied the concept of ‘disability’ to discrimination grounds of religion, race, caste, sex or place of birth. Most disability-related services followed individualised notions of disability (and some continue to do so in contemporary times) and clinical professionals were deemed as the port of authority in finding cures and solutions.

Issues relating to women (including violence against women) and environmental issues were at the centre stage in the 1970s and 1980s (Mehrotra, 2011). Anti-caste movements, in particular ones which sought to fight against barriers experienced by Dalits, emerged in the 1980s and 1990s. Disability rights activism did not come to the forefront until the 1990s in the Indian context (Mehrotra, 2011). Nilika Mehrotra (2011) draws attention to the complex diversity of issues as one reason for the aforementioned; disability affects individuals across different castes and socio-economic backgrounds, among others. Therefore, practicality in framing groups has been a difficult challenge (Mehrotra, 2011). In some rural areas, disabled individuals may not have access to information regarding their rights. In addition, individualised notions, socio-cultural constructs of disability and stereotypes associated with disabled people were among the factors which hindered the mobilization of disabled people. Some policies have reflected these notions (Mehrotra, 2011).

The pressure enforced by some international development organizations is a factor which enabled the mobilisation of disabled people and motivated them to seek opportunities to enhance their rights. Improved access towards funding, networking opportunities and increased access to the internet were the other reasons which led to the mobilisation of disabled people (Mehrotra, 2011). The ‘Asian and Pacific Decade of Disabled Persons’ was initiated in 1993 and a national seminar on disability was organized by the government of India in the same year. Irrespective of such progress, the focal point of every conversation on disability and disability rights primarily was on the daily living experiences of individuals with physical impairments (Mehrotra, 2011). The needs of autistic individuals, for instance, mainly received recognition later in 1999 with the passing of the National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act (hereafter National Trust Act and explored in detail later on in this chapter).

Jagdish Chander (2018) offers a different viewpoint regarding the origins of the Disability Rights Movement (DRM) in India. According to him, it began when people with visual impairments brought their struggles to the public forum. The ‘National Federation of the Blind’ (NFB) or ‘The Federation’, which was formed in 1972, played a crucial role in the disability rights movement in India and the subsequent passage of a comprehensive disability law to protect the rights of disabled people (Chander, 2018). Beginning in the 1980s (specifically from 1988), the NFB first sought to enhance employment opportunities for people with visual impairments. Their efforts resulted in the employment of 239 people with visual impairments between 1987 and 1988. Equally important, was the formation of a committee under the chairmanship of a former judge of the Supreme Court of India in 1986 (Chander, 2018). The committee submitted a report recommending the passage of comprehensive disability legislation. The recruitment/employment of individuals with visual impairments and the formation of the committee strengthened the disability rights movement in India.

Some members of the NFB tried various measures to ensure that the comprehensive legislation would be introduced in the Indian parliamentary session. However, it took many years to be introduced; during this time, some individuals in the NFB pressurised the government by methods including lobbying and picketing (Chander, 2018). More radical measures like hunger strikes, stopping trains and threats of self-immolation were also conducted. Some conducted rallies and picketing in front of the residences of the prime minister and other high-ranking officials. Eventually, the long-drawn-out struggles of individuals with visual impairments paid its dividends with the introduction of the comprehensive law in 1994 during a parliamentary session (Chander, 2018). The Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act was passed in December 1995, and became a law in February 1996 (hereafter, Persons with Disabilities Act; for more details regarding the PWD Act, please refer to the next section in this chapter).

Mehrotra (2011) and Chander (2018) share differing views regarding the Disability Rights Movement in India. Ghai too, offers a different perspective by insisting that the movement began in 1981, which started the International Year of Disabled Persons or IYDP (Chander, 2018). Others like Meenu Bhambhani have argued that the movement started with the cross-disability movement and the establishment of the Disability Rights Group (DRG) in 1994. Chander (2018) admits that the DRM movement, led by people with visual impairments, was characterised by the limited involvement of people with other impairments. However, the goal of the movement was to advocate for the rights of all disabled people, with different types of impairments. The efforts of the NFB began in 1980 and these were documented by the media who drew attention to police brutality or 'lathi' charges against disabled people on World Disability Day (Chander, 2018). The NFB's intensified demonstrations was also a contributory factor in India's involvement in the commemoration of 1981 as the International Year of Disabled Persons. While the Dalit and Women-oriented movements (as mentioned previously) were important in promoting the disability rights movement in India, the efforts of the NFB in the 1980s cannot be understated.

A major criticism levelled at the disability-rights movement in India by female disabled individuals/scholars like Anita Ghai, is that the movement is primarily male-centric (Mehrotra, 2011). The movement had failed to recognize and incorporate the needs of disabled women who have faced oppression/discrimination. Ghai has written a great deal on disability discourses in relation to women in the Indian context. An intersectional analysis on disability at the intersection of social factors like gender, caste/tribe and class has rarely been offered. Nilika Mehrotra (2013) is one among a few scholars who have analysed disability at the intersection of social factors in North India. Over the years, changes in the usage of terms pertaining to disability have occurred, even though some terms continue to retain individualised notions of disability. For instance, 'differently abled' is a term that is occasionally used in contemporary times to refer to disabled people; however, Mehrotra (2011) insists that the term is not accepted by rights activists. In recent years, the word 'divyang' or divine-bodied has been used to refer to disabled individuals by the Indian government which has received mixed responses (Vaidya, 2016a). Some have critiqued the use of the term by insisting that it took attention away from the discrimination faced by disabled individuals (Vaidya, 2016a). During fieldwork for this thesis, some parents/guardians used certain terms to refer to their autistic child, which may be classified as negative by some individuals or scholars with a background in disability studies and sociology. This highlighted their contextual situation/lived experiences and these (experiences) are analysed in detail in the empirical chapters.

The disability rights movement is strongly supported by some parents/guardians and in particular, some mothers of disabled children (Mehrotra, 2011). Some have transformed into activists (like Merry Barua) on behalf of their children and established organizations which endeavour to promote self-advocacy and rights-based opportunities for disabled individuals. Parents/guardians like Shubhangi Vaidya have contributed (and continue to contribute) to the disability arena by producing sociological studies which analyse parental experiences and the needs of parents/guardians. Despite the initiative taken by some parents/guardians, their lived experiences, social interactions, stresses from raising an autistic child and access to support systems require further investigation. For instance, what are the social barriers they face when going as a family to a social space? How does it affect their psycho-emotional well-being? Do instances in social interactions create barriers for them to mingle on equal terms with other parents/guardians of autistic children? What are the support systems which can be offered to parents/guardians who may be affected during social participation and due to the pressures stemming from daily caregiving needs? These are issues which require further analysis. Traditionally, impairment in the family and the experiences of parents/guardians have not been documented; rather, disabled people have been associated primarily with begging in the streets (Mehrotra, 2011). Therefore, the disability rights movements must include the first-hand experiences of disabled individuals and the experiences of parents/guardians (specific to the socio-cultural context; in this case, India) to enhance access to services and social participation. The next section explores and details the disability-related legislations which have sought to enhance the rights of disabled people and their families in India.

Disability Legislations

Impairments are not listed among the top priorities in the development agendas in India, and it is evidenced by the absence of disability in both Articles 15 and 16 of the Indian Constitution which prohibits discrimination based on gender, caste/tribe, class, and religion (Vaidya, 2016a, p. 160). Unlike the United Kingdom, disability-related movements in India have faced complications from the interplay of cultural factors, stereotypes, beliefs and structural factors like poverty, illiteracy, gender, caste/tribe, and access to resources. The increasing globalization in the 1990s promoted identity politics, which in turn paved the way for disability-related activism (Vaidya, 2016a). Globalization led to increased funding from foreign agencies which helped the government as well as the non-governmental organizations (NGOs). The period also witnessed the UN’s agenda on human rights which included addressing the needs of people with both physical and intellectual impairments (Vaidya, 2016a). In addition, Vaidya (2016a) cites Mehrotra (2013) who points to the effective transmission of information and easier funding made possible by globalization.

The Decade of Disabled Persons from 1983-1992 (The UN General Assembly in 1976 decided to provide a time frame during which governments could make amendments to their existing policies), emergence of non-governmental organizations, international pressures and the presence of women’s movements were essential in creating a shift, leading to the promotion of citizenship rights and the inclusion of disabled people as a crucial part of a collaborative effort in policy planning, development and implementation (Mehrotra, 2011). The efforts of the NFB were also fundamental. These influences created a conducive environment for the development of legislations to protect the rights of disabled people.

The limitations in the Lunacy Act of 1912 and 1977 resulted in the implementation of Mental Health Act, 1987, which was formulated to amend the law pertaining to the treatment of ‘mentally ill’ persons and to ensure better provisions in relation to their property and affairs (Ghai, 2015b). Under Chapter VIII of the Act, it is established that disabled people should not be subjected to inhumane treatment and that they may be offered the choice of guardianship, if they are unable to manage their property. Other provisions included pension and free legal aid (Chopra, 2013). However, the Act reinforced stereotypes of the ‘dangerous incompetent person with disability’ and did not address autonomy, discrimination and equal opportunities (Dhanda, 2018, p. 394). The Mental Health Act of 1987 was followed by the Rehabilitation Council of India Act (RCI), in 1992.

Parsanjeet Kumar and Parul Agarwal (2016) assert that the RCI Act of 1992 involved the regulation of training practices and the maintenance of the central rehabilitation register. Standardization of curricula, assessment of teacher training, research and development in the field of disability are key provisions entailed in the Act. It was enacted due to the belief that quality assurance was guaranteed if rehabilitation services were provided by licensed professionals (Dhanda, 2018). However, the Act does not directly impact disabled people, like enabling their access to employment opportunities (Chopra, 2013). The limitations identified and the persistence of disabled people, particularly those with visual impairments, led to a landmark piece of legislation in the form of Persons with Disabilities Act (PWD), enacted in 1995 and covering seven types of impairments including blindness, low vision, hearing impairments, loco-motor impairments, mental retardation, leprosy and mental illness (Ghai, 2015b). The PWD Act of 1995 focused on equality and participation of disabled people, and eliminating discrimination against them (Chopra, 2013).

The main targets of the PWD Act, 1995 were the prevention and early detection of impairments, and the provision of education and vocational opportunities for disabled people. The Act entailed a 3% reservation in government jobs and educational institutions for disabled people and stressed the importance of barrier-free environments as a measure of non-discrimination (Narayan & John, 2017). However, the Act primarily positions disability within the medical realm and it specifies that only individuals with 40% or more impairment, as determined by a medical expert, can obtain access to the provisions entailed in the Act (Vaidya, 2016a). Individuals with 40% or more disability may be characterised by impairments in reasoning, learning, problem-solving and in daily social skills (Narayan & John, 2017). ‘Mental illness’ and impairments in thinking, mood, perception, orientation, and the ‘incomplete development of the mind’ are other features which determine the percentage of impairment among people (Narayan & John, 2017). The PWD Act has also faced criticism because it does not include provisions for all types of impairments, including autism. Thus, this enabled an opportunity for the implementation of the National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act, 1999.

The National Trust Act gives disabled individuals (including autistic individuals and individuals with intellectual disabilities) the right to choose a legal guardian, move out of their family home and live independently with the help of the appointed guardian. The thrust of the Act involves inclusion and it is based on the premise that autistic people, people with a diagnosis of cerebral palsy and the other impairments (specified in the Act) require lifelong support. The Act further recognizes the need for community living and capacity building to ensure that disabled people can contribute ‘meaningfully’ to society (Addlakha, 2016). Irrespective of the positive implications of the National Trust Act, criticism stems from the apparent limitations regarding the involvement of disabled people in the decision-making process once guardians are appointed (Kumar & Agarwal, 2016). Alongside the legislations mentioned, Sangeeta Karmakar and Vandana Saxena (2015) draw attention to the National Policy for Persons with Disabilities passed in

2006, which places emphasis on the prevention of impairments, rehabilitation of disabled individuals, (especially, disabled women and children), a barrier-free environment, social security, and research (Barua et al., 2016). Although the policy aimed to replace its earlier focus on medical rehabilitation through social rehabilitation, it has remained ambiguous with regards to its implementation (Ghai, 2015b). India ratified the UN Convention on the Rights of Persons with Disabilities (UN CRPD) in 2007, which places responsibility on the Indian government to amend various national disability legislations. This has, in turn, led to the formulation of a more comprehensive PWD Act, renamed as the Rights of Persons with Disabilities Act (RPWD Act), 2016.

The RPWD Act, 2016, is characterized by the expansion from 7 to 21 impairments, including autism, to ensure the right to equality, life with dignity, and respect for disabled people. Under the tenets of the RPWD Act, the government is entrusted with the responsibility of providing appropriate accommodations for disabled people (Narayan & John, 2017). Disabled children/individuals (the ones listed in the Act's provisions) within the age group of six to eighteen years are entitled to free education (Disabilities Affairs, 2021). Disabled individuals are reserved 5% of seats in government higher education institutions. The RPWD Act places emphasis on enhancing accessibility in buildings (both government and private) within a particular timeframe. Disabled people are also given 4% reservation in government jobs. The Act entails the 'granting of guardianship' by any authority designated by the state government under which joint decision making between the guardian and the disabled individuals will take place (Disabilities Affairs, 2021).

Autism is, however, grouped under the subtitle of intellectual disability, along with specific learning disabilities, which can derail understanding of autism and related experiences, and therefore the effective implementation of policies pertaining to autism and families (John et al., 2018). Other drawbacks include the insufficient social security situation of autistic individuals. Thus, aside from some exceptions, and irrespective of amendment of certain policies, the history of disability legislation has been instilled with elements of the 'personal tragedy' model which deems disabled people to possess an 'unsound mind' (Addlakha & Mandal, 2009). Although the National Trust Act sought to address the needs of disabled individuals, including autistic individuals, it does not directly identify the immediate needs of children and parents/guardians, so that parents/guardians can be provided access to resources to support their children. Therefore, this research explores parental experiences with the intention to contribute to making policy insights. Additional policy recommendations which seek to enhance the complex experiences of parents/guardians and improve their direct access toward support mechanisms can reduce ‘disabling’ social barriers. The next section provides an understanding of autism and the perception of autism among families in India.

Perceptions of autism in Indian families

A number of autism studies in India lean towards clinical understandings of the same, with a focus on the ‘inability’ factor in terms of daily living skills, language, behaviour, communication, social interaction and bizarre body movements (Das et al., 2017). Autism is considered to be an epidemic and a burden to society; while the statistical rates vary, Anil Chauhan and colleagues (2019) cite current autism estimates in India to surpass 2 million individuals, while Vaidya (2016a) highlights a number close to 8-10 million autistic individuals. The ‘burden’ associated with caring for autistic individuals is said to contribute to the heightened stress levels of family members (Bashir et al., 2014; George & Sakeer, 2015). Alokananda Rudra and colleagues (2017) add that autism estimates in India are extrapolated from studies in the UK and USA; one reason for this drawback being, the lack of adequate diagnostic tools for autism. Socio-cultural factors play a significant role; some parents/guardians may attribute the cause of autism to ‘god’s will’ or ‘karma’ and the existing literature recognizes added uncertainty within the family system as a result of autism diagnosis, which may create interpersonal problems, like blaming one another (Gupta & Singhal, 2005).

The access to services and professionals can become problematic due to India’s wide-ranging physical landscapes and this is highlighted in the current literature (Minhas et al., 2015). Thomas Kishore and Anirban Basu (2011) draw attention to alternate modes of intervention for autism like Pranic healing (an energy-based healing system which is based on the concept that the body has the power to heal itself), reflexology, yoga, and Ayurveda (discussed further in chapter seven). However, in most cases, parents’ first port of call for seeking help upon identifying a ‘problem’ with their child is to consult a ‘Western’ trained doctor or medical professional (Daley, 2004). As disability is primarily considered to be an individual problem, suitable accommodations are equated to clinical interventions or rehabilitation efforts which enable an individual to overcome the disability (Areheart, 2008). The study by Tamara Daley (2004) also highlights differences in access to resource and how it determines diagnosis; children from a lower socio-economic background are less likely to be diagnosed as their parents may possess insufficient economic resources, education or time. Financial constraints prove to be deterrents to the existent parent training programmes in the country (Perumal et al., 2014; Brezis et al., 2015; Minhas et al., 2015). Johansson (2015) notes the different perceptions of aspirations in terms of education among distinct groups; parents in the ‘lower middle’ to ‘lower income’ bracket focus on education to increase employability, while parents of autistic children in ‘upper middle’ to ‘upper socio-economic’ bracket view education as maintaining upward social mobility. There are existing studies which emphasise the need for tools to measure ‘impairment levels’ of autistic individuals (Dalwai et al., 2017). The term ‘measuring impairment levels’ can be changed to ‘recognizing individual differences’; the aforementioned term can be less exclusionary. It is noteworthy that individual differences must be emphasized because it may be a factor which enables access to provisions and services (Anastasiou & Kauffman, 2013).

Vaithiamanithi Perumal and colleagues (2014) draw attention to the increased stress levels amongst parents of autistic children when compared to parents of children with other clinically diagnosed impairments. Siblings of autistic individuals are also said to share the ‘brunt’ of the emotional trauma (Desai et al., 2012; Panjrath & Mishra, 2018). Stigmatising attitudes towards impairments which may arise during interaction and communication play a role in family experiences. For instance, some elder members may view autism as a taboo, and restrict the social participation of the mother and the child. When some autistic children keep to themselves, some people in Indian society may attribute the same to ‘good’ behaviour. This can create serious implications, including causing delays in formal diagnosis of a child (Daley, 2004). Lynn Wilder and colleagues (2004) similarly attribute the widely acknowledged misconception of boys developing speech later than girls as another reason for missed/under-diagnosis. The reduced information among some professionals and the dearth of services also exacerbates the stresses of parents (Barua, 2007). Some mothers take on the mantle of advocates and have voiced their concerns regarding individual interactions and systemic discrimination on different platforms (Singh et al., 2017).

Anugraha Rajan and Romate John (2017) point to Ghai (2002), Green (2007) and Landsman (2003) who insist that parents/guardians face severe pressures when raising disabled children; children are raised in a society where some may devalue any form of impairment. According to Indian social norms, parenting roles are discredited due to the prevalent perception that parenting a disabled child fails to produce socially contributing individuals (Rajan and John, 2017). In India, disabled children are primarily associated with 'deficits' and imperfection; the aforementioned is imputed to the wrath of God, due to sins committed in a previous life. Although some parents experience positive growth, improved tolerance and a sense of optimism, an increasing number of parents face severe pressures because they encounter social barriers (Rajan and John, 2017). Therefore, parental perceptions are a major influence on the life experiences of autistic children (Ravindran & Myers, 2011). Parents/guardians in India are primarily affected by understandings of disability based on the individual model. The individualised understanding, along with the complexity of socio-cultural factors, can create distinctive 'disabling' barriers for them. Thus, a significant amount of research on autism are clinical studies which follow a homogenous approach focusing on treatments, intervention, cure and the 'burden' on the parents. The next section provides a detailed exploration of Kerala, and the need for a sociological study focusing on the disabling barriers faced by parents/guardians in the State.

KERALA: GENERAL INFORMATION

The State of Kerala, which lies in the linguistic-cultural area known as South India is located at the south-western tip, between the Arabian Sea in the West and the Western Ghats in the East, comprising an area of 38,863 sq. km. The neighbouring states are Tamil Nadu and Karnataka (Government of Kerala, 2019). The contemporary state of Kerala was formed on November 1, 1956, when the three distinct provinces of Travancore, Kochi and Malabar were united as one (Desai, 2005). The 2011 Census estimates 33,387,677 inhabitants, making Kerala the twelfth largest state with regard to population. The state capital is Thiruvananthapuram and other major cities include Kochi, Kozhikode, Thrissur and Kollam. Malayalam is the official language and the most widely spoken language across the 14 districts of the State. According to the 2011 Census, Hinduism is practised by 54.9% of the total population, followed by Islam at 26.6% and Christianity at 18.4% (Padmanabhan, 2011). Kerala is noted for having the highest literacy rate in India, as well as for its achievements in education, health, gender equality, social justice, and law and order. The State has the lowest infant mortality rate in the country (Government of Kerala, 2019). N. Padmanabhan (2011) adds to the aforementioned statement by insisting that Kerala is a state with the lowest positive population growth rate in India (3.44%). The reasons to base the research in Kerala will be detailed next.

Why choose Kerala as the site for a field study?

The primary reason for choosing the State of Kerala as the focus of my thesis is because I am a native of Kerala. My hometown is the capital city of Thiruvananthapuram and I have extended family and friends in the three regions which form the State. These social connections make it suitable for a field study to be conducted across the State. I am well versed in two languages; one is English and the other is my mother tongue, Malayalam. As I am not familiar with other spoken languages in other parts of India, my stronghold in the Malayalam language and the general culture makes the data generation phase in Kerala a doable endeavour.

Kerala has a history of promoting social justice initiatives and a study focusing on the disabling barriers experienced by parents/guardians of autistic children can pave the way for more discourses on parental support, awareness, and acceptance of impairment in the family. Rene Véron (2001), cites Ramachandran (1997) when highlighting Kerala’s progress in terms of public actions, state interventions, and movements which have led to high levels of social development and improved living conditions, including among people identifying with the lower social groups, irrespective of the State’s low per capita income and stagnant economic growth rates. Kerala’s literacy rates are among the highest in the country, which is over 90% (94% for males, 88% for females) and the average life expectancy rate of a person is 72 years (Steur, 2009). The government has devised interventions to combat poverty; for instance, Kerala has initiated measures such as a full-coverage network of public distribution system (PDS), which has enhanced people's access to food grains. Other measures include free housing sites and house construction support to people who are displaced and steeped in poverty (Kannan & Pillai, 2004).

Kerala offers pension schemes to agricultural workers, widows, senior citizens and physically impaired individuals, along with other social security and welfare schemes, which have helped to enhance economic freedom. The land reforms have bestowed economic freedom on the agricultural labour households through land redistribution and creation of colonies for 'scheduled castes' (SC) and 'scheduled tribes' (ST) (Kannan & Pillai, 2004). Gender-based movements have been crucial in Kerala; the opportunities to improve the living conditions of women in the State can be dated back to the late 19th century, when education for girls was recognized by the opening of a separate school in the Travancore region. The reforms for women, eradication of poverty by the government-initiated 'Kudumbashree' programme, as well as the matrilineal tradition that was followed across the State, have led to high indicators in women's health, well-being and possession of property rights (Devika & Thampi, 2007). Furthermore, the people identifying with the 'scheduled caste' community, who are sometimes referred to as the Dalits and 'untouchables' (the historically given identifier), were accepted in primary educational systems for the first time in Kerala. In terms of health, Kerala has attained high status with respect to maternal, infant and child health as well as the average health of the general population, due to adequate health care facilities (Kannan & Pillai, 2004). Thus, social justice initiatives have been recorded in Kerala's developmental agenda (Raman, 2009).

Despite the positive achievements, Kerala is characterised by pockets of stark exclusion. For instance, identification with a caste/tribe identity remains a vital marker of socio-economic status; Catherine Sauvaget and colleagues (2011) found that the people categorised as 'forward' or 'general castes' were more likely to use health facilities, resulting in better health status. Irrespective of gender-related social justice movements, an increasing number of women still face gender-based discrimination or oppression. Suma Scaria (2017) reports the discrimination encountered by women in different spheres; for instance, despite the perceived elevated status of women, high literary achievements, and health indicators, Kerala has also witnessed high suicide rates (among women) stemming from barriers which curtail women’s aspirations due to patriarchal attitudes both within and outside the home (Scaria, 2017). When analysing the different indicators, including health, gender or caste/tribe identity, inequality may not be overtly visible but, according to Scaria (2017), inequalities do persist as demonstrated by data which shows higher incidence of mortality rates among women identifying with the ‘backward’ caste category. Thus, gender and caste/tribe identity are cited as factors which may contribute to patterns of inequities in Kerala. Therefore, it is interesting to understand the experiences of parents/guardians coming from different socio-demographic backgrounds.

In terms of autism, the cultural notions of karma, lack of clarity in autism estimates, the need for more effective policies (which is evidenced by the need for better service provision for parents/guardians to support their children (Dhar, 2009; John et al., 2018)), and the focus on individualised understandings of autism has resulted in a homogenous disability model that predominantly focuses on individual impairments. The social model has played a role in the Indian context, and some disability activists have stressed the need for accommodations and policy reforms. The practicality of the social model and its implementation in an Indian setting requires further analysis, but the model can be used to highlight the experiences and oppression in the daily lives of disabled people (Barnes et al., 1999). I, however, use the social relational model, to develop an intersectional study which enhances the understanding of diverse micro-level disabling barriers experienced by parents/guardians across the socio-demographic terrain in Kerala. This thesis remains sensitive to cultural variations when assessing their experiences at the intersection of gender, access to resources and caste/tribe status to understand the intricacies of social interactions, relationships, support systems, impairment effects and access to services. This will ultimately help to understand and question the disabling barriers which undermine parents’/guardians’ psycho-emotional well-being in relation to social interactions, pressures arising from raising an autistic child and their access to services.

In India, although literature on gender, disability, and poverty exists, there is a call for more intersectional analyses focusing on disability. Nilika Mehrotra (2013) uses the intersectional approach to analyse disability at the intersection of gender and caste, thereby highlighting complexities in experiences and oppressions faced by disabled people in northern India. For instance, gendered divisions of roles restrict women from employment and many of them are confined to household work (even if they hold a form of remunerative work) in a patriarchal environment. Mehrotra (2013) insists that some disabled women who identify with the 'scheduled caste' or Dalit ('untouchable') community experience significant oppression due to their gender, caste/tribe identity and their self-identification as a disabled person. India's economy does not favour some women from low-income groups who are forced to take up unregulated informal work (Dey & Orton, 2016). By analysing the complex experiences of parents/guardians, I intend to uncover gender-based and other inequities (as well as privilege) experienced by parents/guardians.

Kerala follows an extensive individualised approach due to the State's exposure to Western health care facilities and treatments. G. S. Ramkumar (2015) cites 49 autism clinical facilities in the State where children get access to specialized tuition which can help them prepare for mainstream education. These facilities are meant to reduce the 'burden' on the parents. Some clinical studies pertain to the early identification of autism, and these studies highlight interventions which seek to cure autism and also explain the coping strategies used by parents (Vinod et al., 2013; Nair et al., 2014; Jaisoorya et al., 2018). The existing literature also explores home care, stimulation and the psychological environment of the child (George et al., 2014). Furthermore, studies based on religion, including those which associate autism to punishment by the snake god can also be found (Das & Balasubramaniam, 2017). Regardless of the individualised notions and the stigma attached to autism, awareness has increased. In Kerala, parents of autistic children do not accept the concept of 'neurodiversity', but the 'reality' of the persistent characteristics associated with autism which must be negotiated in the 'neurotypical' world (Block, 2015). Therefore, a model which solely focuses on the differences of autistic individuals and the impact of social barriers may not be effectively implemented in the Indian context. Rather, the social relational model focusing on economic barriers, 'disabling' experiences arising from unequal face-to-face interactions which may in turn result in ‘internalised oppression’, and the stresses created by some restrictions in relation to impairments associated with autism will enhance an in-depth analysis of parents’/guardians’ stresses/pressures, coping mechanisms and direct needs. This chapter has highlighted some experiences of women in Kerala. However, it is important to provide a further explanation of the historical/cultural perspectives regarding the experiences of women in the State. This will enhance the understanding of the experiences of parents/guardians in the study, the majority of whom are women. Therefore, the next section in this chapter offers an overview on the status of women, who are the primary caregivers for children in Keralan society.

The status of women in Kerala

Historically in Kerala, some households were controlled by matriarchs and land assets were inherited through the female line, even though the main decision makers were men (Chacko, 2003). The matrilineal system was followed by more than half the Hindu population, which forms the majority religion in Kerala. This system has, however, declined since the 1920s and the right to property which was inherited through the female line has significantly been reduced. While Christian ‘succession’ laws were biased against women, the Muslim population had also followed the matrilineal system, which is not practiced anymore in their community (Chacko, 2003). Regardless, the matrilineal system adopted across the State has been praised for enhancing the social position of women. Elizabeth Chacko (2003, p. 54) cites Jeffrey (1989) who draws attention to the Census Report of 1875 which states that ‘a female child is prized higher than a male child’. The importance accorded to women is further highlighted in statistics, which show that females outnumber males in the State. According to Roy (2018), the ratio is 1084 females per 1000 males and female literacy stands at 95.2% against the male literacy rate which is 97.4% of the total population (The Economic Times, 2020).

K. P. Kannan and Vijayamohanan Pillai (2004) place emphasis on Kerala’s achievements in ensuring high standards in terms of maternal, infant and child health. Research draws attention to a significant number of women employed in salaried work, mainly as teachers in government settings, irrespective of caste, religion and other social factors (Jeffrey, 2004). However, the current scenario shows stark inequalities affecting women and this is evident in Kerala’s workforce, where women constitute only 24.8% of the sector (Roy, 2018). Aparna Mitra and Pooja Singh (2007) have stated that the unemployment rates for women in Kerala were among the highest in the country. The conservative social fabric forces women to undertake general education, rather than technical education because they are considered as the primary caregivers for children, older people and those ‘in need’, including disabled people, within the family system (Mitra & Singh, 2007). The ‘domestication’ of Keralan women has modified societal perceptions and an ideal woman is considered to possess both the ‘natural’ qualities and the socially acquired ones to care for family members, especially the children (Devika, 2019). J. Devika (2019, p. 82) further stresses the ‘nurturant’ and ‘non-nurturant’ care of mothers, which is perceived to be vital to the ‘production of the bodies and minds of worthy industrious citizens of the modern state’. Thus, this study intends to explore parenting perceptions (in particular, mothering of autistic children), domestic division of roles and barriers faced by parents/guardians in relation to the same.

SUMMARY

This chapter has discussed the general socio-cultural climate of India and Kerala. India is a country with many different states and union territories, so familiarising the reader with the Indian context is important. The DRM in India is explored and the Indian government’s initiative to implement disability legislation is recognized. However, additional policy recommendations which meet the needs of parents/guardians are needed. Disability is highly individualised, and the primary goal of parents pertains to seeking clinical help to cure the child. The section provides an in-depth understanding of the perceptions of disability by drawing attention to Indian mythology and the existing literature. Autism and family experiences in Kerala are explored; these experiences highlight the individualised view on autism and parental efforts in overcoming socio-cultural barriers. An increasing number of existing autism studies in Kerala primarily focus on interventions and cure. The reason to situate the study in urban Kerala are explained in depth, and Kerala’s history of encouraging social justice and social development initiatives, including the empowerment of women, are detailed. However, female suicide rates, and unemployment rates among women are high, and there is a need to understand gendered divisions of roles and how they affect parents/guardians of autistic children. By considering socio-cultural factors, this thesis seeks to explain the ‘disabling’ barriers that affect parents/guardians through the social relational model of disability.

CHAPTER 4: RESEARCH DESIGN AND PLAN

INTRODUCTION

This study is designed to explore the disabling barriers faced by parents/guardians of autistic children at the intersection of social factors including gender, access to resources and caste/tribe identity. The social relational model of disability is used to examine the barriers and privileges they experience with regard to social interactions, the family environment, access to resources and services, and the effects of the impairments associated with autism. This chapter draws attention to the main research question, along with the sub-questions, aims/objectives and describes the methods/tools that were used to address them. Then, the philosophical basis of the methodology is presented in detail. The section addresses the reasoning behind undertaking a qualitative study, and the methodology used for conducting the fieldwork. The chapter sets out the sampling methods and techniques which were used to choose participants for the interviews. The recruitment of participants is explained in depth, after which I describe the interview process and my experiences, including the challenges that I had faced. The chapter then moves on to discuss the research ethics, consent and confidentiality in relation to this thesis and the fieldwork. I explain the process of coding and analysis, and eventually conclude the chapter by explaining the strengths and limitations of the analysis. Reflexivity during my fieldwork is discussed in depth. The next sections in this chapter highlights the overarching research question and the sub-questions.

OVERARCHING RESEARCH QUESTION

What are the experiences of parents/guardians of autistic children in Kerala, India, in relation to social interactions, the upbringing of an autistic child and the family environment?

Sub-Questions

1. What are parents'/guardians' experiences of social interactions in urban Kerala?
2. What are their perceptions of access to services in urban Kerala?
3. How are parents/guardians affected by the effects of impairment associated with autism?

4. How are parental experiences influenced by social factors including gender, access to resources and caste or tribe identity?
5. How can services in Kerala be developed to better support parents/guardians and their autistic children?

AIM OF THE RESEARCH

The aim of this research is to explore the social experiences of parents/guardians of autistic children in Kerala. The social relational model is used as a tool to understand the ‘disabling’ barriers faced by parents/guardians in relation to social interactions, access to services, and impairment effects. The study entails an intersectional analysis to uncover their complex experiences of privilege and barriers (and how they reinforce each other). Thus, the intention of this qualitative research is to provide an in-depth analysis of the lived experiences of parents/guardians of autistic children in Kerala. The next section outlines the theoretical rationale behind the research strategy.

THEORETICAL APPROACH TOWARD RESEARCH

The research methodology for this thesis employs the social relational model of disability (please refer back to chapter two for further information on the social relational model) as the ontological foundation. This thesis focuses on understanding the experiences, opinions and feelings from the perspective of the participants (more specifically, uncovering the perceptions of parents/guardians of autistic children) and as such, the study adopts a social constructivist/interpretivist approach. Interpretivism is dependent on social constructivism; Göran Goldkuhl (2012) highlights Orlikowski & Baroudi (1991, p. 14) who emphasize that interpretive research is based on interactions in the social world (social relationships, organizations, and division of labour). The world is created and reinforced by individuals through actions and social interactions. The purpose of interpretive research pertains to the understanding of social interactions and the involvement of members in a social group, analysing their specific social realities, giving them meaning, and studying how such meanings create their actions (Goldkuhl, 2012). Cognitive elements like meanings, beliefs, and intentions are seen as critical in comprehending people’s perspectives on their social worlds and roles.

According to Norman Blaikie (2006, p. 115), interpretivism decodes the meanings, interpretations, reasons, and intentions that people utilise in their daily lives to guide their behaviour. As such, social constructivism/interpretivism is a technique which describes an insider's perspective and enables an understanding about why some individuals do what they do by uncovering knowledge, motives, rules and symbolic meanings, among others. As the researcher, my objective is to understand the impact of social interactions and impairment effects on the social realities of the parents/guardians of autistic children. I propose to analyse the experiences of parents/guardians in relation to raising an autistic child in Kerala. To understand the guiding motives of parents/guardians in relation to interactions, access to resources and impairment effects, I intend to decode and bring forth the meanings, reasons and intentions used by them in their daily lives.

This thesis seeks to explore and dissect the complexities in parental perceptions, analyse social interactions and barriers they (parents/guardians) face, with the objective of contributing to existing policies in India, by developing policy recommendations that addresses the direct needs of parents/guardians and their access toward support systems for the child. Emma Stone and Mark Priestley (1996) recognize that the crux of disability research lies in an emancipatory model where the full ownership of the means of research production is vested in the hands of the research participants, rather than those of the researcher. However, this study is conducted and self-funded by the researcher, and it involves the participation of parents/guardians of autistic children, rather than the autistic children themselves. Therefore, it can be said that this study may not be entirely emancipatory in its approach, even though it upholds certain crucial tenets of emancipatory research. The study instead adopted a form of participatory research which called for the direct participation and dissemination of experiences by the parents/guardians themselves (Balcazar et al., 2006).

Barnes (1992) insists that the occurrence of an impairment alone does not guarantee an individual's rapport with disabled people, nor does it give them an inclination to conduct research on disability. Emancipatory research is a process which can enhance the understanding of the structures and processes of disablement. It is also a method which tries to establish a conversation between the research community and disabled people, with the goal of facilitating disabled people’s empowerment (Barnes, 1992). Researchers do not need to be disabled to conduct their work; instead, they must put their expertise to work for disabled people. This study was thus set up to derive the qualitative experiences of parents/guardians of autistic children, some of whom are disabled by barriers in society. Their experiences were then interpreted to develop a comprehensive understanding (Creswell, 2003 p. 8). The next section in this chapter offers the reason(s) for the choice of a qualitative framework for the thesis.

Qualitative research study

John Creswell (2003) suggests that qualitative research studies can aid the researcher in developing a level of detail about the participants or setting and comprehend the actual experiences of the participants. The qualitative approach, which views the social world in holistic terms, can enhance the examination of a social phenomenon through ‘panoramic’ views, which can in turn enable the creation/construction of a complex narrative (p. 182). Shidur Rahman (2016) concurs with Creswell (2003) by insisting that qualitative research holistically understands the human experience in specific settings. Jennifer Mason (2002) too, emphasises the need to conduct qualitative research systematically, while also stressing the importance of context and flexibility. Qualitative research is not only about an adequate strategy, but the researcher must also be aware of/be sensitive to changing contexts and situations. A qualitative research study on the experiences of parents/guardians of autistic children can enhance knowledge of their complex social realities, parenting practices, social interactions, barriers arising from such interactions, and the privileges some parents enjoy (and the reasons why inequities persist with regards to social interactions and access to services) in Kerala society.

Haradhan Kumar Mohajan (2018) cites Punch (2013) who calls attention to qualitative analysis as a type of research which collects and works with non-numerical data. Qualitative analysis seeks to interpret meaning and enable an understanding of social life through the study of a target population. It investigates people’s experiences, meanings, relationships, and social processes that may marginalize a particular group of people (Mohajan, 2018). Qualitative research is also less structured in description because it can help to build new theories. It is a type of social action which places emphasis on people’s interactions, and their sense of social reality (Mohajan, 2018). Qualitative research is useful for studies pertaining to disability as the perceptions, experiences and the complexities of human behaviour are better explained through this approach (Hartley & Muhit, 2003). Statistics and experimental methods, according to Barnes (1992), may be unsuitable to uncover the meanings of everyday life and social circumstances. Large-scale survey research, random sample techniques, and control groups may sometimes prove problematic for grasping social situations adequately. Furthermore, qualitative research strategies are appropriate for small-scale studies in which the researcher engages directly with the study and participants (Barnes, 1992). Qualitative research entails active self-reflexivity by the researcher, who is required to continuously scrutinise their actions, role in the research process and the data collection (Mason, 2002). I have conducted a small-scale study which entails a detailed analysis of the experiences of parents/guardians of autistic children. My aim was to explore the social interactions of parents/guardians and their everyday social circumstances of raising an autistic child. By speaking to and engaging in discussions with parents/guardians, I have enhanced my understanding of the aforementioned, and I intend to explain their perceptions in detail in the forthcoming empirical chapters. A qualitative approach has thus helped me to generate data which probes into their social lives and lived experiences.

To conduct qualitative research, the researcher must first gain a thorough understanding of social situations by delving into the symbolic world of the specific participant (Barnes, 1992). Continued involvement with the research population enables the researcher to discover hypotheses, develop theories and understand others through ‘imaginative reconstruction’, or ‘empathy’. The researcher can find hypotheses, create theories, and understand others because of their continued contact with the research population. Therefore, for this particular thesis, I have investigated the experiences of parents/guardians, including the barriers and any privileges they face, with the help of face-to-face interactions. I have qualitatively analysed their perceptions using an intersectional framework and the social relational model as a tool, something that has been rarely conducted in the Keralan context. By directly engaging with parents/guardians and understanding their experiences, this thesis highlights the interactions, relationships, and social processes that may marginalise some while privileging others. The use of the social relational model facilitates the recognition that ‘disability’ is created by social barriers, economic/environmental barriers, and unequal social interactions that affect individuals' psycho-emotional well-being. Some restrictions (which are not classified under 'disability') may arise from the direct impact of impairments associated with autism, also known as 'impairment effects' (Cologon, 2016).

The use of the semi-structured interview schedule

This thesis used a semi-structured interview schedule to conduct interviews during fieldwork because it was determined to be a suitable technique for achieving the research objectives. A semi-structured interview schedule gives the interviewee a sense of agency and grants the interviewer the freedom to ask and modify additional questions in response to what are perceived to be significant responses (Bryman, 2004). Joanne Horton and colleagues (2004) highlight the importance of semi-structured interviews in qualitative research; irrespective of any limitations which may be otherwise solved, for instance by quantitative methods like statistical analysis, semi-structured interviews ensure the detailed generation of data and experiences of the participants. Semi-structured interviews offer flexibility in designing and refining the interview guides. They can also facilitate the exploration of the underlying motives for participants' responses (Horton et al., 2004). The interviewees are allowed a degree of freedom to explain their thoughts and experiences. David Silverman (2004) too, stresses that interviewing is a method by which the participants construct social worlds through information derived from in-depth conversations. K. Louise Barriball and Alison While (1994) concur and highlight the benefits of semi-structured interviews in enhancing the analysis of the perceptions and opinions pertaining to sensitive issues. Thus, semi-structured interviews can enable an in-depth assessment of experiences and highlight/resolve any contradictions (Horton et al., 2004).

I wanted to adopt a flexible approach while conducting interviews and generating data. Flexibility among the participants was also important, as I wanted them to feel comfortable and explain their perceptions. The parents/guardians were looked upon as the experts in constructing their social worlds, who would help me better understand their lives. Considering the possibility of sensitive issues in relation to parenting being explored, I chose to interview parents/guardians using a semi-structured interview schedule. To be specific, I decided to use a relatively informal style of face-to-face interviewing, rather than a structured questionnaire. Mason (2002) points to semi-structured interviews which can help the researcher identify significant themes from the generated data. In this thesis, semi-structured interviewing has enabled the recognition of different themes. The transcriptions which were created from the recorded interviews went a long way towards highlighting and grouping experiences into different themes. Qualitative research entails the production of knowledge that is contextual; the data is constructed through dialogue and social interaction during the interview (Mason, 2002). As per the literature review that I had conducted, it was brought to my attention that many autism-related studies are clinical. Therefore, I decided to adopt a 'humanistic' approach (Mason, 2002) due to my interest in exploring the perceptions of parents/guardians of autistic children. I wanted the parents/guardians who are an integral part of my research to feel comfortable and explain their experiences through conversations and social interaction. The aims and objectives of my qualitative study necessitates data generation by way of interacting face-to-face with the parents/guardians of autistic children, asking them questions, and listening to them to interpret their perceptions. During the interviews, I was self-reflexive in my role as the researcher and about my place in the data generation process.

In this study, the questions directed towards the parents/guardians were open ended and they were given the flexibility to construct the meaning of their respective situations and direct the flow of the interview. I simplified my questions before putting them forward to the parents/guardians. The participants in my research did not indicate any discomfort with the questions; on the other hand, the questions served them with a platform to express their emotions, experiences and perceptions. The parents/guardians were able to guide me, the interviewer, in sustaining the conversation and recreating their individual story/social experiences. Focus group discussions which involve individuals from diverse socio-cultural levels, social statuses and/or hierarchical positions may be problematic for initiating or maintaining interactions; they can create possible inhibitions among some people and discourage conversations (Acocella, 2011). In some instances, focus group discussions may entail interactions between a homogenous group of individuals (with things in common, similar interests), where the idea is to attempt dialogue among/between them (Longhurst, 2003). This study was aimed at understanding the disabling barriers faced by parents/guardians from various social backgrounds and there is a possibility that some may feel uncomfortable in the presence of others. Therefore, I chose to individually interview parents/guardians using a flexible, open-ended interview schedule to better understand their needs and perceptions. In the next section, I explore sampling, in particular, the sample population for this research and the technique that I had chosen to obtain my sample.

Sampling: Purposive Sampling Technique

Sampling and selection refer to the process where relevant sources of data are identified and accessed (Mason, 2002). This study has accessed parents/guardians of autistic children as the sample population. Their perceptions are crucial in solving the intellectual puzzle in my research questions. The thesis does not include interviews with any autistic children for different reasons; for instance, the primary objective is to analyse the disabling barriers, unequal access and privilege, the impact of social interactions and experiences of raising an autistic child. This requires the selection of parents/guardians as the sample to understand their perceptions. Interviewing children does not serve the purpose of the project, and this study recognizes that parents/guardians along with their children are disabled by barriers in the social environment.

The sample is recruited from urban regions of Kerala; the main reason for this is the existence and concentration of clinical and diagnostic facilities, which may not be available in some rural areas of Kerala. Moreover, this increases the likelihood of obtaining participants appropriate for this study, i.e., parents/guardians of diagnosed autistic children. An increased awareness among the urban population and slightly better/easier access to healthcare services, which may be absent in some rural areas, gives an advantage to the researcher in relation to recruiting participants most suited to the research study (Lakhan et al., 2015). Participants were recruited from the largest cities (Thiruvananthapuram, Kochi and Kozhikode) in the following three regions which historically formed the State of Kerala: Travancore, Kochi and Malabar. The regions have cultural variations; for instance, they are characterised by different language dialects, food habits, religious rituals, and clothing habits, among others (Government of Kerala, 2019). Parents/guardians across Kerala shared similar experiences of raising an autistic child, albeit there are some variations in their individual perceptions. As a result, significant differences in relation to cultural variations were not noted. I included participants who did not have access to mainstream services for autistic children with the help of BUDS institutions (please see point five listed under ‘details of the fieldwork’). Some participants were originally from rural areas; however, they had relocated or had come to the city to access services for their child. Their experiences of relocating, difficulties in travelling and facing loneliness away from family/other sources of social support are analysed in the empirical chapters.

Specifically, I used purposive sampling to select parents/guardians across diverse social backgrounds due to their relevance to my research questions and their importance in data generation in relation to the arguments that I have developed (Mason, 2002). The purposive sampling technique helps the researcher decide what needs to be known and seeks specific respondents (usually a small sample size) willing to provide data-related information through social experiences (Etikan, et al., 2016). The aim of purposive sampling is to enable a deep (rather than a large-scale) understanding of experiences (Campbell, et al., 2020). The purposive sampling may be adopted (based on the aims and objectives of the thesis) if people coming from diverse backgrounds may hold different and important views about the issues in question (Campbell, et al., 2020). This is why I identified and chose the participants in my research with a definite purpose; people in my study came from different gender, caste/tribe, religious and socio-economic backgrounds.

This study utilizes ‘maximum variation sampling’ (also known as ‘heterogenous sampling’), a form of purposive sampling which involves recruiting participants across a broad spectrum of backgrounds, in relation to the objectives of the study. The purposive sampling technique helped to select people based on their relevance to the research questions, analytical framework and the explanation/story being developed. It has thus enabled the construction and recruitment of a sample that is meaningful both theoretically and empirically to the research study, because the goal of the study pertains to recruiting parents/guardians across the social fabric, which is crucial to the development of the theory pertaining to my research (Mason, 2002). I recognized the challenges which may arise from the practicality of including people from varied backgrounds. Therefore, I had attempted and succeeded in recruiting participants across the social system within the set deadlines and generate qualitative data (Mason, 2002).

During the fieldwork, I had collected demographic forms that were completed by the potential participants after participating in an informational session which I had hosted. These forms were used to assess and decide on potential participants based on the purposive sampling technique. The majority of parents/guardians who had expressed their interest were included in the study, but I decided to exclude some of them to ensure that the goal of including parents/guardians of autistic children from diverse backgrounds was maintained. For instance, during the sampling process, if I was convinced that including a parent/guardian may significantly increase the number of participants from one particular background, I decided not to choose them. I also did not recruit participants whom I felt may not be able to help me obtain the relevant diverse experiences required to satisfy the objectives of the study. Some parents/guardians who attended the informational session and completed a demographic form had mentioned their busy schedule as a factor which may prevent them from being engaged fully in the interview. After deciding on the sample population and choosing the sampling method, I moved ahead with the plan to recruit parents/guardians for the interview process. The next section will detail the recruitment process in depth.

RECRUITMENT OF PARTICIPANTS

Blaikie (2006) recognizes the concept of ‘meso-social phenomena’ or organizations as a valid source of obtaining data from natural settings. This study has recruited thirty-two parents/guardians of autistic children aged ten years and below from different types of organizations. Kishore and Basu (2011) call attention to the average age at which a child is diagnosed with autism in India; on an average, children are diagnosed with autism between the ages of one and six in India, when compared to some minority world countries, including the United Kingdom, where children in the one to three age brackets obtain a diagnosis. In some ‘low- and middle-income countries’ (LAMIC), a significant ‘detection gap’ persists; some children are either not diagnosed as autistic or the recognition of characteristics relating to autism occur later on in their lives (Bhavnani et al., 2021). Alongside socio-cultural factors (which have been explained in chapters two and three), the clinical services offered by professionals to diagnose children may not be adequately available in some low resource settings.

The parents/guardians who participated in the study, primarily accessed three streams of services for their children: 1. privatized establishments, 2. non-profit organizations/charitable organizations and 3. governmental initiatives. My previous internship experience at a non-governmental organization enabled some access to parents/guardians and other organizations in different urban areas of the State (the ethical considerations for which will be discussed in the 'Research Ethics' section in this chapter). The staff at this organization recommended other organizations in the city and across the State, where I could possibly meet participants best suited to my project. I also conducted my own research on google to search for autism-related organizations in the three urban areas which were selected for my field study. After conducting research, I made a list of these organizations, along with their contact information, which made it easy for me to communicate with them and determine whether I could access potential participants. Furthermore, I received (and accepted) an invitation to join a support group for parents/guardians of autistic children on the 'WhatsApp' social media platform. The suggestions of a few parents/guardians in the group were vital in guiding me to different gatekeepers to request access and interact with potential participants in order to ascertain whether they were willing to share their experiences.

Once communication with the staff at a particular organization was initiated, I planned and allotted time (across the selected areas) to visit the respective facility in person to explain the reasons, aims and goals of the project (the data generation for this research was completed before the covid pandemic restrictions in India). Some members of staff at one organization had stated their interest in helping me find potential participants by speaking to parents/guardians who accessed their services, on my behalf. I had maintained a clear stance (from the beginning) that this study is entirely independent and voluntary participation is essential to the fulfilment of the objectives of my study and to meet the university's ethical requirements. After reading the University of Leeds ethics committee approval form, the staff members at the organization insisted that they will not interfere as they were concerned about possible repercussions/implications.

Some autism and disability organizations were willing to let me access the potential participants; however, others did not entertain my request. For instance, the director of a private organization which I had approached, shared his concern in allowing me to speak to potential parents/guardians about my research project. The director expressed his belief that the psycho-emotional well-being of some parents/guardians may be affected if they opened up about their social experiences. Therefore, he had requested me to seek other avenues. Once I received the permission from the staff at an organization, I handed out information sheets/posters to some members of the administrative staff, so that they could be distributed to parents/guardians. After conferring with the staff about the best time for me to interact directly with the parents/guardians, I went to the organizations at the designated time to hand out flyers directly to possible participants who had arrived to drop off or pick up their children. The digital copy of the poster was also shared within the organization's 'WhatsApp' group, which was then circulated among the parents/guardians. Some parents/guardians, who did not have access to 'WhatsApp' were made aware of the project by other parents/guardians by word of mouth. They contacted me over the phone to discuss and learn more about the study.

The majority of the parents/guardians had communicated with me over the phone to enquire further about the project. Parents/guardians were requested to come for an information session (lasting no longer than thirty minutes), where I explained the purpose/goals of the thesis project and gauged the potential participants' interest by clarifying misgivings about the focus, relevancy and utility of the thesis. Parents/guardians were primarily intrigued and curious to know more about my study. Some parents/guardians attended the session in the hope of further guidance on immediate interventions. As my research was an ongoing study at the time, I provided information relating to local autism organizations, services, and counselling help for parents/guardians. Some parents/guardians could not make it to the information session(s) due to other commitments. I offered them the opportunity to meet on another day based on their convenience. Those who were unable to attend the information sessions (or meet at a later date) were provided the details over the phone. Interested parents/guardians were requested to complete a demographic form (after the session), with the intent of using the information for purposive sampling. The demographic form included the following: name, age, sex, caste/tribe, monthly income, place, district, mobile number and a box for signature which indicates their interest in participating in the project. Parents/guardians were allowed to opt out from filling any information on the demographic form that made them uncomfortable. The contact details of the parents/guardians were then collected and stored in a personal locker. The details were also added to the OneDrive university system. The contact information was gathered to enquire about their willingness or any further concerns regarding their participation, and to also let them know of their selection for the interview process.

Some parents/guardians volunteered (on the basis of a phone enquiry and their participation in an information session) upon accessing both the hard copy as well as the online poster through the ‘WhatsApp’ platform, which entailed the basic details of the project. There were some parents/guardians (accessing other services) who obtained my contact number from other parents/guardians at an organization, who were present for an information session regarding the project. They directly contacted me to find out more about the aims and objectives of the project. After discussing the basic details, I met them either individually or as a group (depending on their convenience) at a venue comfortable for them to explore concerns and clarify any questions regarding the project. Some parents/guardians volunteered for selection by sharing their interest in participating. The research has included parents/guardians who may not have direct access to the different streams of services which has previously been mentioned. I visited some ‘BUDS’ schools to understand the possibility of interacting with potential parents/guardians and gain access to them. The government of Kerala has established BUDS schools, which are free educational institutions for disabled children whose families may not be able to afford to pay for the services (Kudumbashree Story - BUDS School. n.d). Currently, there are sixty-two BUDS schools in Kerala, which are all owned and managed by the local government institutions with the support of the government’s ‘Kudumbashree’ mission and the community structure (Kudumbashree Story - BUDS School. n.d).

The study included male and female participants from the ‘forward’ or ‘general’ caste and the ‘backward’ caste (‘scheduled castes’, ‘scheduled tribes’ and the OBC/ or ‘other backward classes’). Participants from the three majority religions in the State (Hinduism, Islam and Christianity) were also accessed and included. While Mason (1996) highlights that a sample should be large enough to make meaningful comparisons or inferences, Blaikie (2006) recognizes the possibility of studying large populations with relatively small samples. By utilising Blaikie’s analogy, the study generates data through the in-depth interactions with a relatively small sample of parents/guardians to explore privileges and inequalities in relation to social interactions, access to services and impairment effects, with the intention of making inferences across the larger population. However, the study does not plan on making generalizations about whole populations; rather, it is focused on providing detailed accounts of the complexity of experiences faced by parents/guardians of autistic children which may then be mapped onto broader contexts and debates. Once participants were recruited using purposive sampling, interviews were organized based on the convenience of those who were selected. Before proceeding to the section on the interview process, I want to give details about the fieldwork and to share information charts for the reader’s reference.

Details of the fieldwork

This qualitative study was conducted over a six-month period in three urban districts, namely, Trivandrum, Kochi and Kozhikode located in the three regions (Travancore, Kochi and Malabar) that form the State of Kerala, India. The research gave much consideration to important criteria/factors when accessing potential participants:

1. A total of thirty-two parents or guardians of autistic children aged ten years and below were interviewed.
2. As per the Indian Constitution (central government), people belonging to different caste groups are separated primarily into four different categories: ‘Other Backward Classes’, ‘Scheduled Caste’ and ‘Schedule Tribe’ and ‘GeneralCaste’. I included participants from the aforementioned groups.
3. Participants identifying with the three dominant religions in the State (Hinduism, Islam and Christianity) were included in the study.
4. Parents/guardians of autistic children across the spectrum were interviewed.
5. Participants who did not have access to services were identified and included through BUDS institutions (governmental initiative for ‘low income’ families) which provide free services to people in the lower socio-economic category.
6. Participants coming from differing social locations/situations were included.
7. The research sites were broadened, and participants were accessed via various gatekeepers including government organizations, private

> institutions and charities/NGOs. Some participants had come forward by word of mouth and by accessing the shared digital poster of the project on the ‘WhatsApp’ platform.

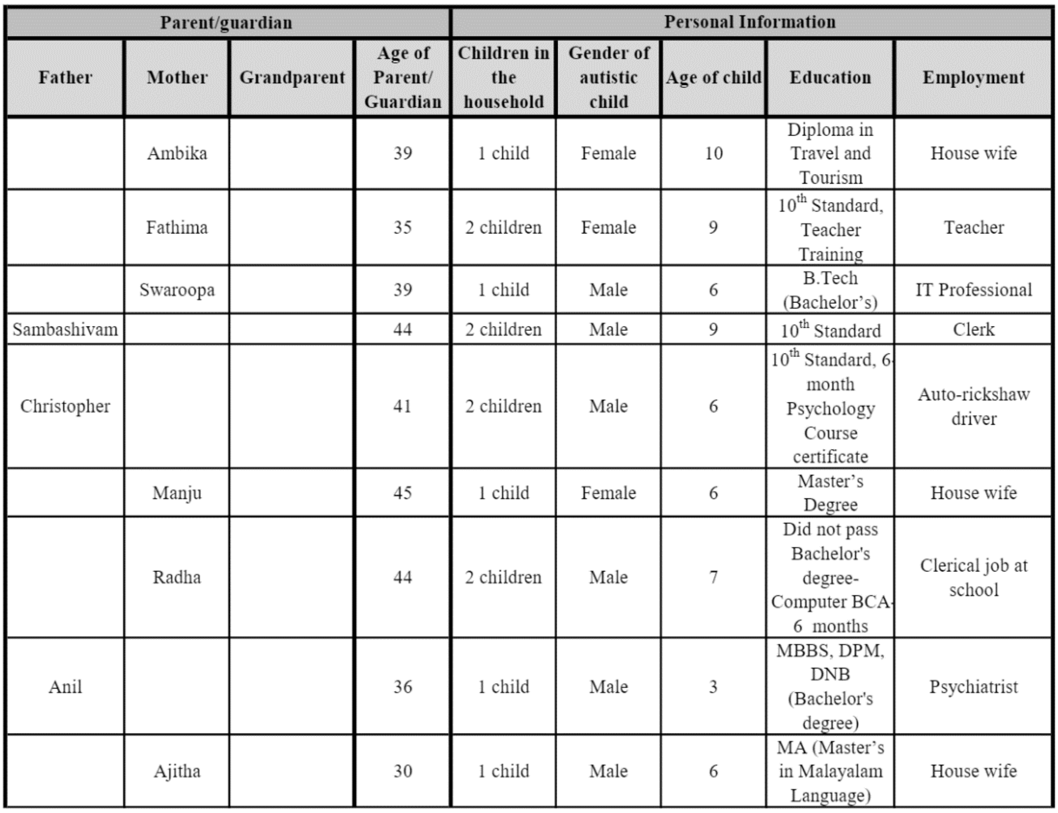
Among the thirty-two participants, twenty-two were female and ten were male, with the oldest being sixty-six years of age and the youngest, twenty-six years. Twenty respondents were part of an extended family system, ten were members of the nuclear family unit, one participant was a member of the grandparent family, while another parent held no responsibility over his children. Parents/guardians of thirty-two autistic children (twenty-two boys and ten girls) were interviewed using semi-structured interviews. The children’s age range spanned between three years (youngest) and ten years (oldest). From the thirty-two children, fourteen were single children in the family, sixteen had one sibling, and two had two or more siblings at the time of interview.

The parents/guardians are from diverse socio-demographic and educational backgrounds; twenty-one participants identified with the ‘Other Backward Classes’, nine can be categorized as being part of the ‘General Caste’, and one participant each identified with the ‘Scheduled Tribe’ and ‘Scheduled Caste’ respectively. Recent estimates show 20% of the Indian population belonging to the ‘Scheduled Caste’, 9% being part of the ‘Scheduled Tribe’, 41% falling into the ‘Other Backward Classes’ category and 30% identifying with the ‘General or Open’ category (Singh, 2019). There were twenty-one Hindus, seven Christians and four Muslims included in the study. Based on the 2011 Census, Kerala has a Hindu majority (54.73% of the population), followed by Muslims (26.56%) and Christians (18.38%).

The consent and willingness of all potential participants were prioritised and while everyone was approached in the same manner, the researcher endured additional difficulty gauging the interests of some parents. Some parents/guardians frankly admitted their uneasiness about participating in the interviews. One parent, a mother of an autistic child, had requested time to discuss her participation with her husband. When I followed up with her, she explained that her husband had advised her against attending the interview. Thirty participants were married at the time of the interview, however, there was one participant who was a widower and another one who was separated. The highest ‘academically qualified’ participant was a doctorate holder, while the ‘lowest academically qualified’ participants had studied up to the eighth grade after kindergarten. There were fifteen parents/guardians who were employed at the time of the interview, while seventeen did not hold any form of employment. All the seventeen participants who were unemployed were identified as women, which highlights the domestic division of labour; an increasing number of women, irrespective of educational qualifications, become the primary caregivers for the children, when compared to men.

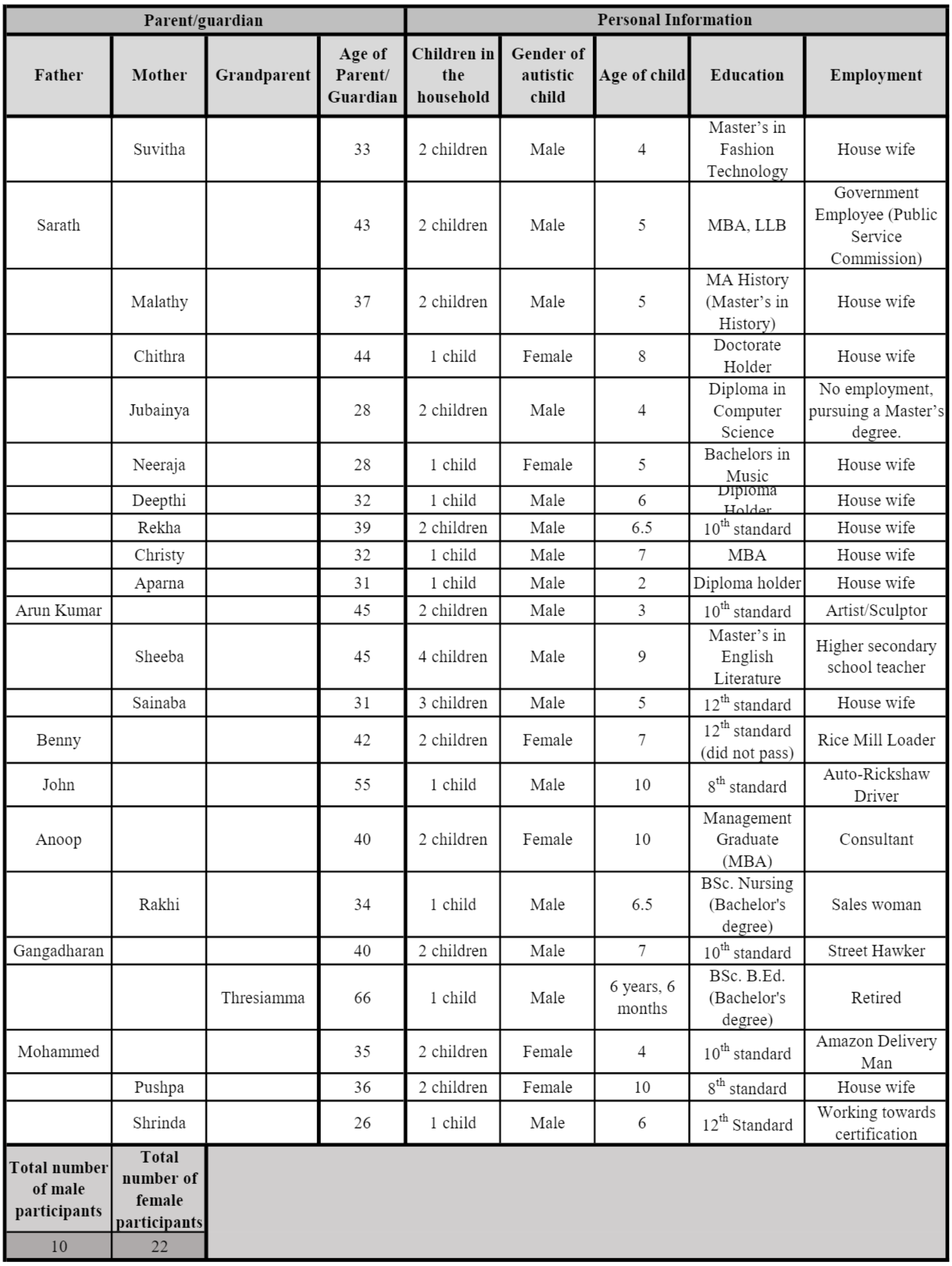
The details of the fieldwork are also provided in a set of figures listed below for further reference:

Figure 1: Social background of parents/guardians



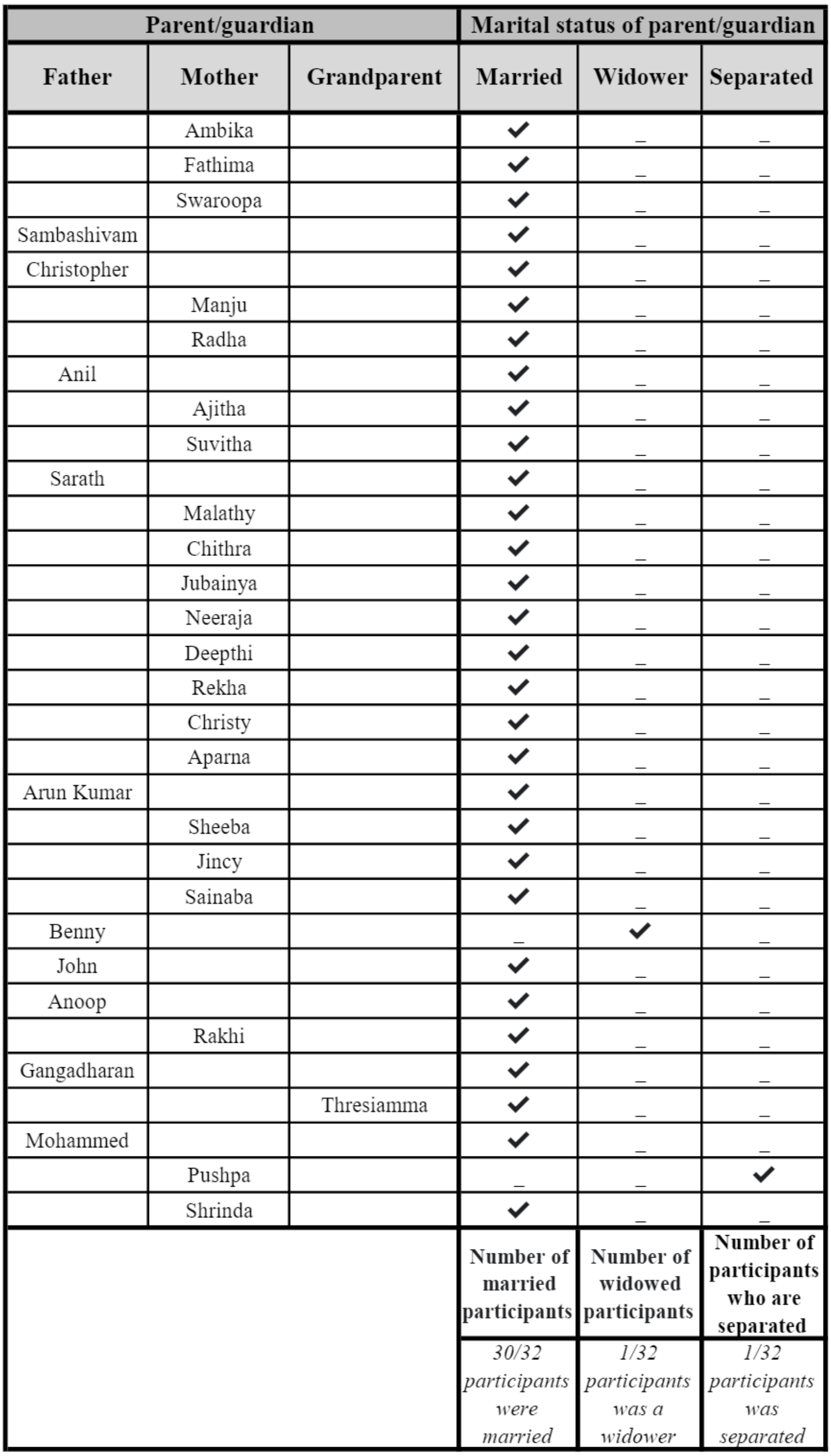
Parent/guardian				Personal Information				
Father	**Mother**	**Grandparent**	**Age of Parent/ Guardian**	**Children in the household**	**Gender of autistic child**	**Age of child**	**Education**	**Employment**
	Ambika		39	1 child	Female	10	Diploma in Travel and Tourism	House wife
	Fathima		35	2 children	Female	9	10th Standard, Teacher Training	Teacher
	Swaroopa		39	1 child	Male	6	B.Tech (Bachelor’s)	IT Professional
Sambashivam			44	2 children	Male	9	10th Standard	Clerk
Christopher			41	2 children	Male	6	10th Standard, 6-month Psychology Course certificate	Auto-rickshaw driver
	Manju		45	1 child	Female	6	Master’s Degree	House wife
	Radha		44	2 children	Male	7	Did not pass Bachelor's degree- Computer BCA- 6 months	Clerical job at school
Anil			36	1 child	Male	3	MBBS, DPM, DNB (Bachelor's degree)	Psychiatrist
	Ajitha		30	1 child	Male	6	MA (Master’s in Malayalam Language)	House wife

Figure 1: Social background of parents/guardians (Continued)



Parent/guardian				Personal Information				
Father	**Mother**	**Grandparent**	**Age of Parent/ Guardian**	**Children in the household**	**Gender of autistic child**	**Age of child**	**Education**	**Employment**
	Suvitha		33	2 children	Male	4	Master's in Fashion Technology	House wife
Sarath			43	2 children	Male	5	MBA, LLB	Government Employee (Public Service Commission)
	Malathy		37	2 children	Male	5	MA History (Master's in History)	House wife
	Chithra		44	1 child	Female	8	Doctorate Holder	House wife
	Jubainya		28	2 children	Male	4	Diploma in Computer Science	No employment, pursuing a Master's degree.
	Neeraja		28	1 child	Female	5	Bachelors in Music	House wife
	Deepthi		32	1 child	Male	6	Diploma Holder	House wife
	Rekha		39	2 children	Male	6.5	10th standard	House wife
	Christy		32	1 child	Male	7	MBA	House wife
	Aparna		31	1 child	Male	2	Diploma holder	House wife
Arun Kumar			45	2 children	Male	3	10th standard	Artist/Sculptor
	Sheeba		45	4 children	Male	9	Master's in English Literature	Higher secondary school teacher
	Sainaba		31	3 children	Male	5	12th standard	House wife
Benny			42	2 children	Female	7	12th standard (did not pass)	Rice Mill Loader
John			55	1 child	Male	10	8th standard	Auto-Rickshaw Driver
Anoop			40	2 children	Female	10	Management Graduate (MBA)	Consultant
	Rakhi		34	1 child	Male	6.5	BSc. Nursing (Bachelor's degree)	Sales woman
Gangadharan			40	2 children	Male	7	10th standard	Street Hawker
		Thresiamma	66	1 child	Male	6 years, 6 months	BSc. B.Ed. (Bachelor's degree)	Retired
Mohammed			35	2 children	Female	4	10th standard	Amazon Delivery Man
	Pushpa		36	2 children	Female	10	8th standard	House wife
	Shrinda		26	1 child	Male	6	12th Standard	Working towards certification
Total number of male participants	**Total number of female participants**							
10	22							

Figure 2: Marital status of parents/guardians



Parent/guardian			Marital status of parent/guardian		
Father	**Mother**	**Grandparent**	**Married**	**Widower**	**Separated**
	Ambika		✓	_	_
	Fathima		✓	_	_
	Swaroopa		✓	_	_
Sambashivam			✓	_	_
Christopher			✓	_	_
	Manju		✓	_	_
	Radha		✓	_	_
Anil			✓	_	_
	Ajitha		✓	_	_
	Suvitha		✓	_	_
Sarath			✓	_	_
	Malathy		✓	_	_
	Chithra		✓	_	_
	Jubainya		✓	_	_
	Neeraja		✓	_	_
	Deepthi		✓	_	_
	Rekha		✓	_	_
	Christy		✓	_	_
	Aparna		✓	_	_
Arun Kumar			✓	_	_
	Sheeba		✓	_	_
	Jincy		✓	_	_
	Sainaba		✓	_	_
Benny			_	✓	_
John			✓	_	_
Anoop			✓	_	_
	Rakhi		✓	_	_
Gangadharan			✓	_	_
		Thresiamma	✓	_	_
Mohammed			✓	_	_
	Pushpa		_	_	✓
	Shrinda		✓	_	_
			Number of married participants	**Number of widowed participants**	**Number of participants who are separated**
			30/32 participants were married	*1/32 participants was a widower*	*1/32 participants was separated*

Figure 3: Religion of parents/guardians

Parent/guardian			Religion		
Father	**Mother**	**Grandparent**	**Hindu**	**Christian**	**Muslim**
	Ambika		✓		
	Fathima				✓
	Swaroopa		✓		
Sambashivam			✓		
Christopher				✓	
	Manju		✓		
	Radha		✓		
Anil			✓		
	Ajitha		✓		
	Suvitha		✓		
Sarath			✓		
	Malathy		✓		
	Chithra		✓		
	Jubainya				✓
	Neeraja		✓		
	Deepthi		✓		
	Rekha		✓		
	Christy			✓	
	Aparna		✓		
Arun Kumar			✓		
	Sheeba			✓	
	Jincy			✓	
	Sainaba				✓
Benny				✓	
John				✓	
Anoop			✓		
	Rakhi		✓		
Gangadharan			✓		
		Thresiamma		✓	
Mohammed					✓
	Pushpa		✓		
	Shrinda		✓		
			Number of participants who were Hindus	**Number of participants who were Christians**	**Number of participants who were Muslims**
			21 out of 32	7 out of 32	4 out of 32

Figure 4: Caste/Tribe of parents/guardians

Parent/guardian			Caste			
Father	**Mother**	**Grandparent**	**Other backward castes (OBC)**	**Open or general caste (GC)**	**Scheduled Caste (SC)**	**Scheduled Tribe (ST)**
	Ambika		✓			
	Fathima		✓			
	Swaroopa		✓			
Sambashivam						✓
Christopher			✓			
	Manju		✓			
	Radha			✓		
Anil				✓		
	Ajitha		✓			
	Suvitha			✓		
Sarath				✓		
	Malathy		✓			
	Chithra			✓		
	Jubainya		✓			
	Neeraja		✓			
	Deepthi		✓			
	Rekha				✓	
	Christy			✓		
	Aparna		✓			
Arun Kumar			✓			
	Sheeba			✓		
	Jincy			✓		
	Sainaba		✓			
Benny			✓			
John			✓			
Anoop			✓			
	Rakhi		✓			
Gangadharan			✓			
		Thresiamma		✓		
Mohammed			✓			
	Pushpa		✓			
	Shrinda		✓			
			Number of participants who identified with the OBC category	***Number of participants who identified with the GC category***	***Number of participants who identified with the SC category***	***Number of participants who identified with the ST category***
			21 out of 32	9 out of 32	1 out of 32	1 out of 32

THE INTERVIEW PROCESS

Parents/guardians who were interested in participating had included their contact information in the demographic form which they were requested to complete. I contacted the parents/guardians by phone, five days after the information session to further gauge their interest in participation and answer any further questions. The phone interaction took place to clarify any additional queries/concerns pertaining to the consent and confidentiality forms which were distributed to the selected parents/guardians. Once participants were selected, plans were made to conduct the interview at a venue that was most convenient for them. Some participants opted to engage in face-to-face interaction at home, while others felt more comfortable doing interviews within the organizational setting. There were a few parents/guardians who had felt comfortable away from home and an organization, choosing to do their interview at a local park and beach, among other settings. Mason (1996) places emphasis on the multi-dimensionality of sampling; a researcher must respect the fact that the sample population is bounded by time and choose to capture experiences at particular locations during specific times.

An interview location, such as the ambience of the home, provided me with an opportunity to make observations about their lived experiences, write them down in a notebook, and implement the same in my data to generate detailed information that may not be obtained from the interview alone; in doing so, a researcher can augment a greater understanding of their (participants') social situations and experiences (Elwood & Martin, 2000). A buddy system was used as it can provide the researcher with protection when entering a field site alone as an outsider (Lopez & Gillespie, 2016). For instance, I had notified a friend on the days of conducting interviews away from the organizational setting (at the houses of participants or a setting of their convenience) to keep track of progress and safety. The semi-structured interview was divided into four sections: 1. Participant background, 2. Individualisation, 3. Social interactions and 4. Family interactions and future aspirations. These sections were developed with the intention of generating data to enhance the understanding of the participant's social context, the psycho-emotional barriers arising from social interactions, and the impairment effects of autism on the family.

In the initial pilot study which I had conducted, I realised that I had to tweak my interview guide because it was difficult to maintain a conversation with some parents/guardians in some instances (further discussed in the section titled, 'Strengths and Limitations'). I found that there were long stretches of silence without a conversation taking place. The initial interviews helped me truly understand the social experiences of parents/guardians. This knowledge/awareness helped me to sharpen my interview schedule so I could explore their experiences and obtain the data required to fulfil my objectives. In general, the polished interview schedule enhanced my interactions with the majority of the parents/guardians. However, I still faced challenges from a few parents/guardians. For instance, one parent/guardian, the mother of an autistic child, kept responding (to my questions) with 'one line' answers. During the interview, I probed more into the strengths of the child in relation to social interactions with family members with whom the child held a close bond. The mother was then able to express her experiences in more detail by speaking about the child's bond with the maternal grandmother.

The open-ended interview questions were asked with clarity to prevent any confusion among the parents/guardians (Mason, 1996), and in cases where some participants could not decipher the questions I had asked, they (the questions) were broken down into sub-questions to enable a comprehensive understanding. During the formulation of the interview schedule, I developed open-ended questions which were straightforward and simple. The majority of the participants went on to lead the conversations. If a parent/guardian felt overwhelmed when speaking about their experiences, I moved towards reorienting the discussion to another topic or provided the necessary comfort breaks respecting the convenience and freedom of the participants. The parents/guardians were also given the option of ceasing the interview and commencing again at a later date or withdrawing from the research entirely, in case speaking about an event in their lives proved too traumatic.

Semi-structured interviewing is designed to explore people's understandings of social reality (Mason, 2002), and this study used open-ended questions to generate interpretations which addressed the direct needs and disabling barriers faced by parents/guardians in Kerala. Michael Patton (2002) recommends open-ended interviews for allowing participants to respond freely owing to their flexibility, spontaneity and responsiveness to individual differences and situational changes. The interview process was beneficial as I could unearth varied experiences of parents through listening and interpretation (Blaikie, 2006). While interviewing, I maintained a neutral stance, even in instances when parents/guardians spoke about highly traumatic experiences. I did not have any inhibitions about conversing with the parents/guardians; nor did I feel any discomfort when I asked them questions. For the sake of clarity, I made sure that questions were asked in a straightforward and professional manner. Even when sensitive topics were addressed, I took care not to probe into them further, and persuaded them to maintain their calm and speak/construct their own experiences. Some parents/guardians stated that they felt comfortable with the interviews because I appeared to be respectful and asked questions in a courteous manner, without putting pressure on them.

After conducting the interviews, the audio recordings were first saved onto a USB drive which was kept locked in a drawer. It was also added onto Google Docs, for which only I held the username and password. The recordings were also kept in the OneDrive university system for added security. They were then transcribed verbatim shortly afterwards. The interview protocol, which was divided into four sections, helped to ensure that the transcriptions were straightforward. The manual copy of the interview protocol had sufficient space for the interviewer to record the participant's comments and add any reflexive notes from the interview (Creswell, 2003). The next section will address ethics, consent and confidentiality in relation to this project.

RESEARCH ETHICS, SENSITIVITY, CONSENT AND CONFIDENTIALITY

I have made genuine efforts to ensure that trust and integrity were maintained so that participants could effectively speak about their experiences freely (BSA, 2017). When conducting the interviews, participants were treated sensitively and were provided the freedom to make decisions regarding participating in, or ceasing, the interviews. The consent and confidentiality forms were distributed to interested potential participants after the initial information session (please refer back to section titled, 'Recruitment of participants'). I had explained to all the parents/guardians that they had the freedom to stop participating in the interview if they experienced any discomfort at any point in the process. I also gave the parents/guardians, who had already completed the interviews, the opportunity to request the withdrawal of their participation and delete their recorded interview. They were given four weeks/one month after the interview to confirm their withdrawal, if at all, they wanted to do so. However, this research has been able to incorporate the experiences derived from the interviews of all the parents/guardians who had participated. Parents/guardians were considered as the ‘experts’ in providing experiential knowledge; the majority of the parents/guardians were able to lead the discussions.

Participants should feel the ability to be transparent in relation to consent and confidentiality, and their concerns are inevitable if they feel unable to express themselves. This study has respected the freedom of participants to make their decisions regarding participation (Patton, 2002). Some parents/guardians had expressed their relief after participating in the interviews. For these parents/guardians, it was the first time (according to them) that they could open up on their stresses, concerns and feelings (be it to family members, friends or others). The fieldwork was conducted in a way which maintained the relationships between the organization (gatekeepers) and participants even after the duration of the research (BSA, 2017). For instance, some staff at a few organizations communicated with me four months after completing the interviews to express that the parents/guardians who had participated enjoyed conversing and expanding on their lives to a person other than someone from their immediate formal and informal circle. For some parents the chance to speak about their experiences was a means to ‘blow off steam’. The staff at these organizations expressed their satisfaction that the parents/guardians were able to undergo satisfactory/beneficial interview experiences.

The research was conducted with the intention of analysing the ‘disabling’ barriers of parents/guardians with regards to social interactions, raising an autistic child, living conditions, social mobility and access to services, and therefore, the researcher had taken the initiative and responsibility to share an accurate account of the report (BSA, 2017). From the outset, I made sure that the role of the interested participant(s) was transparent by sharing the objectives in the language preferred by the parents/guardians. I had also created the informational materials in both

Malayalam and English (some parents preferred to read/speak in English, even though they were well-versed in Malayalam). Jargon-free language was used and it enabled the parents/guardians to make well-informed decisions about their participation (Bryman, 2004). By doing so, I brought clarity to the role of the interviewee, which in turn helped to maintain a professional rapport throughout the duration of the study (Mason, 1996). This further helped to generate the required data through disclosure, trust, and awareness of potential ethical issues. I was also aware that some people may choose to avoid participation, and therefore, I had contingency plans in place (Mason, 2002). I had already made a list and initiated contacts with other organizations to discuss my thesis objectives so that I could access potential participants.

Ethical challenges are difficult to predict and I kept myself aware of sensitive issues and potential conflicts of interest. One ethical challenge that I had faced was the possible interference from some members of staff at an organization, who had provided access to participants (please refer back to the third paragraph under the section titled, ‘Recruitment of participants’). However, the problem was dealt with in a manner which prevented any interference. The approval document that I had received from the University of Leeds Ethics Committee ensured that my research process and fieldwork was free from external influence due to others’ perceived fear of possible repercussions. The form prevented any future external interventions in relation to the recruitment of my participants. The gatekeepers were chosen as the entry point to gain access to parents/guardians because the staff were intrigued to hear more about the project. The staff at some agencies requested that I use my final thesis findings to help the parents/guardians and also the organizations in understanding and meeting the needs of the parents/guardians better by conducting a presentation on the findings and offering sociologically-informed recommendations/suggestions in relation to coping mechanisms which can be directly accessed by parents/guardians.

The relationships in sociological research are characterised by disparities in power and status (BSA, 2017). For instance, the relationships between the researcher, gatekeepers and the participants are crucial. These relationships must be epitomised by trust and integrity (BSA, 2017). I made it a point to treat my participants with genuine warmth and respect. The interactions (between the participants and me) were dealt with in a sensitive manner. The details of the project were explained in simple language and the parents/guardians were given my contact information for any further clarification on the project. I recognize that the gatekeepers may have influenced sample selection by informing parents/guardians (to participate in the information session or to contact me) with whom they hold amicable relations. When I interacted with the potential participants, I explained to them the tenets of informed consent and their right to volunteer or ‘pass’ from participating in the interview. Through this process, I adhered to the principle of obtaining informed consent directly from the research participants to whom access is required, while taking account of the interest of the gatekeeper (BSA, 2017).

I had to consider the practicality of the project, and so I decided to conduct twenty-five to thirty interviews. After completing thirty-two interviews in total, I had generated adequate data which met the objectives of the thesis. The discussions with my supervisors were also beneficial to understand when I needed to stop conducting the interviews. I had kept my supervisors regularly updated on the participant interviews, their diverse responses and experiences. I recognized that the transcription from Malayalam to English would take time and prepared myself to do it for a period of a month. Thus, I was able to realize the size of my commitment, handle the transcriptions and develop themes/categories in a timely manner (Mason, 2002). The participants were given fictitious names to ensure their confidentiality. The study by Angelica Orb and colleagues (2001) recognizes informed consent as something which creates a reasonable balance between over-informing and under-informing. In this thesis, informed consent was a process which could be renegotiated, considering the length of the fieldwork; it took five months to complete the fieldwork and some participants were likely to forget their involvement in the data generation process (BSA, 2017). Therefore, I reminded them periodically of informed consent, confidentiality and their rights/roles as the participants.

The consent form was created in both English and Malayalam (the local language); I ensured that these were handed out, in person or electronically (‘WhatsApp’), to the parents who had expressed their interest in taking part in the research. When some parents (those who did not attend any information sessions) contacted me and expressed a desire to understand more about their role in the project (after accessing the shares on ‘WhatsApp’ or hearing about the project by word of mouth), I provided basic information to them, after which, at a later date, I explained in detail the crucial aspects of my research, informed consent, their rights and roles. Before the commencement of any interview, I remained open to provide any further clarity for the parents/guardians.

The risk assessments pertinent to this project were conducted, along with the moral considerations to ensure that ethical specifications have been met, before the start of the research. An official ethical approval form from the University was completed and approved. The information and confidentiality of the generated data has been protected by storing it on the University of Leeds One Drive with access available only to the researcher through the use of password protection, without any significant chances of breach. Any further identifiers were removed to break the link between the data and identifiable individuals (BSA, 2017). I have safeguarded the data and ensured that (and will continue to do so) the data components will not be released in a way that may enable potential identification of the participants.

CODING AND ANALYSIS

Coding is an early form of analysis that is crucial to qualitative research; it can reduce complex empirical data, make it easier for analysis and help to draw final conclusions (Linneberg & Korsgaard, 2019). It can also enhance the quality of the analysis and findings. Silverman (2004, p. 355) too, mentions that coding is a helpful approach to collect and categorize data as it helps social scientists make the social world more ‘reportable’. Software coding programmes like NVivo can be used; however, I have performed the coding manually to increase the reflexivity in my analysis and research focus. I have further strengthened my own grasp/understanding of the experiences of each individual participant by creating charts and coding the perceptions of parents/guardians. The manual coding of the experiences of parents/guardians has whetted my critical thinking in relation to comprehending and analysing their perceptions. Coding helps to sort data and enables quicker access to data. It is also an approach which makes the researcher revisit the data and identify themes or aspects that may have been otherwise missed during the data generation process (Linneberg & Korsgaard, 2019).

Coding is ‘inductive’ if the codes are developed directly from the data by adhering to the phrases used by the participants. Through this process, codes mirror the data that has been generated. Inductive coding is best suited to an exploratory study, or when it is difficult for the researcher to grasp the concept that is being researched (Linneberg & Korsgaard, 2019). Initially several codes were created which captured the depth of the information in the data that I had generated. Multiple cycling of the data can result in the researcher having a smaller number of concrete themes. Deductive coding refers to a pre-defined list of codes that is created before coding the actual data. This approach enables the coding of concepts that are already relevant in the literature. For this thesis, I used a ‘blended’ approach or the combination of an inductive and deductive approach to sort and separate the themes from the collected data.

The study has implemented a thematic approach (Mason, 1996) for data analysis where the transcribed data was categorised into themes, so that the data can be retrieved and consistently collated. The thematically organized data was constructed in an interpretive sense by drawing inferences from what the data actually represented. As the research entails conversations and interactions between participants and the researcher, themes were derived from the participants’ understandings, meanings and feelings. Themes were identified by collating the experiences of parents/guardians, which in turn enhanced the comprehensive understanding of their social experiences.

The data analysis is a cross-sectional one which required translation from the source language (Malayalam) to the target language (English) (Patton, 2002). Philip Larkin and colleagues (2007) emphasise the importance of the grasp of language along with cultural understanding. Therefore, the transcripts were accurately translated from Malayalam to English without any help from external translators, thereby doing justice to the respondents’ perspectives. Rachel Berman and Vappu Tysska (2011) suggest that external translators can change meanings by omission, revision, and reduction of content. Additionally, translators may produce knowledge that is not attuned to the objectives of my research. Therefore, I did not seek help from translators; there was no need for it because I am very fluent in the Malayalam language. After the translation/transcription, the collated data was analysed thematically to produce results relevant to the research questions.

STRENGTHS & LIMITATIONS

This research used a pilot study to enhance the strength of the research methodology and to be more receptive to the sensitivity of the participants. For instance, the pilot study improved the questions in the interview guide to ensure that the study objectives were fulfilled. As a researcher, the pilot study made me aware of better ways to frame a question, which in turn helped to maintain a conversation about a subject when interviewing the participant. The pilot study was important because it enabled me to ask participants relevant questions, some of which were of value to them as parents/guardians. I also perceived the possibility that some questions may trigger conversations pertaining to sensitive issues. For instance, speaking about social barriers arising from social/family interactions, and about the direct implications of impairments associated with autism, can be emotional for some guardians/parents. Therefore, the pilot study was used to ensure that the interview technique functioned appropriately and could be modified to prevent any unwelcome issues. A pilot study can help address challenges which may arise after initial or pilot interviews (Bryman, 2004). This study is qualitative in nature and it has helped me to unearth rich, nuanced and in-depth data which may not be entirely possible when using other methods.

Aside from the strengths, there are also certain limitations to this project. I had difficulty in gauging the interests of all the parents/guardians with whom I could hold an initial interaction (please refer back to ‘Recruitment of participants’ section for more details). Some parents/guardians chose not to participate and expressed their uneasiness about sharing their experiences. The mother of an autistic child was advised to refrain from interactions by her spouse. She stated that the prospect of being interviewed made her husband feel uncomfortable. The husband of a participant (the grandmother of an autistic child) asserted that my project frustrated him. In his view, the long-term goals of the project were acceptable. However, he was seeking immediate interventions for his grandchild. While I could not give the couple any guidance to immediate interventions, I was able to direct them towards autism-related community services, and counselling support.

This study does not reach people identifying with all the different castes/tribes across the State of Kerala due to practicality issues and time constraints. In contemporary Kerala, there are innumerable different castes; some people may also choose not to identify with any caste/tribe. This makes it difficult in terms of practicality; therefore, I have included individuals from across the caste system for the purpose of this study. I have grouped people identifying with the different castes under the government classification to enhance the feasibility of the project. Another limitation arises from choosing participants from urban regions, resulting in the limited involvement of people living in rural areas (please refer back to the ‘sampling section’ for additional information).

SUMMARY

This chapter explored the methodology that was used to conduct the field work for this thesis. This thesis utilised a methodology which is rarely used in sociological research in Kerala. For this thesis, participants across varied social backgrounds were recruited via purposive sampling method to better understand the barriers they face in relation to social interactions, access to resources and raising an autistic child. The fieldwork was completed before Covid-19 intensified in India. I dealt with distinct ethical issues in the most appropriate manner. The majority of the gatekeepers indicated their interest in knowing the findings and outcomes from the fieldwork, once the thesis was submitted. According to them, the findings may enhance their established understanding of the issues faced by parents/guardians and their children. This may help them better identify possible interventions and better-quality services to meet the diverse needs of the family. The majority of the parents/guardians wanted to help me genuinely and participating in the project offered a platform for them to express their experiences. All the parents/guardians insisted that the face-to-face interviews were the first time they had spoken to anyone in detail (outside immediate formal and informal support systems) about their perceptions. Thus, the field work was conducted with the aim of bringing an added dimension to Indian sociological research by analysing parental perceptions at the intersection of different factors, using the social relational model. The next chapter is the first empirical chapter in this thesis and it explores the complex experiences of parents/guardians, and in particular the mothers, of autistic children.

CHAPTER 5: THE INVOLVEMENT OF PARENTS/GUARDIANS OF AUTISTIC CHILDREN

INTRODUCTION

The first empirical chapter in this thesis places emphasis on the roles and responsibilities of parents/guardians in the lives of autistic children. In particular, this chapter analyses parental perceptions in relation to their roles and the different barriers that may overwhelm them. An in-depth analysis of parenting responsibilities is provided and the same enhances an understanding of the division of roles between them (the parents/guardians). Who is the primary caregiver? What is the role of the mother and the father or the guardian? What are their perceptions of caregiving? What are the disabling barriers experienced by parents/guardians? This chapter seeks to address the aforementioned questions by linking the experiences of parents/guardians to the history, economy and culture of India. Traditionally, women or mothers are the primary caregivers for children and the elderly population in Keralan society. However, contemporary times are characterised by the increasing involvement of men or fathers in caregiving duties. The inequities and barriers arising from the division of roles are explored using an intersectional framework to understand the complex experiences of parents/guardians. Over the years, the joint family structure has gradually been replaced by the nuclear family, even though the joint family system persists among some families. This section intends to enhance understanding of the pressures faced by parents/guardians on a daily basis. The diverse living situations highlight the inequities/social barriers faced by some parents/guardians. The onus of the growth and development of a child is placed on the parents/guardians. The pressures faced by some in relation to juggling caregiving duties and other responsibilities can put pressure on them and create disabling barriers. Gendered divisions of roles were found to be among the major influences upon parenting experiences. Thus, the empirical data demonstrates the varied perceptions of parents/guardians and highlight their pressures. The next section will specifically explore and analyse the pressures experienced by some mothers of autistic children. It will assess the concept of motherhood, identify the crucial support of grandparent(s) in relation to mothering an autistic child, and highlight the importance of spousal support.

THE PRESSURES EXPERIENCED BY MOTHERS

The data generated highlights the overwhelming daily involvement of mothers/women as guardians of autistic children. In India (and elsewhere), women/mothers are expected by the social norm to leave employment and engage in daily caregiving duties at home. Motherhood is associated with constant devotion to the children and the willingness to leave their professional obligations (Gupta, 2020). Sigan Hartley and colleagues (2014) draw attention to mothers of young disabled children (with developmental impairments) who spend less time in paid employment in comparison to mothers of non-disabled children. Fathers of disabled children also leave paid employment earlier than their peers with non-disabled children; however, the number is significantly lower than that of mothers (Hartley et al., 2014). Shruti T. Johansson (2015) too, states that some mothers may leave employment in order to be actively involved in daily caregiving duties and address their child's needs.

Women/mothers are assigned the role of the primary caregiver; the pattern of domestic division of roles, where the mother undertakes the bulk of the caregiving obligations for the child, and the father remains as the primary income earner, is more salient among families with disabled children (Hartley et al., 2014). The majority of the mothers who had participated in my study did not hold any form of employment at the time of the interview. Some mothers, who held high academic qualifications, chose to leave their jobs to care for the autistic child. The following quote by Christy (C/GC) gives evidence of the same:

> After marriage and especially post the birth of my son, I stopped working and now I am a 'Home-maker' [an individual managing the responsibilities at home]. I have an MBA in HR Marketing and had worked for a period of three years. My husband's job requires him to travel extensively and he is here for a short period, every 3-6 months. My strength today is because of my parents who have been the biggest sources of strength.

Chitra's (H/GC) experiences were similar to Christy's. She stated the following:

> I am a PhD holder, but right now, I am not in a position to seek employment due to my daughter's problem. Presently I live with my father and daughter.

> My husband, who is an accountant, is based in Bangalore [different city; Chitra lived in Thiruvananthapuram]. My husband and I hold the same expectations for our daughter, but my father is involved more with her things.

Christy and Chitra hold academic qualifications of Master's degree and above; however, both remain unemployed and engaged in caregiving responsibilities at home. Their quotes indicate gratitude to the maternal grandparent(s) who provide daily support, while the husbands are away at work. The study by Jennifer Hillman and colleagues (2017) stresses the importance of grandparent support for autistic children and their parents. Grandparents not only share the responsibility of daily caregiving needs, but also offer emotional and financial support to the parents/guardians. Paula Prendeville and William Kinsella (2018) call attention to the involvement of grandparents in the lives of autistic children and their parents/guardians. Although their involvement can be complex and oppressive in some instances, some grandparents offer crucial support in terms of caregiving. The calming influence of the grandfather is also highlighted in the study by Prendeville & Kinsella (2018). Some parents/guardians may place value on the support received from their own parents as it enhances their adjustment towards the child's needs and development (Findler, 2016). As per their respective experiences, Christy and Chitra are managing caregiving responsibilities with the economic support (income) of their husbands and the daily help/assistance provided by the maternal grandparent(s). Some mothers had expressed their concerns/frustrations in relation to the husband's limited involvement in the daily caregiving obligations.

The discussions on the gendered division of roles are multifaceted; important discourses have drawn attention to the dynamics of capitalism as a significant contributory factor to the hierarchy within the household which is evidenced by an increasing number of women in 'unpaid' labour (Pilcher & Whelehan, 2017). The work carried out at home by the women increases surplus value and sustains capitalism. Patriarchal hierarchy, prior to the onset of capitalism, is highlighted as another contributory factor which sees the responsibility of domestic chores and caregiving duties being placed on mothers (Pilcher & Whelehan, 2017). These factors weaken their access to resources, increases their economic dependence on men, and create unequal power relations within the household.

Among some cultures in India, gendered division of roles primarily associate women with the reproductive function, motherhood and child-rearing (Dey & Das, 2020). Some gender norms may restrict the social mobility of some women and in such instances, the support of the father becomes especially important (Jose et al., 2021). According to Jose and colleagues (2021), some studies have highlighted the limited involvement of fathers in the daily caregiving needs of disabled children, when compared to fathers of non-disabled children. Adequate spousal support can enhance the adjustment and psycho-emotional well-being of mothers of autistic children. The limited support offered by spouses can create overwhelming stress for mothers (Jose et al., 2021; Mitra & Singh, 2007). Motherhood can be empowering on one hand; however, it can also depict the powerlessness/pressures faced by some mothers on a daily basis (Dey & Das, 2020). The quote by Neeraja (H/OBC), a Bachelor's degree holder and the primary caregiver for her autistic daughter, indicated frustrations stemming from unequal relations within the household:

> I have completed a degree in music and I worked as a music teacher for a year. However, after the birth of my daughter, I stopped working. My husband [a musician] stays with us on and off because he is involved in a lot of music programs. There have been no frictions as such, but I feel that if my husband is present more often, he could've understood my child's emotions and feelings better. I spend more time with my child and my husband does not see everything that goes on.

Neeraja's responses suggest that her stresses and barriers stem from her husband's limited involvement in caregiving responsibilities. The husband's income-earning role may have restricted her own chances of employment. The same factor may have placed the primary child-rearing responsibilities on the mother. Neeraja's perceptions of her role as the parent/guardian highlights unequal social interaction. Her experiences can be better understood and analysed by using Thomas's social relational model of disability. Thomas (1999) focuses on unequal social interactions as a core tenet of her concept of disability; disability occurs during the unequal social interactions between those who are powerful and powerless, where the latter may face internal social barriers which affect their psycho-emotional well-being. The limited involvement of the husband in relation to daily caregiving obligations has created disabling barriers for Neeraja. She aspires for her husband to be more involved in her child's life so that he can be more receptive and understanding of the child’s needs. Neeraja’s indication of her frustration regarding the husband’s limited involvement shows that she can feel emotionally overwhelmed and face severe pressures without adequate spousal support. Thus, Neeraja’s perceptions suggest that caregivers too face disabling barriers, devaluation and oppression within the household.

Social norms place value on autonomy and productivity over social relations which may create added pressures on the family (Ghosh & Banerjee, 2017). In some instances (like that of Neeraja’s), the emotional bond between parents/guardians may be adversely affected when the mother is tasked with the majority of child-rearing duties. Some mothers, however, internalise the notions of ‘good mothering’ which involves sacrifice and selflessness, even though they may endure the pressures of caregiving. Jasjit Sangha (2014) draws attention to some mothers in South Asia (including those in India), who may imbibe a strong sense of obligation to offer selfless service to the family. The needs of the family are placed above their own needs. The caregiving work of a mother is characterised by the privileging of these values (Ghosh & Banerjee, 2017). Jane Pilcher and Imelda Whelehan (2017) highlight the importance of the perspectives of couples (amongst themselves) on what should be their respective roles and whether or not they should consider them (the roles) to be fair. Some mothers may insist that roles within the household are fair, even if they shoulder the majority of the responsibilities of raising the child. Some may perceive that sharing responsibilities equally may include the basic involvement of men in housework and caregiving (Pilcher & Whelehan, 2017). Therefore, men and women have been found in some instances to consider their respective obligations as ‘fair’, even if an increasing number of women are engaged in caregiving duties and experience severe stresses. Domestic division of roles can be determined by context, preferences, job hours and the perceptions of the parents/guardians in managing everything (Pilcher & Whelehan, 2017).

Suvitha (H/GC), a Master’s degree holder and mother of an autistic child, expressed her pressures as the primary caregiver for her son:

> Since moving to Thiruvananthapuram, I am extremely busy with my son's therapies; I have to take him everywhere. As such, I have not been able to go to any employment. When we go for therapy, I have no option but to take my elder son along. He had a blessed life till he was four years of age, after which his life got turned upside down, because I had given birth to my younger son [autistic] by then. We try to make him [elder non-autistic son] happy and not feel neglected. It is difficult; like a careful tight rope- a wrong step can shatter anyone.

Suvitha's experiences indicate the pressures of performing multiple roles without the daily support of her husband. She had drawn attention to facing difficulty in ensuring a balanced life for the family, especially for the non-autistic sibling. The lives of non-autistic siblings too may be adversely impacted when there is limited support from other sources such as the spouse/father. Irrespective of the pressures faced by Suvitha, further responses are evidenced by her strong sense of obligation to provide selfless service to the family. According to the following quotation, Suvitha considered the duties to be equally balanced:

> I resigned from my job in Bahrain and came back home for my son [autistic]. Going ahead, I'm not sure if I will be able to work. If I was employed, I will not be able to devote time for my son. My husband [who has remained in Bahrain] would like to be more involved, but job commitments prevent him from doing so. The [daily] responsibility of looking after my younger son [autistic] is entirely mine. My husband provides financial and emotional support and it is a 50-50 split. Therapies are expensive and financially, we may go through certain challenges as I am currently not earning. At the moment, I am looking after my son with my husband's support and sharing responsibilities equally.

The mothers mentioned come from diverse social backgrounds. The caste/tribe status may have enabled access to institutional/ educational resources for Christy, Chitra, Neeraja and Suvitha. An increasing number of women are absent from political power structures and are engaged in less technological and more exploitative work, with limited decision-making roles in the household (Thresia, 2014). The experiences of all the aforementioned women give evidence to the same. All the mothers were engaged in caregiving work (or had left their employment to engage in caregiving work) irrespective of their educational qualifications and previous experiences of employment. The report by C. U. Thresia (2014) also highlights the exclusionary practices faced by women who identify with the 'scheduled caste', 'scheduled tribe' and 'other backward classes' in different social spheres including education, health and employment. However, the reservation policy in India, based on the caste/tribe system, qualifies some who fall into the ‘scheduled caste’, ‘scheduled tribe’ and ‘other backward class’ categories to education and employment (Kayama and colleagues, 2019). For instance, Neeraja, who identified with the ‘other backward class’ held a Bachelor’s degree qualification. The caste/tribe factor may have opened up her access to education and gainful employment. However, she too, later decided to leave employment and be solely involved in her daughter’s upbringing.

The data generated is indicative of the following: gendered division of roles place pressures on some mothers and they are subjected to unequal social interactions within the household. These unequal interactions primarily stem from the limited daily spousal support offered by the father. It negatively impacts on their psycho-emotional well-being and creates disabling barriers for them. In some instances, mothers accept the ‘bread-winner’ role of the father and continue to be economically dependent on their husbands. This creates a cycle of barriers faced by the mother and continues to subject them to pressures. The caregiving responsibility for the child is primarily placed on the mothers who are expected to leave employment and manage the child and the household. The fathers are expected to follow the traditional role of the bread-winner/income earner, and in some instances may not be involved on a daily basis. The caste/tribe identity may be a factor which enhances parents’ access to educational, economic and social resources. It is possible that reservation in education and employment and the historical privileging of some caste groups may have benefited some parents/guardians in gaining access to educational, social and economic resources. Parents’ desire to access services which they deem as the most appropriate for their child may be achieved with the help of such resources. However, the gendered division of roles remains the primary factor determining the relationship between parents/guardians, spousal support, and the internalization of pressures (by mothers) stemming from unequal social interactions. Irrespective of access to resources (including financial standing and informal support), mothers experience significant stresses without adequate spousal support. When the daily involvement of the father is limited, some mothers feel stressed and their psycho-emotional well-being is undermined, which may strain the emotional bond between the couple and generate overwhelming consequences for the mother. The same factor can add to their stresses by reducing the financial security of the family (and increasing the economic dependency of mothers). Thus, the gendered division of labour is a significant factor which determines the living experiences of mothers. Some mothers are adversely affected by the unequal social interaction in the home, which is considered to be a norm in the society.

Some mothers are engaged in both employment and caregiving responsibilities. Fulfilling multiple roles can create intense pressures and stressful circumstances. The next section analyses the experiences of mothers who work and take care of their autistic children. The section explores the complex factors which influenced their experiences.

Stresses endured by working mothers

Silvia Barcellos and colleagues (2010) insist that some women in majority world nations, including India, obtain lower educational qualifications, have fewer chances to get employed, and are more likely to experience poverty in comparison to men. On the other hand, Manimekalai Kalidasan and colleagues (2019) draw attention to the increasing participation of women in employment in India. They cite inflation and urbanization as factors which enhanced the participation of women in employment. The informalisation of the labour force through liberalization and privatization has witnessed an increase in the participation of women in the labour market (Kalidasan et al., 2019). State provisions regarding child-rearing, community care and social security are limited; such limitations may increase the responsibility of women in both the labour market and the household. Domestic roles are considered to be the natural task of mothers; although employment of women may be accepted in some households, the husbands/partners of some women may not want to share daily caregiving responsibilities (Kalidasan et al., 2019). Some mothers who had participated in the study were the primary caregivers for their children. They were also engaged in paid employment. These mothers had to juggle different responsibilities, while ensuring that the child’s needs were met. Some mothers experienced difficulties arising from their individual contextual situations.

Multiple work-related and caregiving demands may create stresses for mothers. Hartley and colleagues (2014), however, suggest a correlation between paid employment and positive psycho-emotional well-being. The ‘buffering effects’ from multi-tasking can help some parents/guardians to manage any difficulties which may arise. The data generated shows that engaging in a form of paid employment and performing caregiving roles and other tasks may not necessarily generate stress-free experiences for parents/guardians. However, the access to economic resources and a strong informal support system can ease their pressures (in some instances). Economic resources are vital for acquiring other forms of resources, including social and cultural resources (Waterfield & Whelan, 2017). Cultural resources like education, habits, informal social skills and social resources such as social networks can be converted to economic resources (Bourdieu, 1986). For instance, academic qualification from an esteemed institution and access to professional networks can enhance possibilities for an individual to find paid employment. Hence, these resources play a decisive role in determining people’s choices or actions. Pierre Bourdieu (1986) too, places emphasis on economic resources and reveals how these resources can produce social and cultural resources. Thus, an ‘impersonal’ economic material gift can be converted into something ‘personal’.

Swaroopa (H/OBC) is the mother of an autistic boy, who was living with her child and parents. Swaroopa’s husband was employed abroad, while she too was employed at the time of the interview in an IT firm. Swaroopa indicated the stresses she has faced as the primary caregiver for her son. However, her responses suggested that some disabling barriers can be mitigated with the aid of informal support (maternal grandparents) and the availability of economic resources

> I live with my parents and my son, while my husband lives and works in the U.S. The path to autism diagnosis was zigzag rather than straightforward. I went to different organizations to get my son assessed and diagnosed. It would have been great if a child development centre was multidisciplinary. I am able to procure the necessary resources for my child; based on the suggestions of the professionals, I have been able to acquire musical toys and other resources. I drop him off at the centre he attends and comes back late; during that time, he spends time with his grandparents [maternal].

Swaroopa had expressed her difficulties in obtaining a diagnosis for her son and had stressed the need for more multidisciplinary centres which can offer a direct route to diagnosis and interventions for parents/guardians. However, her responses did not indicate severe internal or external disabling barriers. The gendered role as the primary caregiver and her work obligations did not overwhelm Swaroopa. The support offered by the maternal grandparents may have been a buffer to any stresses experienced by her. The access to economic resources is another factor which had mitigated Swaroopa's stresses as it offered a route toward obtaining desired materials/services which were beneficial to the child's development.

Some mothers who lacked adequate informal support and access to economic resources faced severe disabling barriers. Radha (H/GC) is a mother of two children who was employed at the time of the interview. Her youngest son is autistic. She lived with her husband, who was unemployed at the time of the interview, and her aging mother. Radha is the primary caregiver for the child and also the primary income earner in the family. She insisted that her husband did not hold a role in the son's [autistic] life. Radha had drawn attention to the limited support provided by her mother due to age-related difficulties. The mother expressed significant stresses which arose from raising her son and working to make ends meet.

Miriam George (2011) draws attention to the socio-cultural climate in Kerala, which is influenced by patriarchal norms and the dominance exerted by some males. The rise of the nuclear family structure, enhanced access to healthcare, education and employment for women may not mean significant improvement in their life choices. Women's roles are still characterised by unequal relations/interactions with their respective partners (George, 2011). In the household, a woman's role is primarily associated with mothering and child-rearing. In relation to employment, some women may face barriers pertaining to upward social mobility. Women who hold employment and professional aspirations can be deemed as a threat to the patriarchal social structure and this may increase the stressful experiences faced by some women in society (George, 2011). Radha's experiences suggest unequal social relations/division of roles, which creates difficulties in performing multiple roles:

> I work as an office staff at the local all-boys school. My husband is unemployed and I am the sole income earner. My husband's role in my son's life is pretty much non-existent. My mother helps me with caregiving duties. I want to spend more time with my son, but I cannot as I have to earn an

> income to sustain the family. If we were in a better position financially, I could have spent more time with my son.

The gap in relation to the domestic division of roles is evident in Radha's experiences. The gendered expectations placed on her and the prevalent socio-cultural norms are so significant that it has created stressful experiences. Pilcher and Whelehan (2017) explain a set of hypotheses described by Aassye and colleagues (2014). The person (in the household) who earns less is engaged in more household work (also known as the relative resources approach), the partner who earns less performs more caregiving work (the time availability perspective), and the person who brings less income engages in more domestic work (economic dependency model). The perspectives of couples on respective gender roles are also highlighted (Pilcher & Whelehan, 2017). However, Radha's experiences highlighted the stresses piled on her as a result of limited spousal support. She was the sole income earner, and yet she was expected to take on the mantle of the primary caregiver for the child. According to Radha, the differences in expectations of roles had created an unequal social relationship between Radha and her husband. The same factor(s) impacted her access to resources and her psycho-emotional well-being:

> I have my parameters; for instance, I cannot afford a house with more space or a car to take my son to the therapy centre. My husband should stop drinking [alcohol] and find a job. If he had a positive mindset, then things would've been better. He does not engage with my son and all of this creates much tensions. I do not know how I am going to manage things after my mother's time.

The occurrence of an impairment in the family may also affect roles and family experiences. Radha had indicated that her husband had a physical impairment and he was employed prior to the occurrence of the impairment. Disabled parents experience high rates of poverty, lower educational attainment, increased rates of social isolation and limited social support (Albert & Powell, 2020). The husband may have experienced social isolation and discrimination in relation to maintaining his previous job position. He may also have faced barriers to finding another job, which may have in turn factored into his alcohol addiction. The husband's possible experiences of these barriers may have impacted the family's financial standing, and created unequal social relations with his wife and children. According to Radha, the husband had also endured some restrictions in relation to his impairments. However, Radha implies that social isolation and discrimination based on impairments formed the basis of disabling barriers experienced by her husband. Economic resources are influential in determining family experiences; insufficient access to these resources may restrict a family's access to affordable disability-related services (Weiss et al., 2013). The following quote by Radha highlighted her stresses which were a result of the barriers experienced by the husband:

> He [husband] had a good job, but has left that and now sits at home. He also has a physical impairment to his leg and finds it difficult to walk. My husband is also an alcoholic- I believe that my plight is due to his alcoholism. I therefore cannot entrust my son in his care. If he was cooperative, it would've halved my tensions.

Radha had recounted experiencing pressures from raising her autistic son. Specifically, she had mentioned the restrictions which arose from her son's impairments. Impairment effects, according to Carol Thomas (1999), is a bio-social concept, which involves the interaction between impairments and disability. In the social relational model, impairments cannot be associated with a disability because the latter refers to the social oppression and discrimination experienced by people with impairments. However, some restrictions of activity are caused by impairments; for instance, an individual may not be able to engage in a particular activity due to their impairment. An autistic child may interact in certain ways (different across the spectrum) to communicate their needs. When parents/guardians do not have the informal or formal support systems to understand their children, they too face some restrictions in helping their child. Radha expressed feeling overwhelmed and confused when her son displayed actions which she could not understand:

> He is very restless and may try to jump into ongoing vehicles on the road. If there are shops, he may run toward them and I will have to forcibly deter him from doing the same. There is a repetitive element in his actions and affinities. Sometimes, it is difficult to handle him. I like to take my son out for socialisation, but my husband cannot tolerate his antics and we get into an argument.

Thus, Radha's experiences highlighted a mixture of different factors which created barriers for her. The gendered division of roles is the most significant factor, as the expectation of caregiving is placed on the mother along with her duties as the sole income earner in the family. Therefore, the multiple responsibilities created overwhelming stress, which then paved the way for marital problems. When a mother does not receive adequate spousal support, she may experience severe disabling barriers; the unequal social relations can significantly overburden mothers like Radha, who may have multiple responsibilities. The limited upward social mobility of some women was previously explained and Radha's financial concerns may be attributed to the same. These factors not only burden mothers, but they can pose a barrier to obtaining resources and may push them towards deprivation.

Impairment in the family may create some restrictions for the parents/guardians. Radha had explained that her husband had held a job previously until the occurrence of an impairment. The husband may be prevented from accessing paid employment opportunities due to the limited social accommodation in the labour market for people with impairments. These barriers may also stem from the unequal social interactions between people with impairments and people without impairments, where some people (without impairments) with power may impose barriers on people with impairments. These barriers may result in the socially engendered undermining of their (people with impairments) psycho-emotional well-being (Thomas, 1999). When the psycho-emotional well-being of individuals with impairments is negatively affected, some may not want to take the initiative to seek employment, and may feel socially isolated. Radha's husband may have also experienced some restrictions in relation to the impairment. These factors may have resulted in the father resorting to alcohol as a stress buster. His alcoholism had negatively affected the couple's marital relationship and their roles as the parents/guardians. The 'impairment effects' of the child is a factor which had created some restrictions for the mother. Radha had noted some difficulty in looking after her child and understanding her child's needs, especially in some instances when the child had displayed certain characteristics. However, the overlying factor which determined her experiences were the unequal social interactions which stemmed from the gendered division of roles. Radha may not have had time to research and find centres/services which offered support that enhanced her understanding of the child's needs. Although out of work, the husband did not involve himself with the child (according to Radha) and the role of the primary caregiver is shouldered by Radha. Thus, engaging in caregiving obligations and work-related responsibilities can be overwhelming and create significant stresses for the mother.

Praveena Kodoth and Mridul Eapen (2005) draw attention to the low gender disparity in higher education, which is evidenced by an increasing number of women graduates in general arts and sciences when compared to men. However, Radha's unsuccessful attempt at completing an undergraduate degree (according to her) may indicate the possibility that women's education is oriented towards fostering 'female domesticity' (Kodoth & Eapen, 2005). Therefore, Radha may have had difficulty finding opportunities to enhance social mobility. The differences between meritorious and the caste-based reservations have generated added discourses on educational inequality (Kodoth & Eapen, 2005). Some people who had identified with the 'general caste' have argued against the idea of reservations, which they insist have undermined the belief in equal citizenship in the country (Kodoth & Eapen, 2005). Therefore, caste/tribe identity may have affected Radha's access to employment and education, thereby creating structural barriers. Thus, this section has highlighted the influence of the gendered division of labour as the primary underlying factor which affects the experiences of parents/guardians. Unequal social interactions between parents/guardians can create disabling barriers for mothers of autistic children and undermine their psycho-emotional well-being. Impairment in the family and the caste/tribe identity are also significant factors. Out of four mothers who were engaged in paid employment, the experiences of Swaroopa and Radha (in particular) were detailed in this section to provide a nuanced analysis of complex parental experiences and to prevent any possible repetitions. The next section will analyse the experiences of the grandmother of an autistic child and examine the barriers she had faced as the primary guardian.

A grandmother's perceptions

In this study, one participant, who was the grandmother of an autistic child, was also his primary female guardian. Susan J. Kelley and colleagues (2011) draw attention to the roles and subsequent restrictions some grandparents may face when raising grandchildren. Although some grandparents may take on the responsibility of caregiving and remain committed, they may also be subjected to economic barriers and the physical demands of parenting. Thresiamma (C/GC), is the grandmother and primary guardian of her autistic grandson. A retired mathematics teacher, Thresiamma's family experienced the tragedy of her daughter in law's (the child's mother) suicide. According to Thresiamma, her daughter-in law succumbed to depression when the child did not show progressive changes from therapy as suggested by the doctor:

> She [daughter-in-law] was in denial; she was not willing to accept that her son was autistic. The doctor had told her that after a period of three years, the child would become normal and when that did not materialise, she became disappointed…

The quote above highlights the deleterious effects of psycho-emotional disablism and its impact on the family, especially mothers or female guardians. The onus of caregiving responsibility is primarily placed on the mother and the growth and development of the child (based on normative standards) is mainly attributed to the competency of the mother. In this case, the mother could not bear raising an autistic child in a society where some people place emphasis on academic achievement and success in employment. Therefore, it led to the undermining of the mother's psycho-emotional well-being. In addition, after the mother passed away, the primary caregiving responsibility for the child was placed on Thresiamma, and she received some support from her husband (the child's grandfather). She mentioned the pressures and practical difficulties associated with raising an autistic child:

> I cannot replace a father or a mother; my physical problems do not permit me to spend extended time with him (the child). Usually after five minutes, I feel tired and as such, I cannot devote more time for him. He tends to repeat certain habits like putting sand or anything that is on the floor in his mouth. When I raise the cane, he feels afraid and stops doing the same. Sometimes, when he is upset, he will throw plates, glasses and the chairs. When he is asked to put back the plates, he will obey. However, I feel tensed and stressed that he does not behave like a normal child.

Thresiamma expressed difficulties in managing certain ‘behavioural patterns’ of the grandson, which included running away or eating anything off the floor. During the interview, she did not overtly state that she physically chastised the child with a cane; however, Thresiamma draws attention to her age-related ailments and frustrations when indicating that a cane is used as a fear factor to stop the child from engaging in repetitive actions. According to Carol Thomas (2004b), the experiences of disabled people can be explored in relation to the effects of the impairment, also known as ‘impairment effects’. Physical, sensory or intellectual impairments may cause some restrictions in activity; however, these cannot be categorized as disabilities. The grandmother faced some restrictions (from her own ailments) and some restrictions caused by the impairments associated with autism. The same factors created some restrictions for Thresiamma from effectively performing caregiving duties and managing the different needs of the child. These restrictions may have factored into the pressures experienced by Thresiamma as the primary guardian of the child. In Thresiamma’s situation, the limited accommodations for her grandson to express his feelings and the limited support systems or coping mechanisms in place for the primary guardians may be the factors which create disabling barriers. Therefore, the child’s impairments (repetitive behaviour) cannot be classified as disabilities in the social relational sense. However, the impairments associated with the child can become a marker for disability (Thomas, 1999); impairments are bio-social and they are shaped by the interaction of biological and social factors.

Thresiamma experiences pressures which stem from gendered norms and divisions of labour. The norms which impose control over women and determine their role as inferior to men are present in some families, social relations, textbooks, media, and offices (Sultana, 2012). These norms, which are characteristic of the historical experiences of women, can generate practices that may lead to the voluntary acceptance of subordinate status among women (Sultana, 2012). Thresiamma’s stressful experiences can be associated with gendered divisions of labour where men are the breadwinners and women take care of the children and the household. She had voluntarily accepted the caregiving obligations and believed that the ideal situation will entail her son remarrying or finding a woman partner, who is willing to accept and care for an autistic child. Thresiamma did not question the role/responsibility of her son who stayed in another city for the majority of a week away on business:

> My role is to provide my grandson, all the support he needs to improve his ability. Our freedom [Thresiamma and her husband's] has been curtailed and we have sacrificed our personal interests to take care of a child like this. We used to travel, but not anymore and we are currently confined to this house. If she [biological mother of the child] was alive, the child could've definitely benefited and improved significantly- that is my belief. I think my son [father of the child] remarrying can also make this situation better as the child may get the support he needs. A second marriage will ensure that the child receives better care. I pray that a supportive woman, who can accept the child will come into our family.

The pressures placed on the grandmother are evident; however, not all experiences posed barriers for her. Thresiamma's caste/tribe identity may have factored into her access to academic qualifications, employment and economic resources. The economic resources may have enhanced Thresiamma's access to organizations in different cities in the State. She had stated that she was able to gain access to different services across the State to meet her grandson's needs. The grandmother's experiences of building networks with other parents/guardians of autistic children may be attributed to her role as the primary caregiver (gender) and her access to economic resources (in accessing organizations). Thresiamma had stated the following:

> I share acquaintances with the mothers of other autistic children. I have also taken my grand-son for therapy to different institutions, including a 3-month therapy at ICCONS in Thiruvananthapuram city [Thresiamma lived in Kozhikode at the time of the interview].

Devika (2010) asserts that the gradual elimination of traditional caste-based practices (increased oppression and restrictions as you go down the hierarchical ladder) from the general public sphere may not be synonymous with the wholesale erasure of such practices. In some instances, government provisions in relation to education and employment may not equate to the end of some caste-based practices which created disparities. Therefore, Thresiamma's access to resources may be an indicator of caste-based privileges, for someone identifying with the 'general' caste category, that may still exist within the social fabric. Thus, the data highlights the significance of gendered roles and access to resources as factors which influence the experiences of parents/guardians of autistic children. Caste/tribe status may also be attributed as a factor. The gendered division of labour, however, appears to be the most prominent factor affecting parental experiences. Thresiamma had stated that the child's mother, who was the primary caregiver, had succumbed to depression when she did not see the expected 'changes' ('normalcy') as suggested by the child's paediatrician and committed suicide instead of facing the prospect of raising an autistic child. The undermining of the mother's psycho-emotional well-being has resulted in the child losing his mother and placing the pressures of caregiving on the shoulders of the grandmother. The fear of repercussions, unequal interactions and the negative perceptions of raising an autistic child may have impacted on the mother's psycho-emotional well-being. Gendered norms in society had placed the caregiving responsibility of the child on the grandmother after the mother's death. The father of the child continued in his role as the primary breadwinner and his role is never brought into question. Unequal social interactions have thus created disabling barriers for Thresiamma and her grandson. Age-related physical ailments also posit constraints on the grandmother's interaction with the grandchild. The impairments associated with the child also create some restrictions for the grandmother. Although Thresiamma is the primary caregiver, she explains her limitations in caring for the child and states her inherent belief that a step-mother can help the family by taking responsibility for caregiving obligations.

This chapter has so far identified the complex experiences of parents/guardians of autistic children. Some experiences can be severely restricting, while others may highlight the privilege experienced by some parents/guardians. Some mothers may not receive any form of informal support and there is a need to analyse such experiences. Therefore, the next section discusses and enhances an understanding of the same.

The pressures faced by mothers with limited informal support

According to Vidya Bhushan Gupta and colleagues (2012), India is a country with limited formal social support resources. In such a scenario, informal support or support from family and friends become critical for some parents/guardians of disabled children. Adequate social support can generate positive experiences for some parents/guardians of disabled children. For instance, enhanced self-efficacy, lower levels of stress and marital well-being are attributed to the availability of sufficient social resources (Robinson et al., 2015). The absence of such support systems may generate stressful experiences for some parents/guardians (Gupta et al., 2012). Malathy (H/OBC), a married mother of two children (her younger son is autistic), was the primary caregiver for the son. A Master's degree holder, she was unemployed at the time of the interview. Malathy expressed her difficulties and indicated the limited support available to her which has in turn exacerbated her stresses:

> My son received a delayed diagnosis because we had to focus on my husband's cancer treatment. Now that my husband's cancer is under remission, I am giving priority to my son's needs. However, I get criticised because I am unable to devote time for my mother who is unwell and placed in the intensive care unit at the hospital. If I spend time at the hospital, my son will lose grip on his studies and I will have to hear criticism for that as well. As my son does not have any physical markers, people ask me, 'why can't you be by your mother's side at the hospital?' I am in a dilemma; am I to tend to my mother or ensure my son's upbringing?

Social norms may determine the lives of some. Pilcher and Whelehan (2017) draw attention to feminist analyses which suggest that some norms have been traditionally determined/developed by men to restrict women. The informal laws and rules in society are different for both men and women, and in an andro-centric or male dominated culture, some rules may favour men in comparison to women, and these may result in disparities and double standards (Pilcher & Whelehan, 2017). Malathy was required to assume the role of the caregiver for both her son and her ailing mother. When the husband had undergone treatment, she had to take care of him then. Gendered norms are a factor which had influenced Malathy's role as the primary caregiver for her son and hindered her from seeking employment. Malathy had identified pressures which arose from caregiving responsibilities and her experiences of limited access to adequate economic and social resources. She may be considered as an individual who may possess a 'discreditable stigma' (Goffman, 1963). According to her, the son's attributes are not visible to the general public, but they are made visible only when he displayed certain actions. Therefore, the mother is considered discreditable due to experiencing courtesy stigma which stems from her association with her autistic son.

In some instances, in India, women are disproportionately engaged in domestic/unpaid labour due to being the primary caregiver for the children and elders in the family (Kabeer, 2015). Some men are exempt from such responsibilities, leaving the women without sufficient time to engage in employment and earn an income, thereby increasing their dependency on the income generated by men. Naila Kabeer (2015) insists that women who identify with some socially marginalised groups like the 'backward caste' community (which includes the 'other backward classes'/OBC) are not only involved in unpaid or underpaid activities, but are also exposed to exploitative working conditions. Thresia (2014) had mentioned that some women are engaged primarily in less intensive work with limited decision-making roles in the household. An increasing number of women who fall into the 'scheduled caste', 'scheduled tribe' and the 'other backward classes' may face exclusion and severe inequities (Thresia, 2014).

Malathy's gender and her association with a caste/tribe may have enabled access to further educational (governmental provisions in education resulting in the attainment of a Master's degree) opportunities. However, factors like gendered the division of labour, may have influenced her decision to become the primary caregiver and not seek further employment opportunities. The responsibilities at home may have factored into her difficulties in seeking employment opportunities, thereby limiting her access to economic, social and cultural resources. Malathy may have sought domestic help if she held adequate economic resources. This may have also given her more time to spend with both the child and her mother.

Nidhi Singal (2011) highlights the World Bank's (2005) concept of the relationship between disability and poverty which increases the possibility of disabled individuals and their families remaining in the 'inequality trap'. The direct health-related costs and the limited engagement of some mothers in paid employment may create pressures and generate poverty. Malathy's experiences are indicative of the family's continued travails in the 'inequality trap'. This shows that some mothers continue to experience deprivation and pressures imposed on them by patriarchal norms and the limited availability of informal social support.

Rebecca Giallo and colleagues (2011) cite high levels of fatigue among some mothers who may indicate the need for significant social support. Some parents/guardians with limited informal social resources may experience increased physical difficulties, including fatigue, when compared to some parents/guardians with adequate informal support systems (Giallo et al., 2011). The presence of another family member in the household may not always equate to sufficient emotional or practical support for parents/guardians (Muir & Strnadová, 2014). For instance, grandparents may endure age-related physical impairments which can prevent them from supporting the parents/guardians of autistic children. Thus, the mere presence or existence of informal social support may not result in adequate support for the parents/guardians. The availability of support, and the amount of support which can be provided by these social resources, are also factors (Muir & Strnadová, 2014).

Pushpa (H/OBC), a single mother of two disabled children (her elder daughter was diagnosed as autistic, while the younger son who had a physical impairment, was diagnosed with learning impairments), who lived in Kozhikode, shared her pressures which arose from raising her children and the lack of adequate informal support in her life:

> My mother [grandmother] is not well and I also have to look after her [along with her two disabled children]. My mother cannot physically take care of my children due to her ailments and I am in a difficult situation as I do not have any other support.

The role as the sole caregiver for two disabled children and an ageing grandmother had created severe pressures for Pushpa. According to her, the family survived primarily on the donations from other parents/guardians of disabled children at her children’s school. Pushpa cited the unequal social interactions between the ex-husband and herself, which had created disabling barriers and negatively impacted on her psycho-emotional well-being:

> My ex-husband would get angry saying that I am more devoted to my children than towards him. He stated the same as one reason for abandoning my children and I. He also used to get agitated when he saw my children displaying certain characteristics and would constantly quarrel by highlighting their impairments. Now he has nothing to worry- he has no responsibilities, does not need to assume his role as the father and is well taken care of by his new wife. I am under pressure because I cannot go anywhere and there is no one to look after us.

Patriarchal norms imbibed by the husband and the caregiving obligations placed on Pushpa resulted in the husband abandoning the family and increasing the stressful situations faced by the mother. The unequal interactions between the parents/guardians have undermined Pushpa's psycho-emotional well-being and created disabling barriers which confined the family to a cycle of deprivation. Aside from these factors, Pushpa, whose schooling was only up to the 8th standard, may have faced restrictions in relation to employment opportunities due to her low academic qualifications and caste/tribe affiliation. Governmental provisions and its benefits have helped some individuals from certain caste/tribe affiliations (Jangir, 2013). Specifically, reservations have enhanced the access to education and employment for some people identifying with the 'other backward classes' (OBC), 'scheduled castes' (SC) and 'scheduled tribe' (ST). While efforts have been taken to ensure the equitable distribution of opportunities, inequalities and unfairness faced by people in the aforementioned categories have persisted (Jangir, 2013). M. Rajivlochan (2019) too, has shared similar concerns by primarily associating the empowerment and upliftment of people identifying with the aforementioned categories to individual effort rather than governmental reservations. Therefore, Pushpa's caste/tribe status may be a factor which had reduced her access to social, economic and cultural resources.

'Impairment effects' may have played a role in adding to Pushpa's stresses. According to her, there had been instances when the autistic daughter ran out of the house towards the road and physically harmed/hit her disabled brother. These impairments have created some restrictions for Pushpa who, without adequate social support, has found it difficult to manage multiple responsibilities. These pressures had prompted Pushpa to tie her daughter with a rope on the front porch (on a few occasions according to her) and also administer medicine without the doctor's prescription (although she had insisted that she stopped giving medicines after the doctor's warning) in the hope that it would reduce the daughter's 'behaviours'. Pushpa stated the following:

> I tied her [daughter] to one side in the front area. She becomes irritable, and I feel tensed. I was also giving her tablets without the doctor's prescription and I was warned [by the doctor] that doing so can affect my daughter's liver. I was also told that it is an offence, so I have stopped. I told the doctor that I feel stressed when she is restless and goes out of control.

The unequal social interactions which led to the ex-husband's abandonment of the family, the absence of informal social support, and the pressures of raising an autistic child on a daily basis, had increased Pushpa's stresses so much that she had to tie her daughter (sometimes) as a desperate measure to manage the household by herself. Abject poverty and affiliation with the 'backward caste' community (including the OBCs) are interlinked (in some instances), and some people who may live through these experiences are focused primarily on daily survival (Gupta & Singhal, 2005). For Pushpa, daily survival itself was difficult due to the presence of different factors.

Thus, unequal social interactions, the gendered division of roles and responsibilities form the basis of Pushpa's pressures. Malathy's and Pushpa's experiences show that gendered norms can lead to unequal social interactions, which can in turn create disabling barriers for some mothers. Impairment effects may create some restrictions, but disabling barriers are created when the mother is subjected to unequal interactions which undermine their psycho-emotional well-being. When mothers do not have adequate support systems, they may endure pressures and some may experience stressful situations like poverty. This not only affects their well-being, but also their physical health and safety. Thus, access to adequate support systems is paramount; however, it is also important to explore more closely the spousal support received by some mothers. Therefore, the next section enhances an understanding of the perceptions of mothers with adequate spousal support.

Spousal support and mothers' experiences

Spousal support is imperative to stable psycho-emotional well-being; it facilitates the balancing of work and family lives for individuals (Aydogan & Kizildag, 2017). Spousal support is associated with low feelings of isolation/depression and increased harmony between parents/guardians, which may benefit the development of the child (Aydogan & Kizildag, 2017). Ambika (H/OBC), who is the primary caregiver for her autistic daughter, expressed her contentment with the support she received at home:

> My husband and I share the caregiving responsibilities; I take care of her [daughter's] personal needs, while my husband provides emotional support.

> I feel that my daughter is closer to him because he engages in fun activities which she enjoys. He spends quality time with her and supports me in everything. My daughter is also attached to the grandparents, and I feel safe enough to leave her under their care. Everyone involves her in family activities.

Manju (H/OBC), a Master’s degree holder, had remained unemployed by choice (according to her) to care for her autistic daughter. She credited her husband’s support and involvement as factors which had enabled her to spend adequate time focusing on her daughter’s daily needs. Cohesion and cooperation between parents can ensure that caregiving tasks are equally shared (Ganjiwale et al., 2016). Sharing responsibilities and stresses may increase the quality of support for the child and reduce occurrences of burnout (Aydogan & Kizildag, 2017). Manju explained that the support offered by the husband is crucial for the child’s upbringing and helped her cope better with negative feelings:

> My husband is very supportive and that is why I can fully focus on my child’s needs. He manages everything else and his unwavering support is the reason why I could help my daughter develop to an extent so far. When she is required to practice activities learnt at school in our home, my husband sits with her to help and monitor her progress. He also plays with her during play-time. My husband is very strict and if I get too frustrated, I ask him to intervene.

While Manju’s and Ambika’s experiences of spousal support are positive, Rakhi (H/OBC) shared her stresses even though she had stated that she received support from her husband. Rakhi, who lived in Kochi, was the sole income earner in her family and lived with her autistic son and husband who had an epilepsy diagnosis. When she went to work, her husband took over the caregiving duties of the child. She said:

> I have to leave the house by eight in the morning, so before I leave, I brush my son’s teeth and give him food. Then my husband gets him ready for school. When I go to work, my husband takes care of all his needs.

In a South Asian country like India, some individuals who experience poor living conditions may find it difficult to meet their daily needs. Public provisions and healthcare support which are in place may not adequately meet the needs of the entire population (Vera-Sanso, 2012). Those who experience poverty may barely meet their daily needs. Rakhi, who held a Bachelor's degree qualification (mentioned by her), explained her employment history which was characterised by working odd, menial jobs for the family's sustenance. According to Rakhi, the husband had received medical advice from the doctor to refrain from employment for the foreseeable future. The impairment effects associated with the child and the impairment of the husband had created some restrictions for Rakhi and increased her stresses:

> My husband was working, but he had two bad epileptic bouts. He has stopped going to work on the doctor's recommendation who had warned us that it should not repeat. I have not told my husband the complete details regarding our son's autism diagnosis, because he [husband] is already sick and I do not want to compound on his stresses. I am stressed when I think of both my child's and my husband's respective situations. My son can be very restless when we go out and we have to get back quick as his restlessness can be troublesome.

The impairments associated with the child and the husband had created some restrictions for the mother. She had to earn for the family and may not have been able to offer caregiving support to her husband every time. The husband's impairments may have created some restrictions which impacted on his role in raising the child. The child's impairments had created some restrictions for the mother, who may not have been able to tend to the child in some instances when she experienced physical fatigue. Rakhi also indicated her fear that the husband may not be able to withstand the pressure if he is made aware of the intricate details of the child's autism diagnosis. Parents/guardians have to raise their children in a society where some individuals with impairments are devalued. Social interactions which may subject some parents/guardians to hurtful comments or reactions of others can undermine their psycho-emotional well-being (Cologon, 2016). For instance, Rakhi had stated her concerns about spending a long time at social functions due to the possible perceptions of others regarding the child's actions. Disability, thus, occurs when people with impairments face exclusionary practices in a society which is not suited to the needs of people who are deemed different from the social norm (Cologon, 2016).

Poverty is another factor which had created stresses for Rakhi. However, she had maintained that she provided her son with the best resources within her parameters:

> I am providing whatever I can for my son within my boundaries/limitations, as best as I can. So, I do not think that money is everything.

Some parents/guardians and disabled children live within constrained financial circumstances and may endure restrictions in meeting the related costs of services and accommodations, which is estimated to be three times more when compared to non-disabled children (Sloper & Beresford, 2006). Rakhi had support from her husband, but she was ultimately the caregiver for both the child and the husband. Irrespective of her academic qualifications, Rakhi had faced barriers in finding employment. Therefore, to meet the needs of the family on a daily basis, she had worked in different jobs. The gendered obligation of caring for the disabled members of the family had put significant pressure on Rakhi to ensure the daily survival of the family. The lack of adequate economic resources from other sources within the family had created intense pressures for Rakhi to sustain the family and meet the needs of all the members. Her gendered role as the primary caregiver, poverty, and impairment in the family had created some pressures, which affected the stability of the family.

Thus, mothers endure wide-ranging experiences, some which may privilege them, while others can be stressful and create barriers for them. Gendered norms and the division of labour that are engrained in the social fabric significantly influence the perceptions of mothers. Unequal social interactions within the family may undermine their psycho-emotional well-being. Some mothers imbibe patriarchal norms and leave their commitments to take care of the child. The experiences of some mothers can be linked to their caste/tribe status and access to resources. However, the data provides clear evidence of gendered roles as a significant factor in their experiences. The next section analyses the perceptions of fathers of autistic children, their role and the privileges or stresses they may endure.

FATHERHOOD AND AUTISM

The economic and social pressures create a platform for ‘divide and conquer’, where mothers assume the role as the primary caregiver and involve themselves in the child’s medical, educational and disability programming needs, while fathers are tasked with earning income to pay for the family needs and ‘non-publicly funded disability programming and services’ (Lien et al., 2020). Kevin Lien and colleagues (2020) highlight the shift in the economy of some minority world nations (including Canada and the UK) from manufacturing to a knowledge-based economy which has had an impact on the job stability in male-dominated societies. Some men’s levels of education, earnings and employment have reduced, while there has been an increasing trend in the same among some women. This has affected some fathers of autistic children, who are required to juggle both work and family-related responsibilities; for instance, fathers have to ensure access to healthcare, education and social support for their children in a restrictive society (Lien et al., 2020).

In Keralan society, the changing role of fathers in child ‘rearing’ has been documented in previous research which draws attention to the increased practical and emotional support provided by them (Nair et al., 2007). The data generated showed that the majority of the fathers who were involved not only cared for their child, but actively provided the necessary support to their wives/partners. When the wives/mothers were overwhelmed, fathers were present to provide psycho-emotional support. Anoop (H/OBC), an MBA graduate was focused on supporting his wife and two children (their elder daughter is autistic). He had stated that he resigned from a senior level position at a firm to focus more on his daughter’s needs. The commitment of Anoop toward his family, and the willingness to provide practical and emotional support to his daughter, are evident in his words:

> I left my job to come back to Kochi, Kerala for my daughter and now, I primarily work from home. The relationship with my wife remains steady and when there are stressful instances, I try to comfort her. Sometimes, I too feel overwhelmed, but I have to remain strong as no one else will support us. I am very involved; for instance, I drop my daughter off to school, pick her up at the end of the day, and take her to therapy sessions. My wife should feel that the load is being shared; I also help her with the dishes when she is tired. I know that my wife needs a break sometimes from caregiving duties, so I encourage her to let off steam- by spending time with her friends or engaging in any activity of her interest.

Anoop’s dedication to his wife and daughter was clear; he had indicated that he could identify the pressures shouldered by his wife. The active caregiving role he undertook may be a factor in eliminating the pressures faced by his wife. Anoop's case may show that in some instances, fathers of autistic children share child-rearing duties and offer support to the mothers, thereby balancing duties and reducing stressful situations for the family. When the role of the father is limited, they may endure additional stress and limited confidence (Mitchell & Lashewicz, 2019). Anoop's experiences highlight his strength and importance in maintaining the family's stable psycho-emotional well-being. His experiences also show balanced social interactions within the family and between couples, which can reduce or eliminate psycho-emotional disablism which may arise from unequal social interactions.

The changes in the gender-based division of roles in an urban area can be attributed as a factor in the increased involvement of the father in caregiving duties. However, other influences like caste/tribe status may have played an influential role in terms of education and employment. Anoop's affiliation with the OBC community may have enhanced his access to governmental provisions. Some 'upwardly mobile' OBCs may possess economic (land and property) and political power (Gudavarthy, 2012). There are some 'middle level' OBCs who are among the dominant castes, while the 'peasant castes' situated mainly in rural areas are also gradually improving their educational status. The 'anti-Brahmin' (some Brahmins are traditionally categorized as 'General Castes' or 'Forward Castes') movements in the early 20th century were crucial for the OBCs in South India to gain reservations in higher education and employment (Gudavarthy, 2012). An increasing number of people who identify with the OBC caste group hold professional jobs, are well versed in English and enjoy urban lifestyles. The privilege Anoop may have experienced can be attributed to his caste/tribe status, which may have in turn reduced his pressures. Anoop had drawn attention to his financial security and background when he stated the following:

> I am giving her the best of resources and she is accessing services from an esteemed educational institution here. We try different avenues of services/resources to ensure our daughter's well-being. My wife and I discuss how lucky we are to have the resources to support our daughter. I do not need governmental provisions because I do not need them [provisions] to take care of my daughter. The government should set up services that caters more toward people from a lower socio-economic background. When I am paying an 'X' amount from my salary, others may be paying a huge chunk from their monthly income.

Anoop shared his experiences of financial security which have had an influence on the reduced pressures faced by him. However, unlike Anoop, some fathers who may not have access to adequate economic resources may experience barriers. Gangadharan (H/OBC), the sole caregiver for his autistic son and the sole income earner in the family, shared concerns regarding his family’s well-being. According to Gangadharan, the pressures experienced by him were overwhelming; the multiple responsibilities have made him struggle to ensure the financial stability of the family:

> I spend the entire time with my son and I do not have time to go out to work every day. Ever since my son was born, she[wife] has been in a difficult state of mind and cannot look after my children. She is facing psychological problems, but we are trying to bring her back. I cannot move forward without earning adequate income to take care of my family. I have to think about my younger son [non-autistic] as well. If I had more money, my son could have accessed better clinical treatments.

There is disparity in terms of employment and this disparity is said to be higher for individuals who identify with the OBC community, in comparison to those who identify with the SC and ST categories. The reasons cited draw attention to an increase in the number of people with educational qualifications in the ‘general caste’ and OBC category and job reservations (which may lead to increased competition for jobs) beneficial to those who identify with the OBCs, SCs and STs (Bairagya, 2015). Changes in gendered roles and the increased competition for jobs may have factored into Gangadharan’s limited access to resources and opportunities. G. C. Pal (2011) further asserts the correlation between disability and poverty- the economic costs that are entailed (accommodations, therapy and other services) can accentuate poverty. The presence of a disabled family member can increase stresses and poverty, and may exacerbate psychological difficulties, contributing to a dysfunctional social environment for children.

Impairment effects is another factor which had influenced Gangadharan’s experience:

> We did not have a gate or a compound and the child would barge outside and run away. Sometimes, he would take off without any clothes and it has been stressful.

Thus, Gangadharan struggled to move forward in life; the changing gendered role which influences the experiences of some men, highlighted his role as the primary caregiver for the child. However, the child's autism diagnosis has had a negative impact on the mother's well-being (according to the father). The mother experienced psychological problems from raising an autistic child; the perceived discrimination and possible negative reactions which question the role of the mother may have undermined the psycho-emotional well-being of Gangadharan's wife. These factors may have created disabling barriers which impacted on the well-being of the family. Gendered norms in society place responsibility on women to raise 'well-mannered' children. The mother's denial of the diagnosis and detachment from the child had placed pressures on Gangadharan who had to limit his engagement in paid employment to care for his son. Runswick-Cole and Ryan (2019) have emphasised the exclusion faced by some mothers of disabled children in relation to employment and the view of disabled children as a burden to society. Some mothers faced isolation due to the widespread perception that they are responsible for giving birth to children who pose a 'burden' to others. The demands of care, and continued limited access to affordable services, may result in some mothers having to weave through complex social barriers to ensure service for their children (Runswick-Cole & Ryan, 2019). When overwhelmed, mothers can experience strains on their physical and mental health. Thus, the fear of unequal social interactions had disabled Gangadharan's wife, thereby reducing her role and adding pressures on him. The psycho-emotional disablism experienced by the wife had led to Gangadharan experiencing disabling barriers. Gangadharan had also faced some restrictions in relation to the impairments associated with autism. The onus of juxtaposing multiple roles had contributed to his stresses and when the child engaged in an action which may be characteristic of impairments associated with autism, Gangadharan found it difficult to keep his son out of harm's way. Anoop's and Gangadharan's differing experiences also provide evidence that even if one group may have faced oppression historically, both privilege and marginalisation exist among people within a group (Erevelles & Minear, 2011, p. 99). Anoop and Gangadharan have contrasting experiences, but they are both heavily involved in child-rearing responsibilities. The next section will enhance the understanding of a father who is not involved with his children.

An uninvolved father and his perceptions

There are some exceptions among fathers of autistic children; some may not have any involvement in their children's lives. Some fathers imbibe a gendered division of roles which deems mothers as the primary caregivers for disabled children (Chakravarti, 2008). Benny (C/OBC), a rice mill loader, lived with his ageing parents. After his wife passed away [less than a year before the interview, according to Benny], the father placed his autistic daughter in an orphanage, while his younger daughter was being raised by his elder sister. Benny's responses suggested gendered notions which idealised men as the breadwinners, while women were required to manage the household, take care of the children and the elders (Sukhramani & Verma, 2013):

> My mother cannot do it [look after the child] and my wife is also not there [passed away]. I have to go do my job to get income and as such, I have put her in an institution [orphanage]. Both my daughters would be here at home if my wife were alive.

Unequal interactions between couples, patriarchal notions and attitudes were evident in Benny's experiences. The caste/tribe status (which may influence access to resources) and 'impairment effects' may have also played an influential role. Benny's identification with the OBC category may have limited his access to resources/opportunities to pursue college education and seek employment, despite governmental reservations (the previous section had also cited increased competition in employment and reduced spaces due to reservation). The limited economic resources may force some people to find employment for their daily survival. As a result, they may not be able to focus on child-rearing duties, which may in turn affect their daily involvement with the child. Benny's reaction may have arisen from the lack of access to adequate economic resources and reduced opportunities to build parent networks and gain access to educational/informational material on autism and related services.

Article 15(4) of the Indian Constitution, which determines the authority of the government to make special provisions for people identifying with the 'scheduled castes', 'scheduled tribes' and OBCs, does not define the term 'socially and educationally backward classes' nor does it state any specific criteria for determining the category (Laskar, 2010). Benny's limited access to educational/institutional resources and the subsequent financial stringency (from facing employment barriers) may stem from the lack of clarity on the constitutional definition of the OBC category, which may have affected the comprehensive implementation of reservation policies.

However, the gendered division of labour is very influential and may have led to unequal social interactions within the household. Benny did not assume his responsibilities as a father even after his wife's passing. Benny did not see himself engaging in the child-rearing role and placed his daughter(s) away from home.

SUMMARY

This chapter has argued that the gendered division of roles and patriarchal attitudes are the most significant factors which influence the experiences of parents/guardians. Mothers of autistic children are expected to occupy the role of the primary caregiver and they are required to leave other commitments to care for the child. Unequal social interactions were identified in the experiences of the majority of the mothers and female guardians. For instance, mothers/female guardians are required to take care of household work and also care for the autistic child. Some mothers were so accustomed to the role that they did not question it, even when they endured pressures. Some mothers were exposed to disabling barriers which arose from the undermining of their psycho-emotional well-being, creating psycho-emotional disablism. The majority of the fathers, albeit a small number, were actively involved in their children's lives. Others insisted that they had limited involvement in terms of caregiving. Among the fathers who were involved, their wives/partners were subjected to intense pressures as the mothers of autistic children. For instance, Gangadharan had mentioned that his wife, who was yet to accept the son's diagnosis, was undergoing severe psychological problems. In this case the mother felt significant pressures in relation to the caregiving role. Fathers who were involved actively cared for their wives and children.

Some parents/guardians felt that quality services could only be obtained with adequate economic resources. Some mothers indicated pressures arising from the cost of such services and how these pressures could impact on their financial security in the future. Some mothers had left their jobs to relocate and take care of their children, while ensuring access to services for the child. The financial security of the family was a cause for concern among some fathers as well. One father in particular shared his concern by drawing attention to his lack of funds which arose from the father not being able to work due to his responsibilities as the primary caregiver for the child. Impairments associated with the child and impairments among members in the family created some restrictions, and these add to the pressures faced by some parents/guardians. When the child engaged in an autistic ‘behavioural pattern’ considered to be ‘difficult’, the parent/guardian had found it challenging in terms of understanding the child’s needs. The occurrence of an impairment among a parent/guardian had created some restrictions in finding employment and also reduced the time spent to support the family by engaging in caregiving obligations.

The access to resources (economic, social and cultural) and caste/tribe identity too, have influenced the perceptions of some parents/guardians. The experiences show that there are differences in terms of lifestyles, well-being and access to services for the children, not only between people from different social groups, but also within the groups. Although created to bring about equity and equality among all citizens, the ‘reservation’ policies based on caste identity may require additional modifications to comprehend and solve major concerns. The interplay of gender, access to resources and caste identity can combine to create a complex web of experiences where some experience significant barriers, while others enjoy more privilege in accessing resources. Religion has not been identified as a factor which influenced the experiences of parents/guardians. Regardless of social situation, parents showed their resiliency by seeking platforms to enhance the safety and well-being of their children.

CHAPTER 6: THE IMPACT OF STIGMA ON THE EXPERIENCES OF PARENTS/GUARDIANS

INTRODUCTION

This chapter explores the influence of stigma on the experiences of parents/guardians of autistic children. Parents/guardians may be subjected to different types of stigmatised experiences, and this chapter intends to uncover their perceptions and analyse the factors which may increase their vulnerability towards perceived feelings of stigma and the enacted or direct negative reactions of others. The internalisation of the pressures associated with parenting an autistic child and the direct reactions of others may affect the psycho-emotional well-being of some parents/guardians. These factors may restrict social interaction and the family's participation in social activities. Some parents/guardians are increasingly prone to blame by their respective partners, family members and others in society. The gendered division of roles, caregiving duties, social norms, changes in family structure and the occurrence of an impairment can be identified as factors which may subject some parents/guardians to direct discrimination. Irrespective of the disabling barriers and restrictions related to impairments faced by some parents/guardians, the majority of the participants shared their perseverance and determination to protect their child and maintain the family's stability. However, some parents/guardians expressed low perceptions about their children. Enhanced awareness and increased involvement can bring about a broader understanding of autism and the child's characteristics. Thus, this chapter draws heavily from the perceptions of parents/guardians and analyses the influence of stigma and the disabling barriers they face as the primary caregivers for autistic children. It begins with an in-depth analysis of perceived or felt stigma and how it may be internalised by some parents/guardians, thereby creating adverse effects on their well-being. The chapter explores the direct discrimination faced by both mothers and fathers. It also provides an understanding of parents' role as protectors and stigma coaches. By doing so, this section aims to provide a comprehensive understanding of parental experiences in relation to the concept of stigma.

FELT STIGMA, INTERNALISED OPPRESSION AND PARENTAL PERCEPTIONS

Erving Goffman (1963) draws attention to the perceived inferiority among some individuals who may possess an attribute which is considered to fall outside the social norm. The individual may feel ashamed to own this attribute and may feel insecure during interactions with others. Even before social interactions take place, the individual with a particular attribute may be unsure of others' reactions (toward them), which can in turn affect their emotional well-being. Parents/guardians of autistic children are affected by 'felt' or 'perceived' stigma because of their affiliation with the children (Gray, 2002). Timothy Broady and colleagues (2015) highlight the concept of 'felt' stigma which is more widespread and creates greater distress than 'enacted' stigma. Felt stigma can create immense pressures on individuals, including parents/guardians, who put in strenuous efforts to reduce experiencing feelings of stigma (Broady et al., 2015). The perceived fear of experiencing negative reactions and embarrassment may lead some parents/guardians to withdraw from social situations. Doing so may result in fewer opportunities for their children to interact with others. Anil (H/GC), an MBBS (please refer to the 'list of abbreviations' table) degree holder, qualified psychiatrist and the father of an autistic boy, explained his stresses in handling societal pressure. He indicated his concerns when mentioning that he had, on a previous occasion, restricted the child's participation in social functions:

> I remember, at a wedding party, when all the other children present were running around and enjoying themselves, I held onto him [son], probably because I thought he could fall down or people may notice him jumping unnecessarily. I may be more active, but my wife [who is also employed] exposes him to more social situations than I do. I tend to restrict him more.

Anil's response suggested his internalisation of perceived oppression which had impacted his psycho-emotional well-being. Some individuals hold the fear of potential negative reactions from others if they are perceived to fail in leading a life determined by social norms as 'normal' (Gray, 2002). Unequal social interactions can disrupt the notion of 'normalcy' projected by a family. Anil faced barriers which arose from internalising the perceived stigma. The fear of potential unequal social interactions made him uncomfortable to engage socially with others. Anil's internal barriers had affected him so much that the social participation of the child was adversely affected. Anil indicated that he held feelings of low self-esteem and limited confidence when he stated the following:

> I am not particularly nervous to take my son outside, but I am uncomfortable with certain questions people ask. For instance, some have asked me questions such as, 'Why is your son not speaking?'- I do not like these types of questions. I am also worried about people's reactions when I try to implement some techniques to help my son. When I was helping him learn sign language, some have asked- 'Why are you teaching him sign language? Is he deaf or dumb?' I feel pressured and worried about what people may think.

Courtesy stigma associated with parenting an autistic child creates some barriers. Some Indian parents/guardians attach great importance to their children's success in personal and professional spheres. Rajalakshmi Sriram and Gurprit Kaur Sandhu (2012) state that fathering in India entails the fulfilment of multiple roles, including that of the provider, guide, mentor, and nurturer. In Hindu culture (specifically), one aspect of 'Sanskar' or values imbibed from childhood necessitates the 'purification' of an individual, enrichment of their values and making up for their 'deficiencies', which may increase their value and contribution to society (Sriram & Sandhu, 2012). Achieving a social status is imperative among some families in India. Some autistic individuals and their parents/guardians may struggle to attain acceptance and fit in with social norms. When individuals are perceived to veer away from the social norm, they may be overlooked and undervalued. This may subject some parents/guardians like Anil to extreme stresses in order to ensure that their child fits in with the norm or continue facing negative reactions of family members or others in society.

The Indian education system is highly competitive; the child population continues to increase and there are only a limited number of reputed academic institutions to accommodate them (Deb et al., 2015). From a young age, some children (and their parents/guardians) experience intense competition in relation to admission to an esteemed educational institution and the child's subsequent promotions to higher grade levels. Some parents/guardians too, place pressures on children to compete and succeed because of the nature of competitiveness in obtaining admissions. Future unemployability worries and parents' aspirations of fulfilling their own unfulfilled dreams generates increased competitiveness (Deb et al., 2015). In academia, the primary emphasis is placed on evaluations via written examinations, and memorising capacity, which can take the focus away from other areas of development/comprehension for the child (Johansson, 2015). For an autistic child, the prevalent systems may not be adequate enough to enhance their socialization within the classroom setting. Parents/guardians are thus pressurised to increase the child's adaptiveness or face negative reactions, which may in turn adversely impact on their psycho-emotional well-being.

Anil had expressed his hopes before his son received a formal clinical diagnosis; he wished that his child would be diagnosed as a 'high-functioning' autistic. He indicated disappointment (that his son was diagnosed as 'moderately autistic') and expressed his preference for a 'normal' child. Anil shared his discomfort of extended social interactions with others:

> When I hear parents of non-autistic children speaking about their child's academic and extra-curricular achievements, I feel disappointed and uncomfortable. Therefore, I do not interact much with others. I cannot speak about his[son's] achievements because he does not have many. I had hoped that he would be diagnosed with high-functioning autism because his intelligence and social reciprocation has always been adequate. I do not like to speak about it much, even if I am open when asked questions.

Anil had internalised the negative feelings pertaining to raising an autistic child and the social interactions with others. The above quote shows his perceived fear of unequal social interactions. These fears have adversely affected his psycho-emotional well-being. Anil also stated that he felt uncomfortable speaking about his child and disclosing to others about the autism school attended by his child. Graham Scambler (2020) associates the aforementioned feelings to territorial stigma or places marked by shame; some parents/guardians who access these places may be blamed and shamed for creating their own distressing situation. Anil had expressed his difficulty and clearly indicated feelings of shame when he stated the following:

> When people interact with us, I have great difficulty to tell them the name of the school he [son] is currently attending because I do not want it to become awkward.

Anil's response here, is yet again indicative of his experiences of 'felt' stigma. He made no mention of facing structural barriers and the same can be attributed to his educational qualifications, employment and social connections. The access to these resources may have minimised his experiences of structural barriers. Some individuals may use their access to resources to maintain their social status (Waterfield & Whelan, 2017). Economic, social and cultural resources are factors which affect individuals' choices and socially ingrained habits. Anil used his resources to choose services deemed appropriate (by him) for his son. He explained that the path toward finding adequate services for his son had been straightforward:

> I did not have to run around as I am part of the 'medical circle' [he is a registered psychiatrist]. I went to the focused places; I know these places and the professionals who work there. The money matter is also not an issue; my wife and I are both employed and therefore services are affordable.

Anil's perceptions are thus testament to the adverse social and emotional outcomes experienced by some parents/guardians of autistic children. The access to adequate resources is a factor which may have mitigated barriers. The socio-cultural environment (which gives prominence to academic competitiveness), and norms which place expectations on parents/guardians to control their child's behaviours, create pressures for them (Hurley-Hanson et al., 2020). Anil was susceptible to unequal social interactions which had undermined his psycho-emotional well-being. However, mothers are more prone (in some instances) to experiencing pressures and the negative impacts of stigma. Previous research has drawn attention to mothers and their increasing susceptibility to the deleterious effects of stigma in comparison to the fathers (Lilley, 2013). The child-rearing responsibilities primarily shouldered by the mother (which includes pressures to present their family as 'normal') is cited among the reasons for their increased vulnerability towards experiencing feelings of stigma (Gill & Liamputtong, 2011). Suvitha (H/GC) explained her stresses and insisted on using a selective disclosure strategy to share her son's autism diagnosis with only a few chosen people:

> Some people, with whom, I have not had any communication for many years, have suddenly developed an interest in my son's situation. You need solid emotional strength to withstand the pressure arising from people's curiosity. Our current neighbours however, are not nosy and this helps to

> reduce my stresses. I am also choosy about my friends and social circle- I only make friendships with people with whom I can be comfortable.

Mothers face added pressure as they are required by social norms to take on the ‘warrior-hero’ persona. When some mothers experience difficulties in embodying such a persona, they may be subjected to stigmatising reactions. Aside from the physical workload of raising a disabled child, an increasing number of mothers tend to imbibe stresses and are emotionally, deeply affected in comparison to the fathers (Gray, 2002; Van Patten-Walsh, 2013). Suvitha, who is the primary caregiver for her son, described internalised feelings of shame and denial which undermined her psycho-emotional well-being and restricted her (during social interactions) from stating that her son had an autism diagnosis:

> At the moment, I am not mentally prepared to say that he [son] is autistic; I will wait for a period of two years and by that time, I have hope that he can transition into a normal school setting. If there is no substantial change after two years, I may openly say that he is autistic. By then, I would have developed the boldness to say so.

Some mothers are placed under the observation of society to monitor whether they raise children in line with the social norm. Autistic children may be deemed as social problems and mothers are primarily blamed for their (children’s) perceived shortcomings (Khanlou et al., 2017). Suvitha indicated fear of potential negative reactions towards the family and also spoke about some restrictions she faced as a result of impairments associated with autism. These experiences had placed pressures on her:

> My son is restless and we try to restrict social interactions. I have stopped taking him to the fruit shop as there is a chance that he can throw the fruits in different directions. The shop keepers may not know what problems my son is undergoing. We have also stopped going to restaurants- I will have to be with him all the time and my husband had previously felt embarrassed when he dropped a glass of water and made a mess.

Some restrictions associated with impairments can create pressures for parents/guardians. Suvitha had suggested her difficulty in being alert to prevent her son from throwing an item in a store or a restaurant. However, the disabling barriers she experiences arose from her perceived fear of being subjected to negative reactions by others, which in turn undermined her psycho-emotional well-being.

The child's autism-related characteristics can garner discredited stigma due to the visibility of characteristics associated with it (Hurley-Hanson et al., 2020). This may affect the well-being of parents and limit their involvement in social activities. Thus, the parents/guardians in this thesis are disabled along with their children by the unequal social interactions which undermine their psycho-emotional well-being and create intense stresses for them. Awareness levels and the need for coping mechanisms have increased, especially in the urban regions; however, some social norms which aggravate pressures on parents/guardians (specifically mothers), and impact widespread acceptance of autism, continue to persist.

In general, there is limited public exposure to autistic children and some parents/guardians may feel uncomfortable bringing the child into the public eye. They may perceive potential negative reactions from the public when the child displays certain characteristics related to autism. This can exacerbate internalised feelings of oppression and affect the psycho-emotional well-being of parents/guardians and disable them. Courtesy stigma associated with parenting an autistic child can subject parents/guardians along with their children to negative reactions and shame. Some restrictions which may arise from impairments associated with autism are factors which can create some restrictions in terms of daily caregiving obligations. However, there are also other factors which influence parental experiences. For instance, social constructs in the social fabric such as the aspirations to obtain a perceived high social status and academic competitiveness imbibed by parents/guardians can add to the tension of parents/guardians, in particular mothers of autistic children. Some parents/guardians may experience pressures placed on them by society; social interactions are affected and, in some instances, these can undermine the psycho-emotional well-being of parents/guardians. Intense academic competition and upward progression in academic and the professional spheres are given much value by parents/guardians. When a child endures difficulty in adhering to academic standards based on the norm, the blame is placed on the parents/guardians. Mothers are particularly affected due to their association with the traditional gendered role of caregiving.

In relation to 'felt stigma', both Anil and Suvitha were deeply affected and had not entirely accepted the autism diagnosis. Internalised feelings of shame about raising autistic children had negatively affected their psycho-emotional well-being to a point where they did not feel comfortable in a social space or during interactions with others. Parents/guardians are also subjected to enacted forms of stigma and the resulting experiences can affect family life. Among some parents/guardians, direct negative reactions between couples were found to create a strain on marital relationships. The next section therefore delves into the direct experiences of discrimination faced by some parents/guardians of autistic children.

PARENTS' PERCEPTIONS OF BLAME AND DIRECT NEGATIVE REACTIONS OF OTHERS

Historically, mothers have borne the brunt of the blame when there is a disabled member within the family system. Dating back to the 1890s and all the way till the 1950s, mothers in some minority world nations (including the U.K.) were blamed for causing their children to possess any 'condition' considered to be 'abnormal' (Courcy & Rivières, 2017). Previous research has cited terms such as 'refrigerator mother', which was used by Bruno Bettleheim and Leo Kanner (Waltz, 2015). These terms were responsible for creating perceptions which deemed mothers of autistic children as 'cold' individuals who gave birth to 'loners'. An increasing number of mothers were subjected to blame and shame as a result (Waltz, 2015). There has, however, been a change since the 1960s, when studies led by parent-researchers like Lorna Wing turned the focus away from 'mother behaviour'. Nonetheless, in present day society too, mothers face blame and experience the direct blame/discrimination of others.

Parents/guardians of autistic children are considered to be at risk for low self-esteem, and poor marital outcomes including low marital satisfaction and adjustment (Hartley et al., 2017). In particular, mothers are blamed for a child's perceived shortcomings (Khanlou et al., 2017). Sheeba (C/GC), a Master's degree holder and teacher at a government school, lived with her four children (including the youngest son who was diagnosed with autism). Sheeba had moved from her hometown to access services in a bigger city like Thiruvananthapuram. The husband was working abroad and made occasional visits to see the family (according to Sheeba). Sheeba expressed her frustrations at the husband's reactions, who at times, blamed her for the child's perceived shortcomings:

> The harshest remarks have come from my husband; when he [husband] witnesses a behavioural pattern displayed by our son, he would say, ‘why aren’t you strict with him’? or ‘why don’t you make him learn something or ensure that he sits down for a period of time?’ These reactions are depressing and it has made me think- ‘Why did such a child have to be born?!’ and ‘what was God’s plan in giving me this child?’ My husband never accepted that this [autism diagnosis] is a genetic disorder and has blamed me and us as a family for failing to pay attention to our son during the early stages of development.

Mothers are sometimes identified as ‘good’ mothers when they undertake the responsibility of facilitating their child’s progression towards normalcy. If the child’s progress does not go in line with the normative standards of communication or development, mothers are deemed to be ‘bad’ and neglectful (Courcy & Rivières, 2017). The marital stability of the couple may also be affected as a result. The stresses pertaining to marital relationships can also stem from the fact that some mothers blame themselves for their child’s autism diagnosis (Gulyn & Diaz-Asper, 2018). Some social norms suggest that mothers hold primary responsibility for the raising of their child. The child’s progress is associated with the competence of the mother, and some mothers may be subjected to intense scrutiny and blame when the child shows a perceived lack of progress (Bhat, 2011). Sheeba worked and looked after her four children; she was subjected to emotional trauma by her husband, who at times was frustrated (according to Sheeba) when the child displayed certain actions. The unequal interactions in the family system between married couples have led to the mother being overly blamed. This had further undermined her psycho-emotional well-being and posed a barrier for the mother.

Sainaba (M/OBC), a mother of three children, lived with her youngest autistic son and husband in Kochi, which was away from her hometown in order to access desired services. The two older non-autistic children were being cared for by Sainaba’s mother (based on Sainaba’s comments). Sainaba admitted that her husband was supportive; however, she also called attention to his feelings of isolation which had caused frictions between them. When parents/guardians of autistic children invest time and energy to support them, they may feel isolated from other engagements (Byrne et al., 2018). Sainaba described her experiences of being subjected to blame by her husband:

> Sometimes when my husband gets angry, he blames my wrongdoing for my child's situation- he says, 'God has punished us by making our child 'like this' due to the sins that you have committed'. Sometimes he says, 'let's stop therapy and go back home, I think it's enough'- maybe due to the lack of financial resources or because of the sadness of staying away from home.

Sheeba's and Sainaba's responses indicated that even if others negatively commented on their mothering skills, the blame placed on them by their husbands had severely traumatised them and affected their well-being. Thus, the direct comments of others (especially close family members) can affect the well-being of parents/guardians and influence their limited involvement in social activities. Some parents/guardians may not want to face negative reactions of others when a child displays certain autistic characteristics in public. Mothers, especially, may be vulnerable to these reactions and their competence may be questioned. Some parents/guardians may want to shield their child and family from such reactions and may refrain from social participation.

Deepthi (H/OBC) is the mother of an autistic child, and at the time of the interview she was recuperating from a surgery and spending time with her parents (maternal grandparents). Deepthi's husband is an active presence in the child's life (according to her). She had been affected so much by comments endured in a public space that she no longer used the bus for transport in order to reduce face-to-face interaction with large crowds. She said the following:

> I have faced embarrassing and uneasy situations in the public sphere; for instance, I try not to take my son on the bus. Once, we were travelling on the public bus, and he [son] had kicked out due to his frustration. When he did so, he kicked a woman sitting near us by mistake. I apologized and cleaned the dust off her clothes. When she reached her destination, she asked why I take the trouble of taking my son along. She then said that it is better to finish him off by poisoning him, rather than continuing to care for him. These reactions are hurtful and they make you feel numb. Honestly, at that moment, I thought of getting down with my son and jumping in front of the next moving bus. I have now stopped travelling on the bus, rather, I take an auto-rickshaw, even if it is more expensive. I take my son only to places where I feel most comfortable.

The unequal interactions in the public sphere had created barriers for Deepthi. Deepthi's emotional well-being was so undermined to a point where she considered suicide. She also stated that she stopped using the bus for transport to minimise her interaction with others in society. Mothers assume the traditional gender role as the primary caregiver and some mothers may not have the opportunity to engage in employment or lead a life outside of being a mother (Broady et al., 2017). Therefore, some mothers may be more prone to experiencing the direct reactions of others. Unequal interactions between couples and within the household can undermine the psycho-emotional well-being of some mothers. These interactions place multiple pressures on mothers which can affect their emotional well-being (Broady et al., 2017). The same can be attributed to the increasing vulnerability of mothers in relation to facing the negative stigmatising reactions of others. When autism is primarily identified with deficits and shortcomings, mothers are blamed and disabled (by the undermining of their emotional well-being) because the emphasis is focused on the 'lack of' competency of mothers.

Sheeba, Sainaba and Deepthi were the primary caregivers for their children. Sheeba was employed and was also expected to care for all her children, including the youngest autistic child. She had to assume and manage multiple roles, and bear the occasional negative reactions of her husband who blamed and questioned Sheeba's parenting methods. Sainaba too, was subjected to harsh remarks from her husband. Sainaba had mentioned that her husband, who was previously working abroad, had left his job to be with his family. At the time of the interview, he was not engaged in paid labour, but was assisting with the caregiving duties. Sainaba had drawn attention to the high cost of desired autism-related services and how the family was running on the savings of the husband. The drain in economic resources may be a trigger for the husband's occasional outbursts toward his wife. The feelings of isolation experienced by the family can be another factor in exacerbating mother blame. Sainaba, her husband and the young autistic son moved to another city due to the dearth of desired clinical services in their hometown. This has led to separation from their two other children and loss of social relationships. Such factors had created stresses in the family, affecting the marital relationship between the couple.

Deepthi, who was the primary caregiver for her autistic son, was affected by unequal social interactions and the influence of gender roles. She faced barriers because some people may equate parenting an autistic child as a 'burden' for parents/guardians. Some may hold negative perceptions of autistic children because they veer away from the standards set by society. The negative reactions/ discrimination faced by Deepthi and her disabled son had proved to be too traumatic. Thus, these experiences highlight the pressures encountered by mothers who may face blame if the developmental pathways of the child result in non-normative development (Vaidya, 2016b). The private sphere of caregiving and managing the household are associated with femininity and a mother's central domain pertains to child-rearing and managing the home. The binary division of labour is a feature of the contemporary nuclear family system, where the father is the income earner and the mother is in charge of caregiving and household responsibilities (Vaidya, 2016a). Women are subjected to the notion of 'intensive mothering', and they are expected to leave all other engagements to focus on nurturing their children. In India, mothering is traditionally considered as the primary objective in a woman's life and the 'fulfilment of her womanly destiny' (Vaidya, 2016b, p. 121).

The mothers in this thesis had drawn attention to the child's impairments or display of certain autism-related characteristics, which increased their vulnerability to blame and made it socially embarrassing and emotionally overwhelming. The mothers felt especially isolated by their own husbands whose adverse comments questioned their mothering qualities and involvement in their child's life. Thus, the gendered division of labour places the responsibility for the child and their development primarily on mothers. When mothers are perceived to fail, they are subjected to harsh comments and unequal interactions. This pressurises them and reduces their psycho-emotional well-being (and they endure disabling barriers). Fathers too, are prone to the direct negative reactions of family members and others in society. The next section thus enhances an understanding of the blame/shame faced by a father and his perceptions as a parent with an impairment of an autistic child.

A father's perceptions of stigmatising reactions

Parenting offers both positive and negative experiences for some parents/guardians who have impairments. It can enhance self-esteem, positivity, motivation and meaning of life (Parchomiuk, 2014). Some parents/guardians with impairments may face barriers in relation to education and employment. They also experience barriers caused by unequal interactions in the social sphere. Disabled parents who are engaged in employment are likely to be involved in low-paid, part-time work without job security (Clarke & McKay, 2013). These barriers can push disabled parents into poverty, limit their social participation and generate increased feelings of isolation (Parchomiuk, 2014).

The stresses experienced by some fathers in relation to daily caregiving activities and coping with the negative reactions of others have been highlighted in previous research (Burrell et al., 2017). The increasing role of some fathers in child-rearing obligations places them under severe pressures to ensure access to adequate services for the child and maintain the survival and stability of the family by earning income to sustain the household. Mohammed (M/OBC), the father of an autistic girl lived with his wife, two children and mother-in-law in Kozhikode at the time of the interview. Mohammed had revealed that he had a speech impairment:

> You may understand from our conversation that I have some difficulty to speak with clarity. I was a hyperactive child and one day I had fever, after which I lost my speech gradually due to the adverse effects of medicines. Then, I slowly regained my speech, even though I haven't recovered completely.

Mohamed had admitted that his wife is more involved in daily caregiving duties, even though he too undertook responsibilities. However, he explained that he never shied away from taking his daughter to social functions:

> I have no problems to take her [daughter] out. We had recently gone to a marriage reception, where some people were apprehensive or afraid of what she may do. We face issues going outside, but we continue to go.

Mohammed had mentioned that people (especially family members) who were aware of his speech impairment placed blame primarily on him for the daughter's impairments in communication and interaction:

> Society has terms for those who cannot speak- 'pottan' ['dumb']. My distant relatives have blamed me at family functions- they would say, 'Well Mohammed was like this before, maybe that is the reason why the child cannot speak or engage in a conversation.

There are widespread notions that the failure of disabled people as parents/guardians is assured even before they become parents/guardians. For disabled people, it is a matter of ‘when, rather than whether’ (Llewellyn, 1997). The negative metaphors attributed to disabled people can adversely impact on the psycho-emotional well-being of disabled parents/guardians (Björnsdóttir and Sigurjónsdóttir, 2013). However, some parents/guardians may be resilient and imbibe traditional roles including problem solving, providing for and protecting their children at all costs. These roles are considered to be assets for parents/guardians (Alareeki et al., 2019). Mohammed embodied a ‘protector persona’ by reacting against negative responses which were directed towards his daughter and family during social outings (Lashewicz et al., 2016):

> When I hear negative responses directed towards me and my family at social functions, I would react and tell them to get lost. Ultimately, the child must mingle with society, because social interaction is important. I don’t really pay attention to what the society says or how people react.

Although fathers may assume the role of the protector, they may still endure heightened stresses in relation to their role as income earners. Some fathers may strive to ensure the child’s future financial security and may experience pressures related to the same. Mohammed did not indicate any financial pressures, but he insisted that there were other concerning pressures in his life. For instance, the poor health condition of his mother-in-law, who was also part of the family, was a major stress factor:

> I am the sole income earner in my family. My mother-in-law is unwell because she had suffered severe burns four months ago, and she is in the hospital for treatment. She also has a malignant tumour which makes her collapse occasionally. So, these days, I get to spend less time with my daughter and I cannot take her out for social functions.

Mohammed’s experiences highlighted the negative reactions of others who associated the child’s autism to his speech impairment. The speech impairment may have created some personal restrictions for Mohammed when communicating with others. However, during public interactions, he is blamed for his daughter’s restricted speech and social communication. The negative reactions of others (which could affect the psycho-emotional well-being of some parents/guardians) lead to unequal social interactions and is a disabling barrier experienced by the father. The limited access to adequate resources was another factor which created barriers for Mohammed. Mohammed worked as a delivery driver and he highlighted financial constraints, but insisted that it did not deter him from finding and accessing appropriate services for his daughter. Mohammed's role as the sole income earner, and working a job which pays a meagre income, had created intense pressures for him to ensure the survival of his family. Irrespective of his familial situation, Mohammed's experiences indicated his confident and positive attitude in fighting against social barriers to ensure his daughter's well-being, thereby maintaining the stability of the family. Some parents/guardians, like Mohammed, actively resisted negative reactions toward their children and other family members. They sought to protect their family and ensure that their child could participate in adequate social activities. Thus, the concept of 'project stigma' or the active resistance of some parents/guardians against stigmatising reactions, is explained in detail in the next section.

RESISTING STIGMA AND PARENTAL EXPERIENCES

Graham Scambler (2020, p. 26) identifies 'project stigma' as the active resistance to 'felt' and 'enacted' stigma; rather than being a passive receptor or victim of perceived stigma and direct discrimination, a stigmatised individual is determined to be recognized as a 'force for change' (Scambler, 2020, p. 102). 'Project' stigma refers to the serious and genuine efforts taken by some to reject, resist and combat blame and shame directed towards them and their family (Scambler, 2020; Mantovani & Thomas, 2013). Some individuals who use project stigma as a means to resist negative reactions are numb to blame and shame; they show resistance and defiance when subjected to 'felt' and 'enacted' stigma (Saunders, 2018).

Parents/guardians play a central role in improving the perceptions of disabled people and children by rejecting stigmatising attitudes of others and targeting enhanced social participation irrespective of any criticism(s) (Rohwerder, 2018). Neeraja (H/OBC), for instance, stressed the importance of social mingling for her autistic daughter. As the primary caregiver, she had suggested experiencing both 'felt' and 'enacted' stigma; however, this had not barred Neeraja from enhancing her daughter's participation in social activities:

> I take her (daughter) out for social outings so she can learn to mingle and interact with others. I am trying to enhance her opportunities of social

> exposure; initially, I was apprehensive, however, without taking her outside, we won't see any changes in her. I took her to the movies once and many family members shared their concern. I too was tensed, but I was determined to take her and ensure that we sat in the theatre for the duration of the film. We did it, and it has increased my confidence that she can sit down for a long period of time.

Arun Kumar (H/OBC), a sculptor and father of an autistic child, was unfazed by stigmatising experiences. Arun Kumar was adamant that his child should not be restricted and even offered emotional support and confidence to his wife, who at times, had felt uncomfortable about the reactions of others. He had highlighted his active involvement in different local social activities. He sang at local functions and took an active part in organizing social functions. Arun Kumar wanted his son to be active and experience these social functions. He believed that by focusing on his goal of enhancing his son's participation, he could ignore the reactions of others:

> My wife was apprehensive in the beginning; she used to think, 'oh why are they looking at our son like that? Is it because he does not communicate or play like other children?' I have often pacified her by assuring her that he should be let free to decide what he wanted to play and in whatever way he liked to play. The most important thing is that he must be among the group. I don't pay attention to it [reactions of people] and I take him everywhere. I do not restrict him inside the house [due to the fear of public criticism]; I don't have any fears. I try to show him everything and make him get familiarised with the environment.

Arun Kumar had, however, indicated that the young age of his son (three years at the time of the interview) may have a factored into the family's limited experiences of negative reactions:

> My son may have displayed some characteristics, but we haven't received any intense negative responses from others as yet. He is young, but if he was older, people may have reacted differently.

Some parents/guardians actively resisted the negative reactions of others. They protected their children and family against negative comments from family members and others in society. The empirical data indicated the deleterious effects of stigma on mothers. Some mothers were active in resisting the negative reactions and stigmatising responses of others. However, an increasing number of mothers experienced the negative consequences from the internalisation of these reactions. This adversely affected their psycho-emotional well-being, marital stability and quality of life. The adverse impacts of ‘felt’ stigma and ‘enacted’ stigma are evident among some parents/guardians, including Deepthi, Gangadharan and Thresiamma.

Deepthi had indicated that she took her son to different social settings. The negative experience when using the bus transport system had undermined her psycho-emotional well-being. She had stated that in the immediate aftermath, she had contemplated committing suicide. However, she stopped using the bus for transport as a way to reduce unequal social interactions with others. Gangadharan reiterated his unconditional support for his wife and his children. As a means to protect his family’s stability, Gangadharan has mentioned that his wife was utilising counselling help which he had arranged for her. The pressures of mothering an autistic child had caused psychological problems for the mother and created barriers for the father, to a point where he expressed intense pressures when he thought about the future of the family. Gangadharan explained his struggles performing multiple roles and insisted that he had not yet placed enough trust in his wife to leave the children in her company when he went off to work. Thus, the internalisation of oppression/stigmatising reactions of others may have created disabling barriers for the mother and undermined her psycho-emotional well-being. These experiences have disabled both Gangadharan and his wife, even though he was intent on protecting his wife and children from the negative reactions of society.

Thresiamma struggled to find words during the interview when speaking about her daughter-in-law’s suicide. According to her, the child’s mother took her own life when she did not see progress in her child as suggested by the child’s paediatrician. The mother decided to take her own life rather than raise an autistic child. The mother’s untimely death had placed the onus of the child’s responsibility on the grandmother who had expressed facing restrictions from her own health ailments. Thus, mothers remain vulnerable to the negative effects of stigma, even if some actively try to resist them. When mothers are affected by stigmatising experiences, fathers are also impacted. While some parents/guardians are involved and support their family, they can be classified as ‘stigma coaches’ due to their inherent negative perceptions of autism. Some have expressed their low opinions of their children by using negative language or terms. The experiences of such parents/guardians will be explored further in the next section.

STIGMA COACHES

The family unit is important as it shields the children from negative reactions. Some parents/guardians may act as 'stigma coaches'; parents/guardians are referred to as stigma coaches when their attitudes to and interpretations of impairments are negative (Benson et al., 2016). For instance, some parents/guardians may associate impairments or any disability-related discussions to shame, and thus disability becomes a subject which should not be openly spoken about (Scambler & Hopkins, 1986). Some parents/guardians may not understand the complexities involved with disclosure, and therefore, may not be considered as 'safe people'. Some parents/guardians may resort to confidentiality to protect the child from 'felt stigma' (Davidson & Henderson, 2010). Anoop (H/OBC), had mentioned that any discussion on autism occurs only between him and his wife within the family system. He admitted 'societal pressure' and his decision against disclosing his child's autism diagnosis to another person. Anoop had stated the following:

> No one is really aware that my daughter is autistic. I have never discussed it with anyone else. That is because, if I did engage in these discussions or open up about her diagnosis, people will point fingers at me and say, 'oh you have done this and this, therefore, your child is like this'. I haven't even discussed my daughter's diagnosis with my own father, with whom I usually share everything. Therefore, I have consciously prevented any opportunities which could lead to such conversations.

Jubainya (M/OBC) is the mother of an autistic boy who lived in an extended family unit, which included her husband and in-laws. She shared her experiences of overt discrimination by family members. Jubainya's responses suggested the initiative she took to ensure that her child could access the best services within her parameters. She had insisted that she defied family members (and her husband) to take her son for a diagnosis and seek clinical services. Although the son was her priority (according to Jubainya), she also indicated feelings which devalued her son:

> It is true that if I was in a social space, I would be thinking in the same way like everyone [when they witness an autistic individual engaging in a 'behavioural pattern']- 'Oh my God, that child is coming and he is going to

> mess things up here'. Even now, with my experience, I may still think in the same manner with regards to any autistic child I may come across.

The negative perceptions of autism and an unwillingness to disclose are prevalent among some parents/guardians. However, two fathers in particular, who had participated in the interviews, stood out amongst the group and adhered closely to the 'tag' of a 'stigma coach'. Sambashivam (H/ST) was a clerk, who was involved with his autistic son on a daily basis. He explained that his wife was the primary caregiver for his son, while his obligations were primarily limited to income earning and dropping off/picking up the child from school. Sambashivam was the sole income earner in the family and his reactions/opinions regarding his son suggested negative attitudes he had held toward autism:

> He [son] has a habit of splashing water everywhere in our house and he bites on different furniture. I have heard that autistic people have 'exceptional' qualities, and if you ask me what his [son's] additional quality is, I point to these behaviours [sarcastic laugh].

Benny (C/OBC) had placed his autistic daughter in an orphanage, which he insisted was 'necessary' due to his wife's death, the child's grandparents' old age and his personal financial situation, which required him to work daily for the family's survival. Benny had also stated that his two children would have been by his side if his wife was still alive. The negative terminology he had used to describe his autistic daughter suggested his insufficient awareness of autism and the distance in his relationship with her. The responses of the father can be used to question his role; his responses made it evident that there was no involvement as a parent/guardian in his daughter's life (the daughter was placed in an institution). Benny used terms like 'goshti' (grimace) and stated the following:

> My daughter displays peculiar actions with her hands ('goshti'), and she is backward in studies/education and also has an uncontrollable craving for food.

Ryan and Runswick-Cole (2008) highlight the oppressive attitudes of some parents/guardians who may devalue their children and deem them as 'incapable' of engaging in activities. The experiences of Sambashivam and Benny can be further analysed; both fathers did not hold academic qualifications past the 12th standard and the lack of further/higher education may have been a factor in restricting their social mobility, despite governmental reservations for people identifying with the ‘scheduled tribe’ and the ‘other backward classes’. It is noteworthy that governmental reservations may have enabled a clerical opportunity for Sambashivam at a research centre. Sambashivam identified with the ‘scheduled tribe’ and was eligible for the governmental reservation in relation to employment in a government institution. However, Benny, unlike Sambashivam, could not find access to any other employment.

The limited cultural resources (institutionalized) held by both fathers may also serve as a factor in their limited awareness and acceptance of autism. They may not have had the opportunity to access further information regarding autism and the related strategies or interventions. In general, fathers have experienced a shift in roles and responsibilities and the number of fathers involved in caregiving duties has risen considerably in contemporary times. However, the empirical data from the field study shows that the responsibilities at home, of the family and child-rearing obligations, primarily rest with the mother. The father continues to be active in their role as the primary income earner which can limit the time spent with their child. Therefore, in some instances, the mother may be more receptive to the child’s needs. Poverty may also influence a father’s role in a child’s life; some fathers are required to earn an income to reduce instances of deprivation. The pressures of ensuring the daily survival of the household may create a situation where fathers spend less time with their children. Therefore, after the pressures endured by fathers during work, they may feel frustrated when children display certain characteristics; some fathers may not accept these characteristics and may deem them as ‘undesirable’. Thus, gendered roles, access to resources, and caste/tribe identity have all had a significant influence on the attitudes perpetuated by parents. Regardless of negative attitudes of parents, some actively take steps to dispel and react against stigmatising responses toward the family.

SUMMARY

This chapter has explored the different types of stigmatising reactions faced by parents/guardians of autistic children. The gendered division of roles led to an increasing number of mothers assuming the role as the primary caregiver. This may increase their vulnerability to both ‘felt’ and ‘enacted’ stigma. Mothers endure severe psycho-emotional stresses, especially when subjected to blame by their own husbands. Some mothers undergo severe psycho-emotional distresses and may not be actively involved in caregiving for the child. The data also shows that in some instances, mothers have resorted to suicide or contemplating suicide as a means to escape from the harsh remarks endured from raising an autistic child. When this happens, primary responsibility is placed on the grandmother or other female guardian. Some fathers are also required to juggle responsibilities at home and work when their wives experience psycho-emotional disablism. Fathers too, face stigmatising reactions; when a father has an impairment, the impairment of the child is associated with his own impairments. Unequal interactions can negatively impact the well-being of both parents/guardians (specifically, mothers). Irrespective of stigmatising reactions, parents/guardians take a stand and protect their child and family. Gendered roles play a significant role in influencing parental experiences; however, access to resources is also an important factor. For instance, a lack of adequate access to economic, social or cultural resources may reduce the aspirations of parents and can determine their negative opinion of the autistic child. Acceptance and awareness may be affected when parents/guardians are compelled to work for their daily survival. Impairment in the family can create some restrictions; for instance, in the case of a grandmother, the impairments associated with autism and her personal health problems create a difficulty in engaging with the grandson on an extended basis. Ultimately, the factor of gender stands out; an increasing number of mothers face unequal social interactions due to their traditional role as the primary caregiver and the ‘overseer’ of the household. They are thus disabled along with their children.

CHAPTER 7: INDIVIDUALISATION, NORMALCY AND PARENTAL PERCEPTIONS

INTRODUCTION

This chapter delves into the medicalisation of autism and its impact on parents/guardians of autistic children. The State of Kerala has alternate modes of health care (including Ayurveda and Homeopathy) alongside biomedicine. The State is home to many clinical hospitals and facilities. When parents/guardians identify a difference in their child, they primarily seek the help of a paediatrician or doctor. Autism, the features associated with autism, and related interventions are predominantly understood in clinical terms. Some parents/guardians are provided with information/awareness which constructs autism mainly as a clinical disorder which requires therapies/interventions for normalisation and cure. The pervasiveness of an individualised understanding of autism can negatively impact on parents/guardians. The aspiration for ‘normalcy’ may become the sole or primary objective, and if interventions are perceived by parents/guardians as unsuccessful, their psycho-emotional well-being can be adversely affected. The diagnostic scales, some of which are clinical, creates binary divisions of ‘normal’ and ‘abnormal’. When parents/guardians are provided with the diagnostic confirmation that their child is autistic and is determined to fall outside of what is clinically deemed as ‘normal’, they may endure exacerbated stress levels. Some parents/guardians may resort to comparisons with non-autistic children both within the family and outside. Some parents/guardians are then placed under severe pressures to seek services/interventions which can bring their child close to ‘normalcy’. Some may hold aspirations for their child to become independent in life, so that they [children] are not seen as a burden to others. Although, the concept of interdependent support may exist among some families, some parents/guardians in contemporary families strongly value the quality of being independent and standing on one’s feet without any other sources of support. The individualised understanding of disability has drawn attention to the need for ‘integration’ and additional socialisation opportunities for autistic individuals; however, locating autism primarily in a narrow, individualised framework may generate concerning implications for the family. Thus, this chapter explores in detail the pervasiveness of individualised understandings of autism and its impacts on the experiences of parents/guardians in Kerala. This chapter specifically begins by highlighting traditional health systems (in particular Ayurveda), and then moves onto explain the emergence of clinical systems and biomedicine in Kerala.

THE MEDICALISATION OF HEALTH IN INDIA AND ITS INFLUENCE ON DISABILITY

The traditional 'Ayurveda' system ('ayu'- longevity and 'ved'- knowledge), has been practiced for more than 5000 years. It was transmitted from generation to generation before colonialization brought the Western health care system (Kutty, 2000; Mishra et al., 2001). According to Sanskrit scriptures, Ayurveda originated between 4500-1600 BC; the concept of disease management using herbs and dietary interventions was developed into a science, also termed as 'Ayurveda', around 2500-600 BC (Mishra et al., 2001). In earlier times, Ayurveda was devised by sages without animal testing or randomized controlled trials. They (sages) received knowledge of Ayurveda through divine intervention; the sages were devoted to God and considered health as an important aspect of spiritual life. The knowledge they derived was transmitted orally to subsequent generations and eventually transcribed into books (Mishra et al., 2001). In the present day, Ayurveda and other systems of indigenous medicine are still officially recognized in India alongside the prominent biomedicine system. The government of India had established a separate department known as AYUSH (Ayurveda, Yoga, Unani, Siddha, Homeopathy) in 1995 to promote these systems (Patwardhan et al., 2011). There are a number of hospitals, dispensaries, educational institutions and registered medical practitioners practising Ayurveda in India.

The popularity of traditional medicinal practices like Ayurveda declined during the British rule of India. Initially, indigenous medicinal practices were accepted. Some educational institutions which were established during colonial rule taught both biomedicine and traditional medicinal systems (Jaiswal, 2018). However, the underlying reasons for the development of these training institutions slowly came to light: the objective was not to promote traditional medicinal systems or to encourage their coexistence with biomedicine. Rather, these institutions sought to train indigenous medical practitioners in biomedicine, so that they would eventually recognize its superiority (Jaiswal, 2018). The medicinal system developed in some minority world nations (in particular, the United Kingdom) thus became prominent during colonial rule, and continues to hold its status as the most prominent system in India. Trained doctors in biomedicine and diseases continue to be preferred to practitioners of traditional medicinal systems in contemporary India (Jaiswal, 2018).

The State of Kerala is known to have the highest density of medical institutions (both public and private) in the country, and its developed public health care system comprises medical colleges, district and local hospitals, along with primary health centres (PHC) and sub centres (Levesque et al., 2005). Public health services are accessible due to the availability of road networks and transportation systems (Narayana, 2008. p. 215), and the tradition of government support for health care development has enabled Kerala to reap health benefits. The State's success in health outcomes is attributed to an increased awareness of health, the optimum utilization of health-care facilities, and a strong emphasis on immunization programs which has generated high consumption of health-related services (Narayana, 2008. p. 206). The services of ground-level health workers are available alongside varied medical professionals including doctors, nurses, and policy makers who are committed to maintaining high health care standards (Nikarthil, 2015). Preventive and curative medicine is widely practiced and Kerala has become a frontrunner in palliative and rehabilitative care.

The development and practice of biomedicine in Kerala was complemented by other social programmes including the initiative to provide safe drinking water across the State and the establishment of mission hospitals by Christian missionaries, particularly in rural areas (Kutty, 2000). Over the years, the growth of health-related services was characterised by the increase in the number of institutions and beds. The government had also maintained an allocated budget for healthcare (Kutty, 2000). Fiscal problems became an issue for the government in the mid-1980s and it slowed down the growth of healthcare institutions. This paved the way for the growth of privatized health care services in the State (Kutty, 2000). Irrespective of low per capita income and the lack of industrialization or agricultural production, Kerala has witnessed an enhanced development in the health care sector.

The overwhelming focus on biomedical systems and the clinical services offered by clinical institutions, has contributed to the pervasiveness of the individual model of disability, which has permeated across some policy decisions for disabled people in India, where the primary target pertains to clinical intervention to get them close to ‘normalcy’, without adequate consideration of their lived social experiences. Some policies on disability are implemented in order to assimilate disabled people into the social norm (Kumar et al., 2012). Socio-cultural beliefs too, factor into the focus on the ‘deficits’ and ‘unwanted’ characteristics of an individual. The concept of ‘karma’ is widespread in Indian society, where the beliefs of some are situated in the notion that an individual’s present life is based on their actions and deeds in a previous life (Kumar et al., 2012). For instance, impairment, the birth of a girl child, or being born into a ‘Dalit’ or ‘scheduled caste’ community, are among some occurrences that are viewed as the result of ‘misdeeds’ committed by an individual in their past life. This can further generate low self-esteem and feelings of guilt or shame amongst some parents/guardians of disabled children.

In Post-Independence India, the main responses toward disability are rooted in medical interventions which seek to ‘treat’ and cure the ‘disease’ or the ‘problem’ (Addlakha & Mandal, 2009). The intensity of medical interventions was significantly greater in Kerala (Daley & Sigman, 2002), the primary reasons for which has already been cited in this section. India had undergone changes in the early 1990s; the role of governments decreased, while privatization of governmental organizations increased. The primary focus was placed on foreign investment and imports, while public expenditure decreased (Kumar et al., 2012). Increased privatization and the limited involvement of governments adversely impacted on disabled people’s access to basic services. Many NGOs are involved in the disability sector in India, even though some primarily adopt a charity-based approach towards disability (Hiranandani & Sonpal, 2010). Some multinational companies have also incorporated in-house NGOs with the intention of achieving a reputation for ‘corporate social responsibility’. However, the role of some of these organizations in relation to meeting the needs of disabled people remains vague (Hiranandani & Sonpal, 2010). Neo-liberalisation and globalization processes have enhanced for disabled people, communication and access to information, which has in turn proved beneficial to the mobilization of disabled people in India (even though the impact of neo-liberalisation for some disabled people in rural areas has remained ambiguous). Privatization has commodified basic necessities like health care, food and education, and by doing so has reduced the access of some disabled people to these services (Hiranandani & Sonpal, 2010).

Increased privatization has enhanced opportunities for some disabled people, who have found employment in highly skilled jobs (Kumar et al., 2012). However, these opportunities may not be open to everyone; they may only be accessible for disabled individuals who have had access to adequate academic qualifications and vocational training. The era of neo-liberalisation has promoted individualism as the basis of citizenship. For instance, value was placed on individual contribution, and individuals had to take responsibility for their actions and inactions (Kumar et al., 2012). Thus, neo-liberalisation promoted individualistic notions which have in turn created the dichotomy of an ideal individual and the 'other' disabled individual. Kerala's adoption of neoliberal practices in the 1990s was fundamental in promoting an idea of 'citizenship' which was influenced by the individual model of disability; people are measured by their capacity for 'self-care', ability to provide for themselves, and service their own ambitions (Kumar et al., 2012). Such perceptions have negatively impacted on some disabled people who have faced oppression and exclusion from social, cultural, economic and political spheres.

In India, some clinical professionals are accorded an 'elite' status and they primarily decide 'treatments' for disabled people based on 'correcting' the 'deficits' to bring them close to 'normalcy' (Beauchamp-Pryor, 2011). Jennifer Sarrett (2015) asserts the importance given to physicians trained in some minority world nations or nations in the industrialised West, by mothers of autistic children who approach them as a first step toward gaining further clarity and understanding regarding their child's development. Parents/guardians of autistic children are primarily influenced by individualised understandings of autism. Some seek alternate modes of intervention or any type of system which they feel may be beneficial to the child. However, the majority of the parents/guardians rely on the advice of a clinical professional to enhance their understanding of autism and to chart out their child's future. The information transmitted to some parents/guardians may make them view autism primarily as a clinical disorder with characteristics that require clinical intervention, treatment or cure. Thus, the next section will explore ‘normalcy’, ‘normalisation’ and its impact on the experiences of parents/guardians.

ASPIRATIONS FOR ‘NORMALCY’ AND THE PERCEPTIONS OF PARENTS/GUARDIANS

Some cultures in India place great emphasis on the adaptation to the social norm. Differences among some people may not be accepted; rather, these people are excluded and rehabilitated in the hope of getting them back to normalcy (Dimech, 2014). Impairments for instance, are not considered as part of the standards of normalcy and it is deemed to be a problem which requires cure. The status of ‘normalcy’ can lead to the exclusion of some disabled people, while others may be included as part of the norm (Dimech, 2014). Autistic individuals are identified among those who fall outside the standards of normalcy; some parents/guardians hope for an ‘ideal’ child and when they receive the diagnosis confirmation of autism, the child may be pushed to the periphery of ‘normalcy’ standards (Broderick & Ne’eman, 2008). Some parents/guardians cling onto the hope that the child who is ‘withdrawn’ is waiting to be ‘reclaimed’ and in such instances, parents/guardians may imply their desire for a child that is not autistic, but normal (Broderick & Ne’eman, 2008). Christy (C/GC) is the mother and primary caregiver for an autistic child. She lived with her mother and son in Kochi city (the biggest city in Cochin region, which is one of the target sites of the field study- please refer back to chapter four, under the ‘sampling’ section), while her husband was employed abroad. Christy’s response suggested her initial disappointment when she had received the confirmation of her son’s autism diagnosis:

> We were ‘gone’…. absolutely hopeless for a year. My husband and I could not digest this fact and we endured some marital problems. We have come across special children and they all have something different- they may not be able to walk or walk a different way or something else. Our child has no markers and he is cute and handsome- so we were astounded when they [diagnostic/clinical professionals] said that he has autism. As a parent, this was a huge shock- the biggest in my life. When I see Jayden [son] doing something weird or awkward, I totally breakdown and realise that he is indeed autistic.

Individualised understandings of disability draw attention to autism as a 'neurological deficit' or disorder which is characterised by problems in communication and interaction. This understanding may sometimes fail to acknowledge the differences among autistic individuals and may primarily associate their qualities with impairments (Theerasilp & Sherer, 2014). Some autistic people endure negative reactions, face devaluation and oppression as a result. 'Normal' standards are mainly considered as the 'ideal' standards and clinical interventions are set up to facilitate disabled people and their families to achieve normalcy or a level as close to normalcy as possible (Theerasilp & Sherer, 2014). Parents/guardians who hold individualised understandings of disability may subject their child to diagnosis and rigorous therapy in order to increase chances that the child is brought back to a level close to 'normalcy' (Theerasilp & Sherer, 2014). Christy had indicated her aspirations for her son to attain normalcy status or a level as close to normalcy as possible. She believed that the support provided to the son will increase his chances of achieving the status:

> It will be a dream come true moment for me if my son becomes normal. I told you before that his autism diagnosis was the most shocking moment of my life to date. In the future, if he were to undergo tests/observation to determine progress and the professionals deem him as normal or near to normal, it will be a huge accomplishment for me. Yes, my child coming to a position that is near 'normalcy' will be the highest point for me.

Christy had access to different forms of resources. She lived in a two-storied house with her child and the maternal grandmother. The husband, who is employed abroad, is the sole income earner in the family. Christy had mentioned that she owned a piece of land/property. She did not indicate any financial insecurities or shortage of money. The child-rearing obligations did not permit Christy to engage in paid employment despite high academic qualifications (MBA degree holder). She had also indicated that she had access to adequate social resources. Christy deemed her friendships with other parents/guardians of autistic children, whom she had met at the centre accessed by her son, to be beneficial:

> We have a parent group and we maintain contact through group social media chat where everyone shares their experiences. All of us plans trips, like picnic trips etc. Staying in touch helps to maintain one's positive outlook and I get quality suggestions from other parents as well.

Christy's access to networks and relationships has given her much courage. Pierre Bourdieu mentioned another resource alongside economic, social and cultural resources- symbolic resources. The other types of resources are transformed into symbolic resources when a particular individual enters a field (Power, 1999). For instance, Christy had used the resources she had possessed to find services which are satisfactory. The services, according to her, are also beneficial to the child. Christy had insisted that economic resources alone were not helpful for her child. Rather, time spent and the quality of services were the most important. She had used her economic resources and social contacts to ensure that her son had access to services which sought to improve his daily living skills. According to Christy, her goal was to primarily 'improve' the child to the level of normalcy. However, she also believed that life lessons were important:

> At home, I try to engage him in social interactions and daily living skills. When I am cooking in the kitchen, I make sure that he is present to watch what I do. I want him to observe and learn; I try to help him fold his own clothes as well. The organization he attends focuses on daily living skills and exposes children to social activities. I can see the benefits because now, he has better control of his urges. It does not matter where you send your child, time spent with them is of prime importance.

Christy's experiences show that some parents/guardians who may have imbibed individualised understandings of impairments are also willing to consider and enhance the social experiences of their children. The goal of 'normalisation', developed in Scandinavia, pertains to creating an adequate environment for disabled people to lead normal lives. Nirje maintains that the primary objective is not to ensure that people fit in with the social norm, but the differences among disabled people must be accepted in a normal society (Culham & Nind, 2003). While Christy's responses indicated the acceptance of differences in her son, and the determination to engage the child in daily living activities, her primary objective continued to be the focus on bringing the child close to 'normalcy'. Individualised understanding of autism may have factored into the undermining of her psycho-emotional well-being. However, access to economic, cultural and social resources have played a role in reducing the barriers experienced by Christy.

Impairment effects had also influenced Christy's experiences; according to her, the impairments associated with autism had made it difficult (in some instances) to predict her son's behaviours or people's reactions toward them. However, she believed that media and society could play a role in dispelling negative attitudes toward impairments, autistic people or their families, and promote inclusionary practices:

> In some situations, we may not be able to understand him [son] and it can lead to a melt-down. In most situations, I have been helpless. These days, it is easier, because he could pull and guide me to something which has caught his attention. In case I do not understand, he would run into a shop and pick up something to show me. However, it can be problematic because some shopkeepers may not be receptive. This is why I believe that awareness is important, so that the general public would be more compassionate. Once, he had a meltdown when we were at a mall and he made a scene, screaming, crying and rolling on the floor. Thankfully, a bystander bought a chocolate and gave it to him, which made him calm and happy. So, people in the society can be of help. Media can also play a role by making people aware of certain actions of the child and enhancing their knowledge on how to approach autistic children and understand their needs.

The individualised understanding of disability and the power of medical institutions has shifted the focus towards finding a cure for disabled people. The pervasiveness of individualised understandings is a key factor which determines whether a child is normal or abnormal (Bumiller, 2009). Medical and diagnostic testing is performed on a child to see if they fit in with the standards of normalcy. If an impairment is confirmed after testing, the child is considered to fall outside the social norm. Disabled people are viewed in relation to markers of otherness, and yet are expected to adapt to the norm (Bumiller, 2009).

John (C/OBC) is the father of an autistic child, who lived with his son, wife and mother (the paternal grandmother of the child). He had stressed that he was involved in the daily life of his son and supported his wife. John held an individualised understanding of autism; he associated the impairments associated with autism to shortcomings. He hoped for a recovery or cure with the help of medical intervention:

> If my son becomes normal, I will give thanks to God and move ahead. At the moment, with the help of a doctor, I am trying to improve his speech and get him to talk. If I am successful in this attempt, I am a winner! If my son can talk and actively communicate and interact with others, I will not have any shortcomings. It will indeed be a massive victory for me. We [John and his wife] are praying that this happens before the end of our time. Honestly, I want him to become like us [John and his wife], without any impairments-

> if he becomes normal, then I am a King! Otherwise, I feel sad thinking about why my son is like this' [with shortcomings].

The overwhelming focus on autism in individualised terms is a factor which had influenced John's aspirations for his son. John had indicated that his ultimate aspiration for his son was to overcome a perceived shortcoming or be cured of autism. The understanding and awareness of autism that has been passed onto the father, or the information accessed by him, had enabled the pathologisation of autism as a disorder and deficit. Thus, John primarily understood his son's characteristics based on the individual model of disability; rather than seeking other forms of intervention, including social accommodations, the primary goal was focused on subjecting the child to rigorous clinical therapy in the hope of restoring him to 'normalcy' (Dowse, 2017).

Lennard Davis (1995) draws attention to the standard bell-shaped curve in society; some individuals are required to adapt to the norms and fall into the curve bracket. The central idea of statistics pertains to the identification of the level of 'normalcy' of individuals by using clinical measuring tools. When an individual does not conform to the norm, they are subjected to interventions which primarily seeks to facilitate their restoration to 'normalcy' (Davis, 1995). An overwhelming focus on individualised understandings of disability may point to the individual and their impairments as the main problem, instead of the way 'normalcy' is socially constructed to create the problem for the disabled individual. Christopher (C/OBC), the father of an autistic child, lived with his family (which included his wife and his non-autistic child) in Thiruvananthapuram city (please refer back to chapter four, under the 'sampling' section). Christopher had been primarily exposed to individualised services when he had initially noticed that his autistic son engaged in actions that were different to a 'normal' child. These services have factored into his belief that his son's autistic characteristics are not normal:

> When I noticed behavioural patterns that were not similar to the behaviour of other children, I took my son to a neurologist. The neurologist referred me to a doctor who confirmed, after testing that he is autistic. My brother has some awareness because he has some knowledge in family counselling, so he uses his practical knowledge to mingle with my son. We know that he is not normal and he would display certain behavioural characteristics. So, we restrict his interactions with others. My mother shows compassion

> toward him because she knows that he has an abnormality. No one really harasses him because everyone knows that he is not normal.

Christopher had comprehensively imbibed the DSM-V understanding of autism, so much so that he had initially planned to send his child to an institution in the hope that his younger non-autistic child did not 'learn' the characteristics of the autistic child:

> I was apprehensive of the possibility that my normal son may learn certain behaviours from my autistic son, so, I planned to send my autistic son to an institution where he could learn discipline and manners. I had initially thought that it would benefit both him [autistic son] and my younger son, who would not need to grow up watching his older brother engaging in abnormal actions. However, I realise that it is best if they stayed together so that my younger son can understand the shortcomings of his brother and help him in the future.

Christy, John and Christopher were influenced primarily by individualised understandings of autism. They identified and associated their children with impairments and behavioural patterns which fall outside the status of 'normalcy' that was determined by the society. When the focus is overwhelmingly on 'deficits' and 'disorders', some parents/guardians may not entirely accept their child's diagnosis even with time. Individualised understandings and socio-cultural constructs of autistic individuals reduce the psycho-emotional well-being of some parents/guardians and increase their stresses. For instance, Christy had specifically mentioned that her world had come 'crashing down' when the diagnosis was disclosed to her. Consequently, she endured marital problems with her husband. She had stated that her husband, who had been in denial for a long period of time, had also begun to side with family members who had placed the blame on her. These unequal interactions affected her well-being even more. However, after witnessing Christy being engaged in the role as the primary caregiver (according to Christy) and enduring the pressures entailed in raising an autistic child, the father's attitude changed and he became more supportive. Christy focused on providing opportunities for her son to learn daily living skills, but ultimately believed that services should cater to ensuring that the child is brought back to 'normalcy' or as 'close to normalcy as possible'. John wanted his child to be cured of autism and insisted that a recovery from autism (for his child) would be his biggest achievement in life. The influence of individualised understandings of autism on Christopher is so great that he had seriously considered separating his two children (and the family in the process) due to the fear that the non-autistic son may imbibe characteristics of the elder autistic son through mere observation. Individualised understandings can reduce a parent's/guardian's outlook on autism and increase their pressures to seek clinical options that may reduce the 'undesirable' characteristics and restore the child back to 'normalcy'. In some instances, when the results of clinical interventions are not perceived to be satisfactory, some parents/guardians may endure increased stresses, affecting their psycho-emotional well-being.

Thresiamma had suggested that her daughter-in-law and mother of her autistic grandson fell into depression when she perceived that her child (the grandson) was not progressing toward 'normalcy' based on the doctor's advice and input. The mother's psycho-emotional well-being was so damaged by what she saw as a lack of progress in the child's development that she resorted to committing suicide rather than taking care of an autistic child:

> She [daughter-in law] did not believe that her son had a shortcoming- she was not willing to accept it, even when we pointed out the boy's shortcomings. She vehemently declined to accept and was in denial. The doctor had told her that after three years, the child would become normal and when it did not materialise, she became disappointed and took her own life.

The overwhelming focus on individualised understandings of autism can generate desperation among some parents/guardians, and even stretch them to commit self-harm that may destroy family life, separate family members and have serious implications on the well-being of the children. Individualised notions affected the psycho-emotional well-being of the Thresiamma's daughter-in-law. The internalised oppression created internal barriers for the mother and ultimately had a deleterious effect on Thresiamma's family. The gendered division of roles is a significant factor because mothering an autistic child places pressure on the caregiver to ensure that the child is brought up in a manner that is acceptable to society. When children are perceived to fall outside the standards of 'normalcy', their characteristics are deemed as unnatural and parents/guardians seek clinical interventions to rectify the 'deficits'. Mothers are more affected because, as the data shows, they are expected to be the primary caregiver for the child and they tend to imbibe the stigma of raising an autistic child more than fathers. Some mothers may resort to committing harmful acts like suicide, instead of raising an autistic child. Thus, parents/guardians ultimately hope for their child to attain 'normalcy' status. Individualised understandings not only create aspirations of attaining 'normalcy', but they can also adversely affect some parents/guardians by instigating comparisons between their child and others, which may lead to reduced psycho-emotional well-being. The next section explores comparisons and how they affect the parents/guardians.

Individualised understandings and comparisons

An individual who is adjudged to deviate from the standard social norm may face exclusion and their actions may be termed as 'abnormal'. When the diagnosis of a disability is confirmed, it may create negative physical and social consequences for people associated with the concerned individual (Dowse, 2017). 'Challenging behavioural patterns' are identified through statistical measurement of an individual's IQ, their adaptive functioning and participation in activities. This may lead to the identification of clinical services which are primarily based on the binary concept of 'normal' and 'abnormal'. The diagnosed impairment is considered to be an 'abnormality' and the social structure seeks to manage and rectify the 'abnormal' behaviour and actions (Dowse, 2017). The individualised focus on impairments and rectification of the perceived 'deficits' can generate comparisons with others who are deemed by society to fall within idealised norms. Some parents/guardians may compare their children with others and experience reduced emotional well-being (Thawani, 2013).

Rekha's (H/SC) experiences draw attention to her commitment in ensuring the adequate provision of affordable therapeutic services for her autistic son. She is the primary caregiver and lived with her husband, who was a mason, and elder non-autistic daughter in Kochi. Rekha's understanding of autism as a clinical disorder is a factor which created much grief when she was asked whether, at any point, there were comparisons with other children. She provided a response with much difficulty and had requested a break (from the interview) due to feeling overwhelmed:

> I have not compared, but when I see other [normal] children doing things [engaging in normal daily activities] which he [the son] cannot do, I am overcome with sadness…[cries].

The dominance and pervasiveness of the individual model of disability can undermine the psycho-emotional well-being of some parents/guardians. Their well-being is adversely affected as their awareness/understanding of autism is based on individualised notions and the binary concept of normal and abnormal. When thinking back about the instances where Rekha had engaged in comparisons (between her son and other non-autistic children), she felt so upset (being reminded of the son's impairments) that she could not control her emotions and cried. Individualised understandings primarily frame autism as a medical problem which requires clinical intervention so that the concerned individual can be brought back to 'normalcy' (Shyman, 2016). The autistic individual is considered to be 'abnormal' and abnormality may be associated with 'tragedy' and 'undesirable characteristics' (Shyman, 2016). This can in turn result in a narrow outlook on autism, where the ultimate solution pertains solely to accessing clinical interventions which can bring an individual back to 'normalcy' (Shyman, 2016). The ideal standard is embodied by the 'normal', 'able-bodied' and 'able-minded'; any deviation is considered to fall outside social norms and the individual is subjected to rehabilitation.

Some comparisons may arise when parents/guardians imbibe the notion that their child/children veer away from the standards of 'normalcy'. These notions can trigger feelings of sadness and inferiority among some parents/guardians. Anoop (H/OBC) is a father who was emotionally involved in the daily activities of his daughter. Anoop cited societal norms as a factor which pressurized him to pursue rigorous clinical interventions which he felt would enhance his daughter's prospects of achieving 'normalcy' and project his family as 'normal'. The father's reactions highlighted comparisons which stemmed from individualised understandings of autism and his sadness which had negatively impacted on his psycho-emotional well-being and reduced his aspirations for the daughter:

> It happens [comparisons]… for instance, my friend's daughter who is of the same age as my daughter is a district level swimming champion; there are times when I think that my daughter could have been the same. During festivities, when other children are participating on stage, dancing, singing,

> performing, I will be holding onto my daughter tight so that she does not run or show any actions. Again, in these instances, I feel that she could've also been up on the stage singing or performing. I hide such thoughts otherwise; my wife may feel upset [tears up].

Anoop's understanding of autism, based on the individual model of disability, had been transmitted to him via clinical services. His psycho-emotional wellbeing was deeply affected and he ultimately viewed his daughter as an individual with a shortcoming. Some people in the social world may treat a disabled person as an individual whose abilities and functionality are characterised by deficiencies (Davis, 1995). This may have played a role in Anoop's initial reluctance to try for a second child. He had stated his relief that his younger son was non-autistic and shared his aspirations:

> When we [Anoop and his wife] planned on having a second child, we were afraid that the child may end up like her [daughter]- honestly, I was afraid. However, by God's grace, he [son] is healthy. Regarding my daughter, my wife and I understand that she is different and we do not hold high goals. It is different with our son- we want him to be successful professionally and send him abroad for studies- we do not keep such goals for our daughter.

Anoop had held lower expectations for his daughter, because he believed that she was different and had shortcomings. He had also maintained that his goal was to find and access clinical services that would ensure that an 'absence' is filled with a 'presence' (Davis, 1995) or that the perceived 'deficits' are cured with the aid of rigorous clinical treatments. Anil (H/GC) is a therapist whose psycho-emotional well-being was adversely affected when engaging in comparisons. As a clinical professional, Anil's awareness of autism was primarily individualised. He specifically used medical terms to refer to autism and insisted on practicing clinical interventions on his son, which were accessed by him via books and online resources. Anil had mentioned the following, which highlighted the undermining of his psycho-emotional well-being, as a result of imbibing individualised understandings of autism:

> My issues stem from comparisons- for instance, when I hear other parents of autistic children speaking about their child, and about the fact that the child speaks more or that the child is a high-functioning autistic child, I feel upset. When I listen to parents of non-autistic children speaking about their child's achievements in relation to academics or sports, it is also very

> disappointing. My son does not hold many achievements that we can speak about.

Aparna (H/OBC), the primary caregiver and mother of an autistic child lived with her son in Kochi city to access desired services. Aparna's husband had remained abroad where he was employed. She indicated that individualised understandings of autism had adversely affected her psycho-emotional well-being:

> I used to compare and think that my child does not behave like other children. However, I have stopped comparisons, even though sometimes these comparisons pop up. I feel distressed when it happens. Autistic children are not normal, but I am trying my best to get him as close to normalcy as possible.

The parents/guardians who were mentioned in this section were all adversely affected by individualised understandings of autism. Comparisons had continued to cloud their minds and affect their psycho-emotional well-being and opinion of their children. Parents/guardians were disabled to a point that it affected family life and social interactions. Anoop had expressed his concerns when speaking about trying for another child. He had feared that the child may be autistic like his first-born daughter. The father showed his inherent feelings which were determined by individualised notions; he pathologized autism and associated the same with impairments and 'deficits'. He indicated his frustration at having a child with 'undesirable' characteristics and comparisons with other non-autistic children exacerbated his disappointment. Anil too, insisted that he became demoralised when interacting and listening to other parents/guardians. Therefore, he tried to reduce his involvement in social interactions and participation.

The data generated highlighted a pattern where an increasing number of parents/guardians identifying with the OBC caste category rejected comparisons (of their child), in contrast to parents/guardians identifying with the other groups. Some parents/guardians did not indulge in comparisons, even if they targeted individualised services. Arun Kumar, who was living with his wife and two children (the elder son is autistic) called attention to the importance of finding opportunities for his son to develop at his own pace without any external pressure. He believed in adapting towards his son's needs to provide a safe and sensory environment. Arun Kumar stated the following:

> I have not compared my child with others because every child is unique in their own way- the reality is that we all have our flaws. However, I accept the defect/limitation of my child and my only focus is to correct it- not to make him like this child or that child.

Neeraja too, is a mother who is not fixated on attaining the status of normalcy for her daughter or engaging in comparisons with other non-autistic children. She, however, believed in subjecting her daughter to intense clinical training programs to enhance communication skills:

> I have never compared my daughter to other children, autistic or non-autistic. There are different types of autistic children- one child may face difficulty in one aspect which may not be shared by another autistic child. Likewise, my daughter may endure difficulty in one aspect but may possess an attribute that others may not have. So, there is no point [in comparisons]- I accept my daughter as she is; she may have both positive and negative traits. We will reap the rewards based on the way we train them.

Gangadharan’s perceptions were similar to both Neeraja and Arunkumar. Although his dire circumstances (please refer back to chapter five and six for more details) and deprivation had exacerbated his stresses, Gangadharan placed emphasis on the differences of all individuals and stood firm on his rejection of comparisons:

> Yes, I have compared, however, it is not something that I can say out loud, but I keep it in my heart. I do not have such thoughts any longer; some people may do things quicker than my son who may take his time. Some may not have a shortcoming, while others may have a shortcoming. There are qualities which he has which others may not possess. So, I don’t really compare him to others; I focus on therapies to ensure that he is brought to a level of normalcy so that he can also live life in a normal way like his brother. I have to bring him to a normal level somehow- It may or may not happen, we’ll just have to try.

Although the individual model of disability had significantly influenced the understanding of some parents/guardians, some moved away from deficit-based comparisons, even if their ultimate goal pertained to targeting clinical consultation, therapies or treatments. Shaima Ahammed (2019) recognized the unique traditions and sacred rituals as occasions for collective action by some people who identified with the ‘backward caste’ community, including the OBCs. The existence of such traditions indicated the possibility of group cohesion among people in the aforementioned category, and this may be a reason why some parents/guardians who identified with the OBC category held a strength-based view of autism that was different from the views of others who were intent on finding clinical solutions of cures and achieving a ‘normal’ status. What had remained etched was the individualised notions of autism imbibed by some parents/guardians which was based on the knowledge transmitted by clinical professionals.

Some parents/guardians modified their expectations upon receiving the confirmation of the diagnosis (Boström et al., 2009). Research has highlighted the ‘maladaptive behaviours’ of autism which is a source that had increased the stress levels among parents (Hall & Graff, 2012). Individualised notions of autism can produce negative opinions which prevent some parents from making comparisons. For instance, John, an auto-rickshaw driver, asserted his daily involvement in supporting his autistic son and wife. The father explained his desire for the son to attain ‘normalcy’ status through clinical intervention. John stated the following:

> There is no point in comparing him [son] to others, because it has gone off the rails to a point where it cannot be corrected.

Jincy (C/GC) too, shared similarities with John in her experiences. Jincy, whose daughter accessed charitable services, had mentioned that she was ‘aware of the shortcomings of her daughter’ and ‘saw no point in comparisons’. Thus, some parents/guardians may compare their children based on an individualised notion of disability which may create psycho-emotional disablism. Others may not compare due to their acceptance of the ‘shortcomings’ of their children. Some parents/guardians stay away from comparisons due to the inherent fear that their parental capacities may be questioned by the public.

Individualised notions can lead to negative perceptions of impairments. When some parents/guardians internalise such perceptions, they associate impairments with short-comings. Academic achievement and contributing to society are important values in India. Some parents/guardians may engage in comparisons of their children with other non-autistic children. Comparisons which arise from individualised notions that promote the dichotomy of normal and abnormal can negatively impact on their psycho-emotional well-being. Comparisons suggest that some parents/guardians may hold a preference for a non-autistic child or ‘normal’ children over autistic children. Even in cases where comparisons do not exist, some parents/guardians are determined to seek therapies/interventions which can correct the ‘deficits’ associated with their child. Some parents/guardians may not want their parental capacity to be questioned. The negative connotations generated by the individualised focus on rectifying impairments and deficits have had an adverse impact on some parents who choose selective disclosure. Thus, barriers created by individualised notions can affect the well-being of some parents/guardians and disable them. It is therefore imperative to explore more aspects of individualisation of autism and the subsequent efforts of parents/guardians in accessing services aimed at attaining ‘normalcy’, and how this can affect the psycho-emotional well-being of parents. The next section focuses on the concept of being independent and parental perceptions attached to the same.

Self-reliance and ‘treading the correct path’

Disabled individuals have generally been identified as passive recipients of care and assistance. Their marginalization and vulnerability are attributed to the notion that they cannot receive care/assistance and empower themselves at the same time (Rabiee, 2012). The concept of independence/self-reliance is defined in different ways- some service professionals may define independence in terms of disabled peoples’ ability to engage in self-care activities, while some disabled people may define independence as a way to possess autonomy and decision making in one’s life. (Reindal, 2010). Individualised understandings equate doing things independently with self-reliance or taking care of oneself. Some disabled people value autonomy to make decisions and reach their objectives (Rabiee, 2012).

The term dependency can be linked to negative connotations like ‘burden’ and ‘deficiencies’ on the part of the individual requiring help or assistance. However, over the years, these concepts have been the subject of much discourse and analysis, and it has been argued that the ‘individualizing and exclusionary’ language of dependency should be replaced by a recognition of ‘interdependence’ and solidarity (Fine & Glendinning, 2005). The belief that an ‘independent’ individual requires minimal assistance is rooted in the individual model of disability, which has permeated to the political arena; there is an overwhelming focus on competitive individualism (Carnaby, 1998).

The majority of the parents/guardians in the study stated their belief(s) that independence and self-reliance were important as they could pave the way for their children to engage in daily living activities without ‘burdening’ family members or others. Neeraja offered specific reasons as to why she aspired to find and access therapeutic services to enhance the independence of her daughter. Neeraja insisted that she did not hold high academic or professional hopes for her daughter; rather, she wanted the child to be able to do things independently:

> I am not hoping for academic excellence; being a girl child, she should be able to react or respond in a situation where she may feel threatened. She should be able to do that by herself, without the help of others.

Neeraja’s concerns, as the mother of an autistic daughter, are understandable. Abuse and violence against children and women have plagued India and any parent/guardian would encourage their child to learn and implement safety techniques themselves. Abuse against disabled individuals (especially girls) may go unreported and the child may endure difficulty due to impairments in relation to speech and communication. Neeraja had wanted the child to be able to communicate her concerns during a situation where she may feel threatened.

Christy and Gangadharan shared similar aspirations for their children- both were of the opinion that the pursuit of academics is only secondary to becoming more self-reliant. Christy stated the following:

> After realising that my son has this condition, we [Christy and her husband] did not put our focus on his success in academics. Our focus is on improving him as a person, while academics is secondary. I want to see him become independent so that he can get his things done by himself. For instance, if he is hungry, he should be able to communicate his hunger and ask for food.

Gangadharan indicated his inherent frustrations and desperation when he said the following:

> I hope that he can do things by himself; at the moment, it is okay because he is a child. However, when he becomes older and he is able to do things by himself, I would be at peace. Academics is not of paramount importance- he should be able to do his daily routine activities by himself, without being a disturbance or botheration to anyone else.

The notions of independence and self-sufficiency are considered to be ideal; those who are dependent on others are seen to deviate from these ideal norms (Ward, 2011). They are deemed to be lesser human beings and in need of constant care and protection. Dependency is associated with vulnerability and weakness; these notions situate disabled people as inadequate and incapable (Ward, 2011). Neeraja, Christy and Gangadharan wanted their children to achieve the ideal status of ‘independent’ and held aspirations to find services and therapies which could enhance the child’s self-reliance. These aspirations indicated an understanding that is primarily influenced by the individual model of disability. This may create barriers within the family system and generate low opinions of their children, and reduced aspirations for the autistic child in comparison to other children in the family.

Some parents’/guardians’ aspirations for their child to become self-reliant with the help of clinical interventions can be associated with their personal circumstances. Pushpa, a mother facing deprivation and abject poverty, stated her desire for the daughter to achieve normalcy through clinical interventions and medicines. She has two disabled children and an ageing mother to look after, and asserted her sadness at both children being disabled. The ex-husband had abandoned the family and she explained disabling barriers arising from the unequal interactions with her husband, and some restrictions she had faced when interacting with the children (impairment effects), which had created intense pressures and affected her psycho-emotional well-being. According to Pushpa, an ideal situation would be one where her autistic daughter, who did not have any physical impairments, became normal and self-reliant. The daughter could have then pursued employment opportunities or engaged in labour to contribute to the family income and improve daily sustenance (as per Pushpa’s statement):

> She [daughter] has to do things by herself. If my daughter was normal, she would not have been like this. She could’ve gone to work in a shop or done tailoring or be engaged in any type of paid vocation.

The identification with the ‘backward caste’ community (including the OBCs) and abject poverty are interlinked (in some instances), and the primary goal of people who lived these experiences was based on daily survival (Gupta & Singhal, 2005). Therefore, Pushpa continued to hold the desire for her daughter to become independent and normal. Thus, the individualised understanding of disability as deficits/impairments that require cure or intervention is a major factor which increased parental stresses. Some parents/guardians wanted their children to obtain a level that is close to ‘normalcy’ and an idealised state where the child was independent or self-reliant. Anything that veered away from the norm was associated with deviance, inferiority and weakness. After the diagnosis of an impairment, the individual is considered to be a dependent recipient of care who may also be unappreciated. They are targeted primarily by clinical interventions which seek to remove all the perceived ‘undesirable’ characteristics (Stone, 2003).

The dependence/independence dichotomy may create pressures on some parents/guardians. They may become desperate for their child/children to become self-reliant and ensure that they are not a burden to others. This may be indicative of the pressures to conform to the social norm and attain the ‘ideal’ status of being self-reliant. It can also suggest possible fear of discrimination directed towards the child who may be considered by some in society to be ‘burdensome’. Fingers are also pointed at parents/guardians whose capacities may be questioned. The binary division of dependence and independence should be replaced by ‘interdependence’. Mutual dependence among human beings should be promoted as a core value and social interactions should be based on a partnership or a two-way responsibility (Rabiee, 2012). Dependency is individualising and may lead to exclusionary practices against those who are deemed to be dependent (Rabiee, 2012). The overwhelming focus on individualisation can disable parents/guardians and affect the family system by undermining the psycho-emotional well-being of parents, and reduce their social interaction and participation.

SUMMARY

This section has highlighted the stronghold of medical institutions and the pervasiveness of the individual model of disability in influencing parental perceptions. The overwhelming focus on the individual model creates a fixation on ‘deficits’ and ‘problems’ by drawing attention to a preoccupation with idealised notions of the body and the mind. Judged by the normative yardstick, the ‘imperfect’ attributes of autistic children are considered to be inferior. Autism and childhood are presented on the basis of dependency and the emphasis has been on finding interventions which can increase the chances for a cure. When parents/guardians imbibe a reductionist approach which constructs autistic children as individuals with disorders, they seek services for a cure. When some parents/guardians perceive their attempts as unsuccessful, they are adversely affected to a point where some may resort to self-harm measures, instead of raising an autistic child. They are disabled by unequal interactions which place emphasis on parents/guardians to raise normal children. These interactions (which specifically affected mothers) undermined their psycho-emotional well-being and reduced social interactions and created negative perceptions about autism and their child.

A narrow outlook on autism and the focus on certain characteristics displayed by some autistic children can result in comparisons. The psycho-emotional well-being and self-esteem of some parents/guardians are affected when they indulge in comparisons based on their individualised understandings of autism. Social norms play a factor in constructing what is ideal in society, and when children do not fall within the ideal standards, parents/guardians are adversely affected. They seek clinical services which may enhance (according to the parents/guardians) the prospects of the child to achieve normalcy or a level which is close to normalcy. There is still a long way to go in terms of strategies/policies for autistic children and families due to the pervasiveness of the individualised notions of disability. Models based on interdependence and diversity of experiences may increase opportunities that value differences. Although individualisation efforts have promoted the integration of disabled people, the primary use and focus of individualised terms and understandings have narrowed down the understanding of autism to a deficiency which is in need of ‘cure’ or ‘correction’. When parents/guardians associate children with ‘deficiencies’, they may deem their family as ‘inferior’ due to the fear of exclusion from the social norm. The competitive academic culture is also a factor which can create complex mental trauma for some parents/guardians. When children are measured using standardized scales, it can create comparisons and unequal interactions, which may reduce the psycho-emotional well-being of some parents/guardians. All the parents/guardians had imbibed individualised notions of impairment irrespective of gender, caste and/or class. In some instances, both mothers and fathers had expressed their fear of comparisons, and how that may turn into parent blame or the questioning of parent capacities. Thus, individualised notions can create complex barriers, some of which may disable parents/guardians.

CHAPTER 8: CONCLUSION AND RECOMMENDATIONS

INTRODUCTION

This thesis is concerned with the experiences and perceptions of parents/guardians of autistic children in Kerala. The empirical chapters centre on the input of participant interviews, place emphasis on their complex experiences, and finds that whilst, some may privilege parents/guardians, others may create disabling barriers for them. Furthermore, the influence of gendered division of roles, access to resources, and the barriers created by unequal social interactions within the family and the broader society are detailed in the previous chapters. The chapters also entail an exploration of the pressures stemming from raising an autistic child, and the influence of patriarchal attitudes, social norms, poverty and caste/tribe identity on parental experiences. Some parents/guardians undergo immense stresses and pressures when parenting an autistic child. When parents/guardians are subjected to unequal social interactions, their psycho-emotional well-being is undermined. Their social interactions, participation in social activities, caring for the autistic child and relationships within the family are adversely affected. Parents/guardians may undergo some restrictions which arise from the impairments associated with autism, also known as ‘impairment effects’. However, impairments do not constitute the primary disabling barriers experienced by parents/guardians. The pressures to conform to the norms in society, blame and shame experienced by mothers and fathers, and impairment among parents/guardians are factors which have created significant stress among parents/guardians. Other major stresses stem from the difficulties in understanding the needs of their autistic children, lack of acceptance among parents/guardians, the negative responses of some members in the family and society, and the lack of access to adequate services. The social relational model was employed and an intersectional framework was incorporated to understand the diverse and complex experiences of parents/guardians. By utilising the aforementioned concepts, this thesis has offered a detailed analysis of the social lives/experiences of parents/guardians, with the intention to highlight the barriers they face and enhance the reader’s understanding in relation to the influence of factors like gender roles, access to resources, and caste/tribe identity on family interactions/social participation. This chapter seeks to revisit the key themes and discussions which are detailed in this thesis. It provides a summary of the findings and then recommendations are presented with the intention of enhancing the awareness of grassroot social barriers experienced by some parents/guardians of autistic children. These recommendations are provided with the aim of contributing to sociological knowledge, debates, and policies that help parents/guardians of autistic children to access psycho-emotional support services and vocational opportunities. Any limitation(s) will be briefly identified and considered.

SUMMARY OF FINDINGS

The data generated draws attention to gendered divisions of roles and patriarchal notions as the most significant factors influencing the perceptions of parents/guardians in Kerala. Other factors like access to resources, caste/tribe status, and poverty are also important factors which determined their experiences. The majority of the parents/guardians who participated are mothers or female guardians. This can be attributed to gendered divisions of roles which see mothers become the primary caregiver for the child. Mothers were more likely to leave their employment (if they had held one previously) and focus their attention upon meeting the needs of the child. Among the participants who had identified themselves as the father (ten participants in total), four admitted to their supporting role, while citing the overwhelming involvement of their wives as the primary caregiver for the child. One father (among the four fathers who were identified as the primary income earner in their family) had indicated his limited involvement in his autistic daughter’s life. The father’s responses highlighted his imbibed and inherent values, which can be associated with patriarchal norms in society. According to the father, his autistic daughter would be a daily presence in his life, if his wife (whom he had considered to be the primary caregiver for his children) was still alive. Access to resources and poverty can also be identified as factors in the experiences of some fathers, including the one mentioned above. Some fathers had expressed their difficulties in undertaking caregiving duties, as they had to earn an income for the basic survival of the family.

The negative implications of raising an autistic child on a daily basis are highlighted in this thesis. In particular, mothers may undergo exacerbated levels of stresses and barriers when parenting an autistic child. The majority of the mothers left their employment (irrespective of academic qualifications or employment experiences) to care for their child. In some instances, the husband continued to be the primary income earner, while the mother moved with their children to another area to access desired services. This led to the break-up of the family system and reduced the informal support of some mothers. Mothers then faced pressures from occupying multiple roles, and these pressures affected their emotional well-being and created some barriers for them. The majority of mothers of autistic children are subjected to unequal social interactions, and some may possess limited access to economic, social and cultural resources, which impacts on their well-being. The impairment effects associated with autism is another factor which created some restrictions for them. Some mothers like Pushpa (whose situation was explored in depth in the empirical chapters) faced disabling barriers arising from the unequal social interactions with their husbands or ex-partners. For instance, unequal interactions arose when caregiving responsibilities for the autistic child were not equally shared between the husband and the wife. Some husbands/fathers placed the caregiving responsibility of the child entirely on the mother. In some instances, mothers imbibed their domestication and expressed that the husband's income-based contribution to the family was fair. Patriarchal notions held within the family were factors which determined unequal interactions and adversely affected the psycho-emotional well-being of mothers.

The patriarchal notions held by some fathers are a factor which resulted in unequal social interactions between the parents/guardians. These interactions negatively affected the psycho-emotional well-being of some mothers and maintained their continued dependence on the father of the child. In some instances, these unequal social interactions resulted in the continued deprivation experienced by some mothers and their children. The shame of raising an autistic child was a factor which influenced the interactions of some parents/guardians. Some fathers blamed the mother for giving birth to an autistic child, and some associated the child's 'deficits' with insufficient or bad mothering practices. These reactions too, adversely impacted on the psycho-emotional well-being of some mothers. The existing research on parenting disabled children draw attention to the following: mothers of disabled children are judged more harshly than mothers of non-disabled children. Child rearing and unpaid labour within the home are still undervalued and mothers are primarily blamed for the children's perceived shortcomings (Khanlou et al., 2017). My findings confirm that mothers of autistic children are predominantly subjected to blame and the negative reactions of others. However, I propose a need for additional sociological studies focusing on parental experiences and the daily stresses faced by parents/guardians of autistic children (using the social relational model of disability and an intersectional framework). Conducting these studies can enable the identification of a set of measures which can significantly enhance parental experiences, address the barriers, improve public perceptions of autism and improve access to support systems which can be directly used by parents/guardians.

The lack of high academic education/qualifications, and the limited access to adequate resources, were other factors in the experiences of some parents/guardians. Some parents/guardians experienced practical difficulties in raising their autistic children. For instance, some restrictions arose when the children displayed certain actions like screaming, running towards the road, running outside from inside the home in an instant, experiencing an uncontrollable 'melt-down' and being physically aggressive toward the parent/guardian or other family members. Some mothers/female guardians in particular had admitted their helplessness in relation to managing impairment effects. For example, one interviewee, Thresiamma, the primary guardian and grandmother of an autistic child, had mentioned sprinkling crushed black pepper on the floor, as a final resort to deter her grandson from picking up and eating anything off the floor. Thus, the majority of mothers/female guardians faced barriers when raising an autistic child. The unequal domestic division of roles and the unequal social interactions between spouses create disabling barriers (which primarily undermined the psycho-emotional well-being of mothers) and a cycle of deprivation for some families. The majority of mothers in the study were domesticated, and they experienced disabling barriers arising from unequal social interactions and limited access to resources. The 'impairment effects' in relation to autism was also a factor which created some restrictions for parents/guardians.

The availability of adequate economic resources may increase some parents'/guardians' access to desired services. Some even make a choice to move to another city or area to increase their access to desired services. In some instances, families are separated and the mothers (primarily) and their children are cut off from daily interaction with the respective spouses/fathers. This can generate feelings of isolation among some mothers. Some parents/guardians cannot afford to relocate to another place as they may not have access to adequate economic resources. Irrespective of parents' access to adequate economic, or social and cultural resources, some mothers continued to experience stresses which stemmed from their role as the primary caregiver for the child. While the caste/tribe status can be attributed to some parents' enhanced access to resources, employment and economic position, the domestic division of roles was a factor which had a major influence on their experiences.

The majority of the fathers of autistic children who had participated were involved in daily child-rearing duties. Fathers not only actively involved themselves in raising their children, but also protected the child, and took care of the wife and the family. Some fathers remained flexible with their employment and other engagements, so that their wives, who were the primary caregivers, could take time off from caregiving responsibilities when necessary. In some instances, fathers were even willing to forego career advancements to take care of their child and maintain the family's stability. For instance, one interviewee, Anoop's commitment to his family is evidenced by his responses which indicated a father who strived to maintain the stability at home and be a support to his wife. The father had taken a step back from his job by choice to ensure that he got an opportunity to work remotely and be more involved in child-rearing duties. The shift in the roles among some fathers can be attributed to an increase in the number of nuclear family systems in urban Kerala. There are also a number of women who are in employment and some parents/guardians decide to share caregiving responsibilities. Thus, the involvement of fathers in caregiving obligations has increased. However, mothers continued to be the primary caregivers and those who were primarily affected by stigmatised reactions and disabling barriers.

Parents/guardians were affected by 'courtesy stigma' or the stigma attached to parenting an autistic child due to their association or relationship with the child. The behavioural patterns and 'undesirable' characteristics displayed by an autistic child were attributed to the role of the parents/guardians as caregivers. Parental roles and capacities were placed under question when the child engaged in actions which veered away from the social norm. Some close family members and people in society may associate the characteristics displayed by an autistic child with 'bad parenting', which shows that informal support systems can be oppressive in some instances. Some parents/guardians were found to internalise the open/direct and perceived negative reactions of others, often resulting in negative consequences including reduced psycho-emotional well-being, friction in marital relationships, resorting to self-blame, and increased feelings of isolation. Again, gendered division of roles factored into these experiences; social norms place the responsibility of caregiving primarily on mothers. Mothers are pressured by norms which promote the development of children who fit the social norm. Some mothers considered the negative reactions of their spouses as the harshest they had faced. Mothers struggled with unequal interactions and their psycho-emotional well-being was adversely affected to a point where they engaged in reduced social participation due to the fear of possible negative reactions. The findings from my thesis confirm that mothers are primarily blamed (by close family members) when the child's development is adjudged to veer away from normative pathways (Vaidya, 2016a). Although some negative reactions may be attributed to the limited awareness/knowledge of autism, blaming and shaming can adversely impact on the psycho-emotional well-being of parents/guardians, especially mothers. In some instances, the media projects unreasonable standards to which people are expected to adhere. However, there are some safe spaces on social media which enable positive conversations on inclusion and facilitates networking possibilities for parents/guardians and their children. These spaces can address/change the discursive notions held by people and reinforced by broader society.

This thesis highlighted the negative impact of individualised understandings of disability/autism on the psycho-emotional well-being of some parents/guardians. Specifically, some mothers of autistic children were so affected that they resorted to extreme measures due to the shame of raising an autistic child in a society which favours competition and places the onus of the developmental responsibility on mothers (Pilcher & Whelehan, 2017). A mother had committed suicide because she could not cope with the thought of raising an autistic child. Another mother had contemplated taking her own life and the life of her autistic son so that they did not have to face the negative reactions of the public anymore. Internalised oppression led to psycho-emotional disablism and fractured the family system. Thresiamma was placed with the responsibility of caring for her autistic grandson in her old age. The grandmother’s age-related impairments created restrictions for her in effectively interacting with the child on a daily basis. Thus, psycho-emotional disablism can create barriers and adversely impact on the stability of the family. The barriers created by psycho-emotional disablism primarily affect mothers, even though they impact on some fathers. Gangadharan, the father and primary caregiver for his autistic child, experienced significant stresses (which undermined his psycho-emotional well-being) due to his wife’s internalization of negative implications associated with mothering an autistic child. This had further impacted on the family’s access to adequate economic resources. The father had also stated being subjected to additional restrictions arising from ‘impairment effects’.

Some parents/guardians were not affected by unequal social interactions. These parents/guardians valued social interactions and were not too bothered about negative reactions; rather, they were determined to ensure that their child could access social activities just like other children. Some fathers were subjected to unequal interactions, blame and shame due to their own impairments. For instance, Mohammed faced the negative reactions of others who had subjected him to blame due to his speech impairment. Impairment in the family or among parents/guardians may lead to some restrictions for them. However, parents/guardians like Mohammed face disabling barriers which stemmed from unequal social interactions. An overwhelming emphasis on the individualised understanding of autism has been transmitted to the majority of parents/guardians. This had led to internalised feelings of shame when raising an autistic child. The large majority of parents/guardians who had participated held an individualised understanding of autism: they considered autism to be a disorder and targeted rigorous clinical and therapeutic interventions as a means to find a cure or bring the child to a level close to ‘so called normalcy’. Specifically, mothers imbibed these negative notions and it led to the undermining of their psycho-emotional well-being. In comparison to fathers, an increasing number of mothers experienced the traumatising consequences of psycho-emotional disablism. Some parents/guardians held a perception of autism that was different from the pervasive clinical understanding. However, these parents/guardians were ultimately found to associate autism with ‘shortcomings’ and ‘deficits’. Parents/guardians experienced the shame of raising a child who was characterised by perceived ‘deficits’ and ‘shortcomings’. Some parents/guardians engaged in comparisons.

In Indian society, academic competitiveness is given great value by some parents/guardians, who may endure disappointment when they compare their child with other non-autistic children. Comparisons also arose from individualised understandings of autism based on statistics and standardization, which may in turn exacerbate feelings of inferiority among some parents/guardians, often leading to reduced aspirations for the child. For instance, Anil, a qualified psychiatrist and father of an autistic child, is one such parent/guardian who had internalized these negative feelings. He expressed disappointment that the child was diagnosed as ‘severely autistic’. Anil had hoped that the child would be a ‘high-functioning’ autistic (he had stated that he understood his child was different from an early age). He had admitted comparing his child, and how these comparisons negatively affected his psycho-emotional well-being. The negative emotions which arose from comparisons suggested parents’/guardians’ innate preferences for non-autistic or ‘normal’ children over autistic children. The generated data also showed that some parents/guardians did not engage in comparisons. For instance, Arun Kumar had explained his belief that his child possessed unique characteristics; according to him, the child must be given the space to develop his characteristics, even though the ultimate solution that he was seeking was cure. Arun Kumar insisted that he will never compare his child as every child had unique characteristics. Among the parents/guardians who did not engage in comparisons, the majority identified with the ‘backward’ caste category due to their belief regarding individual uniqueness (which also included flaws). Their reactions may indicate the historical collectiveness among some people identifying with the ‘backward caste community’ (please refer back to chapter seven).

Some people identifying with the ‘backward’ caste category, in particular, some from the ‘scheduled caste’ group, may also have accepted a status ascribed to them by society and may not feel entitled to greater economic facilities or provisions. Rather, they may believe in unity and fighting against barriers to protect their family. The same could be attributed as a reason for some parents’/guardians’ acts of resistance against the internalisation of stigmatising attitudes and comparisons. Among some parents who fall into the ‘general caste’ category, the experiences of an increasing number of participants indicated the internalisation of stigma. Some people in the ‘general caste’ category may not be subjected to certain barriers due to their affiliation with a particular caste/tribe identity, while they may also feel entitled to an economically privileged rank when compared to people in the ‘backward caste/tribe category’ (Biswas & Pandey, 1996). It can therefore be inferred that some parents/guardians in the ‘general caste’ category may feel that raising an autistic child can challenge their social status.

Some parents/guardians placed value on self-reliance and performing daily living activities by oneself. The majority of the parents/guardians sought services which aimed at enhancing the child’s opportunities to be self-reliant over the pursuit of academics. When some parents/guardians imbibed such norms, it reduced their autistic child (in their eyes) to a ‘weak’, dependent individual in need of ‘rehabilitation’. For instance, Sambashivam held negative opinions of his son and chastised the son’s autism-related characteristics and dependency on his mother, who was the child’s primary caregiver. Some parents/guardians like Sambashivam, assumed the role of a ‘stigma coach’ by holding negative perceptions of autism and considering their children as inferior to ‘normal’ children. The domestic divisions of roles have limited the involvement, awareness and acceptance of some fathers due to their status as the primary income earner. For some parents/guardians, including Sambashivam, earning an income was a pathway towards the daily sustenance of the family. Regardless, parents/guardians remain central in improving the perceptions of autistic children and families who may be subjected to stigmatising attitudes by others.

The pervasiveness of gendered roles, patriarchal notions, and an understanding of autism primarily based on the individual model of disability, can produce debilitating effects on parents/guardians, thereby affecting their psycho-emotional well-being. Previous research had called attention to positive indicators for women in Keralan society in relation to reduced stress levels, increased education, improved employment opportunities and enhanced social mobility; however, women continue to be at an increased risk of experiencing high rates of mental stress, suicidal tendencies, and violence/neglect across all social groups (Thresia, 2014). The experiences of the majority of mothers give evidence to the aforementioned statement. This thesis has also found that both mothers and fathers try to ‘hold on’ for their children through their perseverance and commitment toward enabling access to services and social participation which meet the needs of their children.

Caste/tribe-based reservations/provisions in education and employment may be attributed to the enhanced opportunities to access economic, social and cultural resources for some parents/guardians of autistic children. The experiences of some parents/guardians identifying with the ‘other backward class’ category may suggest the role of reservations in improving opportunities toward education and employment, which in turn allowed them to acquire economic, social and cultural resources. This further enabled better access to desired clinical services for the children. Some mothers who had identified with the ‘other backward classes’ category had adequate access toward desired services for their children. Their experiences can be linked to social justice initiatives for women in Kerala (explained in chapter three).

While caste/tribe-based reservations have seemingly enhanced the distribution of educational and employment opportunities for some people who identify with the ‘backward caste category’ (OBC, SC/ST), inequalities have continued to persist. The low academic qualifications and restricted employment status of some parents/guardians can be attributed to their caste/tribe identity. The hierarchical caste structure may be a factor which continues to segregate people and determine their access to services/resources. However, it is difficult to pinpoint caste/tribe status as a factor which privileges people identifying with the ‘upper caste’, while creating barriers for people identifying with the ‘backward caste’ category including the OBCs, SCs and STs. This is because some parents/guardians identifying with the ‘backward caste’ category have increased access to resources in comparison to some who identify with the ‘general caste’ category. Thus, provisions may have helped reduce the inequality gap in relation to education and employment to an extent. However, the gendered division of roles is the most significant factor which has influenced the experiences of the majority of parents/guardians. Some mothers who held high academic qualifications were not involved in any form of paid employment due to the norms requiring them to assume responsibilities as the primary caregiver. Even in situations where the father was the primary caregiver, the mothers are the parent/guardian who are more affected psycho-emotionally. Gender roles and access to economic resources are the primary factors influencing parental experiences. Unequal social interactions which undermined the psycho-emotional well-being of some parents/guardians created severe disabling barriers for them. These interactions and the impairment effects affected the mothers more than fathers. The pressures on mothers to ensure that the family conformed to the social norm was immense and subjected them to much strain and severe barriers.

DISCUSSION

The role of parents/guardians in the lives of autistic children is important. The caregiving role of mothers is imperative and follows suit with the social norm of India. The increasing involvement of fathers shows changes in the structure of the family. Joint families exist, but nuclear family structures are increasing in urban areas. The change in family structure places the responsibility for the child and the household primarily on mothers. Patriarchal notions are still embedded in Indian society and the social fabric places added pressures on the mothers of autistic children who are required to raise them (the autistic children) in accordance with the social norm. Gendered divisions of roles subject women to domestication and may increase their caregiving responsibilities for the child, which leads to the reduced involvement of some fathers who are also the primary income earners.

Autism continues to occupy a complicated realm in Indian society. There is an overwhelmingly individualised approach to autism in Kerala. I found that at the ground level, the social experiences of parents/guardians of autistic children are sometimes not adequately addressed. Socio-cultural understandings of disability, the presence of a large number of medical institutions, and widespread medical knowledge of disorders and social norms factor into the pervasiveness of individualised understandings of autism. The narrow outlook on autism, which is primarily based on individualised understandings, can create barriers for the family. The benefits of medical facilities, clinical interventions and treatments cannot be underestimated; there has been significant improvement in terms of transmission of information, the number of accurate diagnoses, availability of psychological support/counselling help for parents/guardians, and access to health-related interventions. Knowledge and awareness of autism can be powerful, but there is a need to transmit information in a way that offers different perspectives on understanding the autism spectrum, with a focus on acceptance, rather than the widespread misconceptions of autism as a disorder. Some medical professionals and researchers root autism and related interventions to the characteristics associated with it. The experiences of parents/guardians cannot be solved by merely subjecting the child to interventions and cure. Clinical professionals must listen to the experiences of parents/guardians and design study programmes (in collaboration with parents/guardians and the children) to understand the contextual environment of the family. The sole focus on individualised understandings of autism can increase the stresses experienced by parents/guardians.

The experiences of parents/guardians are so complex that it is imperative to analyse their perceptions and interactions at the intersection of other influential factors. Gendered divisions of roles, access to resources and caste/tribe status affect parental experiences. Among the aforementioned factors, gendered divisions of roles were the most influential in determining the experiences of parents/guardians. These factors cannot be analysed in isolation, rather, the influence of all the factors in interaction with each other and how it creates privileges for some, while producing irreversible barriers for others (Nash, 2008), should be topics for further discussion in sociological research.

Using an intersectional framework, this thesis has explored the complex experiences of parents/guardians. For instance, some mothers had experienced both privilege and barriers. In addition to their employment, some mothers were tasked with child-rearing duties. Mothers experienced stress as a result of their diverse roles. The parenting capacity of some mothers was questioned and they were subjected to harsh reactions by immediate family members, including their spouses. High educational qualification and employment were factors which enabled the access of some mothers to desired services for their children. However, gendered division of roles was a primary factor which subjected some mothers to unequal social interactions that undermined their psycho-emotional well-being. Thus, their experiences enable an understanding of not only a multitude of oppressions, but also the ‘multiplicative relationships among them as well’ (Strand, 2017).

In this thesis, an intersectional framework has highlighted that privilege and marginalization can exist and co-exist within, among and between groups. Furthermore, this approach has enabled an analysis of how factors like gendered division of roles, access to resources and caste/tribe status work together to produce privilege and oppression (Erevelles & Minear, 2011). Using an intersectional approach which embraced privilege and oppression as complex and simultaneous, this thesis has produced new understandings of the complex experiences endured by parents/guardians (Nash, 2008).

Large scale changes are necessary to find wholesale inclusive solutions to removing barriers. Indian society, as a whole, should be provided with large scale awareness/acceptance training and be made aware of multiple understandings of autism and the autism spectrum, rather than an overwhelming focus on autism through the lens of the individual model of disability. Training on the importance of spousal and other informal support should be provided and practiced to mitigate against unequal social interactions which may disable some parents/guardians, especially the mothers. The experiences of parents/guardians are crucial and their needs must be made comprehensible to policy makers and the general public (Vaidya, 2016a. p. 173). The internalisation of social norms, with strong roots in gender divisions and hierarchical organization, along with neo-liberalisation and consumerism, has intensified the drive for homogeneity and unacceptance of differences in a society where intense academic competition emphasises conformity and performance (p. 174).

Strategies should address the challenges faced by parents/guardians in urban and rural areas. The acceptance of diversity must be emphasised and autism should be considered as a spectrum of different experiences, one that is separate from diseases. It should also be classed alongside oppressions faced by women, people identifying with a gender (or those who do not identify with any gender), oppressions based on caste/tribe identity, and poverty. The biological reductionism of autism must be rejected, and this will reduce the barriers experienced by parents/guardians. Such changes will lead to the formulation of alternative models or ways of understanding.

This study draws attention to the role of patriarchal notions and social norms which create a gendered division in terms of caregiving roles; mothers/female guardians of autistic children are more vulnerable to unequal social interactions, negative reactions and the pressures of raising an autistic child. Information platforms and acceptance/awareness opportunities should be made available to parents/guardians (especially fathers). Professionals should also cultivate an understanding of parental experiences and give value to such experiences. This will reduce the narrow outlook on autism and give the family a platform to engage in social participation and remain active. The inferences laid out in this section are not intended to criticise the existing services, service providers or the government. The study has already outlined the benefits of the existing services and the role of the government in enhancing the lives of autistic children and their families. However, the findings suggest a need for more sociologically-informed interventions which take into consideration the diverse experiences of parents/guardians of autistic children.

The government has already initiated opportunities for autistic individuals and their parents/guardians by creating autism-centred spaces and institutions which identify and cater to people from low socio-economic backgrounds. However, there is much more to be done which will enhance the output and efficiency of such initiatives. The hierarchy and unequal relations embedded in the social fabric may create barriers to interaction and peaceful living opportunities. When gender-based and communal divisions exist, we must identify the need to provide access to information and services/resources even for some people who may be marginalized due to their perceived ‘inferior’ status. The competitive academic environment and the pressures on parents/guardians, in particular mothers, to maintain high standards may result in the devaluing of differences, when such differences need to be included in the social fabric of society.

The shift in attitudes needs to start within the family in order to trigger a change in societal perceptions. Therefore, the grounded/raw social experiences of parents/guardians will be helpful for future researchers too, in creating a change that can improve the social interactions and well-being of parents/guardians and their children. Analysing the complexity of parental experiences at the intersection of gender, access to resources and caste/tribe identity will help to uncover the oppression/discrimination some parents/guardians may face. This can also facilitate the implementation of sociologically-informed interventions that can reduce disabling barriers experienced by some parents/guardians. This study has found that parents/guardians are disabled along with their children and they continue to experience oppression due to the unequal social interactions they face and the limited support mechanisms available to them. Conducting sociological intersectional research on parental experiences can enhance the possibility of identifying support mechanisms that can be implemented for parents/guardians. Changes must be focused on this gap. The key to such changes begins from research where the disabling social barriers (unequal social interactions which can undermine the psycho-emotional well-being of parents/guardians, and lack of adequate access to resources) experienced by the parents/guardians are given serious consideration and importance. Some restrictions which may arise from impairments (‘impairment effects’) associated with autism and raising an autistic child should also be assessed and addressed. Thus, the following short-term and long-term recommendations will lead to practical social interventions and improve the scenario. They involve action at global, national and grass roots levels.

RECOMMENDATIONS

1. A participatory research study involving parents/guardians of autistic children at the local self-government unit level: Historically, the majority of developmental activities in India have entailed a ‘bottom-up’ approach; however, the experiences of parents/guardians in the study indicate the need for added consideration to be given to the social experiences of parents/guardians by those who plan and prepare interventions. Therefore, even if a framework entailing a ‘bottom-up’ approach is in position, there is a need to implement this approach by giving added value to parental experiences. A participatory planning committee involving parents/guardians of autistic children must be established at the local self-government unit level to understand their needs and the barriers they experience, and to take in suggestions. There are over 1,000 local self-government units (self-government units are autonomous, democratic government units that represent the needs and affairs of the locals in the area) in the State of Kerala. An adequate study must be compiled and any suggestions must be recommended to a state-level forum. The State Planning Board can act on these recommendations and include them in the development plans of the State. Thus, it will also help in allocating the required resources to reduce disabling barriers for parents/guardians.

2. The inclusion of disability as a primary agenda in women-oriented groups/councils: The data has highlighted the prominence of the gendered

division of roles as a factor in parental experiences. Kerala holds a matriarchal legacy and there are social and legal systems in place to protect the rights of women. The decentralised government of Kerala has witnessed a 33% reservation for women in local self-government units or councils. However, disability/autism, disabled women, mothers of disabled children, and mothers of autistic children do not form a large part of these movements or women-oriented councils. Along with issues such as violence against women, disability/autism and the needs of mothers must be added as a core issue in order to ensure that unmet needs are addressed. Women's groups can reach out to parents/guardians of autistic children, establish professional relationships, build networks with more parents/guardians, and plan/offer training sessions/educational sessions to parents/guardians (in particular, mothers). This can enhance parents' understanding of autism and offer them a support platform to reach out and address their immediate needs. An accurate account of autism prevalence does not exist (due to varying socio-cultural factors) and women's groups can help bridge that gap through the awareness/educational sessions. 'Kudumbashree' (explained previously in chapter four), a women's self-help group (an internationally acclaimed model) can incorporate action plans for mainstreaming mothers of autistic children through networking and advocacy.

3. Legislation which enhances mothers' direct access to support, services and opportunities: Strategies/policies should be implemented by the government which can then be directly used by mothers (primary caregivers) of autistic children. Currently, the disability legislation/policies do not entail any provision(s) specifically for mothers of autistic children. Government can execute legislation for mothers to directly obtain access to psycho-emotional support, autism acceptance and awareness training and vocational opportunities.
4. Community-based inclusive living opportunities for autistic children and their parents/guardians: A model intervention focusing on deinstitutionalisation and the establishment of community-based living initiatives/opportunities (must be adopted by the government and relayed to autism organizations/service providers), rooted in interdependence, can enhance parent-child relationships and offer increased opportunities for social participation. However, these initiatives must ensure that community-based living opportunities do not

segregate the parents and their children. Rather, inclusive opportunities must be identified and implemented.

5. Establishment of a research-focused organization run by autistic individuals in collaboration with parents/guardians: An independent organization run by autistic individuals in collaboration with parents/guardians must be established to develop participatory research focusing on autism at the intersection of gender, access to resources and other social factors, spread awareness on a spectrum of different experiences, and provide awareness services and support to parents, in particular for mothers of autistic children. It would also contribute to the discussion on the influence of unequal social interactions which may undermine psycho-emotional well-being, pressures from raising an autistic child, access to resources, and the rights of autistic individuals and their families in relation to social participation. Work can be done in collaboration with media to identify safe spaces that enable positive conversations on inclusion and facilitate networking possibilities for parents/guardians and their children. These spaces can address/change the notions held by people and reinforced by broader society.
7. These recommendations can be later replicated in the national agenda and later in the South Asian context which will enable the social inclusion of parents of autistic children.

The enactment of the above recommendations will aid in creating meaningful social changes and alleviating disabling barriers experienced by parents/guardians of autistic children.

CONTRIBUTION TO KNOWLEDGE

Parents/guardians of autistic children are sources of knowledge in relation to their personal experiences. In addition to medical research, when studying parents/guardians, they provide awareness of the barriers affecting the family; for instance, in a society, social interactions are inevitable, and some may undermine the feelings of parents/guardians, specifically mothers. The unequal social interactions experienced by some parents/guardians highlight the need for more sociological research on parental experiences and sociologically-informed interventions focusing on the family. The researcher and intervention specialist must comprehend the experiences of parents/guardians. Engaging in professional interaction in the home or a place of their convenience is necessary to understand such experiences. Unequal social interactions disable not just the autistic child, but also the parents/guardians who are associated with the child. A mother is chastised more harshly due to prevalent notions of gender roles which places the caregiving responsibility on the mother. In urban regions too, such norms are persistent, and they affect the marital relationship between couples/parents and create immense stresses.

Pressures when raising an autistic child should not be considered as a barrier; rather they are restrictions faced by parents/guardians. When the child displays a behaviour, the role of parents/guardians should not be questioned. Everyone is unique and has differences of their own; differences are to be respected/accepted. The value of interdependent support is necessary to enhance the provision of support toward parents/guardians. If a child is going through a 'melt-down', people in society can also be of help, in case the parent/guardian is struggling. Practical help can be offered to parents/guardians who may want/need it.

Access to services is important and services must be provided to parents/guardians irrespective of their social background. Children and their parents/guardians deserve access to services and this study has shown disparities in relation to access to services. If some parents/guardians are unable to access services, they should only be made to pay a nominal fee to access the same. Parents/guardians are affected by barriers pertaining to parenting an autistic child, but their personal social background must not be ignored when devising interventions. Thus, this research study has contributed to expanding the existing knowledge by highlighting the disparities in experiences of parents/guardians by using the social relational model of disability (which has been rarely used in Indian sociological research). By placing emphasis on the role of parents, the courtesy stigma experienced by them, and the pervasiveness of the individual model of disability, this study has incorporated an intersectional framework to explain the social experiences of parents/guardians of autistic children in Kerala. To the best of my knowledge, this method has not been often used previously. It will aid future researchers in understanding parental experiences and the pressures faced by them an thereby contribute to autistic children and their families leading fulfilling lives.

BIBLIOGRAPHY

Acocella, I. (2011). The Focus Groups in Social Research: Advantages and Disadvantages. *Quality & Quantity, 46*(4), 1125-1136. doi:10.1007/s11135-011-9600-4.

Addlakha, R. (2016). *Disability Studies in India: Global Discourses, Local Realities*. Routledge.

Addlakha, R., & Mandal, S. (2009, October). Disability Law in India: Paradigm Shift or Evolving Discourse? *Economic and Political Weekly, 44*(41/42), 62-68.

Agarwal, K. (2020, August 13). India’s Population Will Be 1.52 Billion by 2036, With 70% of Increase in Urban Areas. The Wire. Retrieved from https://thewire.in/government/india-population-growth-government-report-2036-projections-urban-migration.

Ahammed, S. (2019). Caste-based Oppression, Trauma and Collective Victimhood in Erstwhile South India: The Collective Therapeutic Potential of Theyyam. *Psychology and Developing Societies, 31*(1), 88–105. doi: 10.1177/0971333618825051.

Akire, S., & Seth, S. (2008). (working paper). *Measuring Multidimensional Poverty in India: A New Proposal* (pp. 1–49).

Alareeki, A., Lashewicz, B., & Shipton, L. (2019). "Get your child in order:" illustrations of courtesy stigma from fathers raising both autistic and non-autistic children. *Disability Studies Quarterly*, *39*(4). https://doi.org/10.18061/dsq.v39i4.6501

Albert, S. M. & Powell, R. M. (2020): Supporting disabled parents and their families: perspectives and recommendations from parents, attorneys, and child welfare professionals, *Journal of Public Child Welfare*, *15*(5) 530-564. DOI: 10.1080/15548732.2020.1751771.

Alexander-Floyd, N. G. (2012). Disappearing Acts: Reclaiming Intersectionality in the Social Sciences in a Post-Black Feminist Era. *Feminist Formations*, *24*(1), 1–25. https://doi.org/10.1353/ff.2012.0003.

Ali, A., Hassiotis, A., Strydom, A., & King, M. (2012). Self stigma in people with intellectual disabilities and courtesy stigma in family carers: A systematic review. *Research in Developmental Disabilities*, *33*(6), 2122-2140. doi:10.1016/j.ridd.2012.06.013.

Aluas, M., Colombetti, E., Osimani, B., Musio, A., & Pessina, A. (2012). Disability, Human Rights, and the International Classification of Functioning, *Disability, and Health. American Journal of Physical Medicine & Rehabilitation*, 91, S146–S154. https://doi.org/10.1097/phm.0b013e31823d5437

Anastasiou, D., & Kauffman, J. M. (2013). The Social Model of Disability: Dichotomy between Impairment and Disability. *Journal of Medicine and Philosophy,38*(4), 441-459. doi:10.1093/jmp/jht026.

Anthias, F. (2012). Intersectional what? Social divisions, intersectionality and levels of analysis. *Ethnicities*, *13*(1), 3–19. https://doi.org/10.1177/1468796812463547

Areheart, B. A. (2008). When Disability Isn't "Just Right": The Entrenchment of the Medical Model of Disability and the Goldilocks Dilemma," *Indiana Law Journal: 83*(1), Article 5. Retrieved from : https://www.repository.law.indiana.edu/ilj/vol83/iss1/5

Ariz, D. (2018). Disabled Population in India: A Regional Analysis. Annals of Valahia University of Targoviste, *Geographical Series*, *18*(2), 136–143. https://doi.org/10.2478/avutgs-2018-0015.

The Economic Times (2020, September 07). At 96.2%, Kerala tops literacy rate chart; Andhra Pradesh worst performer at 66.4%. Retrieved from https://economictimes.indiatimes.com/news/politics-and-nation/at-96-2-kerala-tops-literacy-rate-chart-andhra-pradesh-worst-performer-at-66-

4/articleshow/77978682.cms?from=mdr#:~:text=In%20Kerala%2C%20the%20male%20literacy,male%20and%20female%20literacy%20rate.

Aydogan, D., & Kizildag, S. (2017). Examination of Relational Resilience With Couple Burnout and Spousal Support in Families With a Disabled Child. *The Family Journal*, *25*(4), 407–413. https://doi.org/10.1177/1066480717731215

Bairagya, I. (2015). Socio-Economic Determinants of Educated Unemployment in India (343). The Institute for Social and Economic Change, Bangalore.

Balcazar, F. E., Keys, C. B., Kaplan, D. L., & Balcazar, Y. S. (2006). Participatory Action Research and People with Disabilities: Principles and Challenges. 1-11. Retrieved from https://www.researchgate.net/profile/Christopher_Keys/publication/239921190_Participatory_Action_Research_and_People_with_Disabilities_Principles_and_Challenges/links/0deec53260cdd4e251000000.pdf.

Barcellos, S. H., Carvalho, L., & Lleras-Muney, A. (2010). Child Gender and Parental Investments in India: Are Boys and Girls Treated Differently? *SSRN Electronic Journal*. https://doi.org/10.2139/ssrn.1604233.

Barnes, C. (1992). Qualitative Research: Valuable or Irrelevant? *Disability, Handicap & Society, 7*(2), 115-124, DOI: 10.1080/02674649266780151.

Barnes, C. (2000). A working social model? Disability, work and disability politics in the 21st century. *Critical Social Policy, 20*(4), 441-457. doi:10.1177/026101830002000402.

Barnes, C., & Mercer, G. (2005). Disability, work, and welfare. *Work, Employment and Society, 19*(3), 527-545. doi:10.1177/0950017005055669.

Barnes, C. and Mercer, G. (2010). *Exploring Disability*. Polity Press.

Barnes, C. (2019). Understanding the social model of disability: Past, present and future. In Watson, N., & Vehmas, S. (Eds.), *Routledge Handbook of Disability Studies*, 2nd ed. (pp. 14–31). Routledge.

Barnes, C., Mercer, G., & Shakespeare, T. (1999). *Exploring disability: a sociological introduction.* Polity Press.

Barriball, L. K., & While, A. (1994). Collecting data using a semi-structured interview: A discussion paper. *Journal of Advanced Nursing, 19*(2), 328-335. doi:10.1111/j.1365-2648.1994.tb01088.x

Baron-Cohen, S. (2015). Leo Kanner, Hans Asperger, and the discovery of autism. *The Lancet, 386*(10001), 1329–1330. https://doi.org/10.1016/s0140-6736(15)00337-2.

Barua, M. (2007). Lessons from Neeraj, My Son with Autism. *Journal of Religion, Disability & Health, 11*(2), 29-40. doi:10.1300/j095v11n02_05

Barua, M., Kaushik, J. S., & Gulati, S. (2016). Legal Provisions, Educational Services and Health Care Across the Lifespan for Autism Spectrum Disorders in India. *The Indian Journal of Pediatrics, 84*(1), 76-82. doi:10.1007/s12098-016-2261-5

Bashir, A., Bashir, U., Lone, A., & Ahmad, Z. (2014). Challenges Faced by families of Autistic Children. *International Journal of Interdisciplinary Research and Innovations, 2*(1), 64-68.

Beauchamp-Pryor, K. (2011). Impairment, cure and identity: ‘where do I fit in?’. *Disability & Society, 26*(1), 5-17. doi:10.1080/09687599.2011.529662.

Benson, D., & Keyes, S. (2014). Challenging Barriers and Enabling Inclusion: The Role of Families. In J. Swain, S. French, C. Barnes, & C. Thomas (Eds.) *Disabling Barriers - Enabling Environments,* (pp. 149-156). Sage.

Benson, A., O’Toole, S., Lambert, V., Gallagher, P., Shahwan, A., & Austin, J. K. (2016). The stigma experiences and perceptions of families living with epilepsy: Implications for epilepsy-related communication within and external to the family unit. *Patient Education and Counseling, 99*(9), 1473–1481. https://doi.org/10.1016/j.pec.2016.06.009.

Berman, R. C., & Tyyskä, V. (2011). A Critical Reflection on the Use of Translators/Interpreters in a Qualitative Cross-Language Research Project. *International Journal of Qualitative Methods, 10*(2), 178-190. doi:10.1177/160940691101000206

Bhat, P. (2011). *Issues concerning South Asian parents raising children with autism spectrum disorder* [Master's Thesis, California State University San Marcos]. https://scholarworks.calstate.edu/downloads/3197xm658?locale=en

Bhattashali, A., Ostrosky, M. M., & Monda-Amaya, L. (2018). Perceptions of typically developing children in India about their siblings with disabilities. *International Journal of Inclusive Education, 22*(12), 1257-1271. doi:10.1080/13603116.2017.1420253.

Bhavnani, S., Lockwood Estrin, G., Arora, R., Kumar, D., Kakra, M., Vajaratkar, V., Juneja, M., Gulati, S., Patel, V., Green, J., & Divan, G. (2021). "I was Confused … and Still am" Barriers Impacting the Help-Seeking Pathway for an Autism Diagnosis in Urban North India: A Mixed Methods Study. *Journal of Autism and Developmental Disorders*. https://doi.org/10.1007/s10803-021-05047-z

Bickenbach, J. E., & Bickenbach, J. E. (2009). Disability, culture and the UN Convention. *Disability and Rehabilitation*, *31*(14), 1111–1124. https://doi.org/10.1080/09638280902773729

Birenbaum, A. (1992). Courtesy Stigma Revisited. *American Association of Intellectual and Developmental Disabilities, 30*(5), 265–268.

Biswas, U. N., & Pandey, J. (1996). Mobility and Perception of Socioeconomic Status among Tribal and Caste Group. *Journal of Cross-Cultural Psychology, 27*(2), 200–215. https://doi.org/10.1177/0022022196272004.

Björnsdóttir, K., and Sigurjónsdóttir, H. B. (2013). The internet's empowering and disempowering qualities: online (re)presentation of disabled parents. *Disability Studies Quarterly, 33* (3).

Björnsdóttir, K., & Traustadóttir, R. (2010). Stuck in the land of disability? The intersection of learning difficulties, class, gender and religion. *Disability & Society, 25*(1), 49-62. doi:10.1080/09687590903363340.

Blaikie, N. (2006). *Designing Social Research*. Polity Press.

Block, P. (2015). The Emergent Landscape of Autistic Communities and Autistic Studies. *Culture, Medicine, and Psychiatry, 39*(2), 351-355. doi:10.1007/s11013-015-9453-8.

Boström, P. K., Broberg, M., & Hwang, P. (2010). Parents' descriptions and experiences of young children recently diagnosed with intellectual disability. *Child: Care, Health and Development*, *36*(1), 93–100. https://doi.org/10.1111/j.1365-2214.2009.01036.x

Bourdieu, Pierre. 1986. “The Forms of Capital.” in G. Richardson (Ed.) *Handbook of Theory and Research for the Sociology of Education* (pp. 241-258). J. Greenwood Press.

Brezis, R. S., Weisner, T. S., Daley, T. C., Singhal, N., Barua, M., & Chollera, S. P. (2015). Parenting a Child with Autism in India: Narratives Before and After a Parent–Child Intervention Program. *Culture, Medicine, and Psychiatry, 39*(2), 277-298. doi:10.1007/s11013-015-9434-y.

Broderick, A. A., & Ne’eman, A. (2008). Autism as metaphor: Narrative and counter-narrative. *International Journal of Inclusive Education, 12*(5-6), 459-476. doi:10.1080/13603110802377490.

Broady, T. R., Stoyles, G. J., & Morse, C. (2015). Understanding carers’ lived experience of stigma: The voice of families with a child on the autism spectrum. *Health & Social Care in the Community, 25*(1), 224-233. doi:10.1111/hsc.12297.

Bryman, A. (2004). *Social Research Methods*. 2nd Edition. Oxford University Press.

BSA Statement of Ethical Practice. (2017). *Sociology*, 1-10. doi:10.1177/0038038592026004011

Bumiller, K. (2009). The geneticization of autism: From new reproductive technologies to the conception of genetic normalcy. *Signs: Journal of Women in Culture and Society*, *34*(4), 875–899. https://doi.org/10.1086/597130

Burrell, A., Ives, J., & Unwin, G. (2017). The Experiences of Fathers Who Have Offspring with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders, 47*(4), 1135-1147. doi:10.1007/s10803-017-3035-2.

Byrne, G., Sarma, K. M., Hendler, J., & O'connell, A. (2018). On the spectrum, off the beaten path. A qualitative study of Irish parents' experiences of raising a child with autism spectrum conditions. *British Journal of Learning Disabilities, 46*(3), 182-192. doi:10.1111/bld.12227.

Campbell, S., Greenwood, M., Prior, S., Shearer, T., Walkem, K., Young, S., … Walker, K. (2020). Purposive sampling: complex or simple? Research case examples. *Journal of Research in Nursing, 25*(8), 652–661.

Carnaby, S. (1998). Reflections on social integration for people with intellectual disability: Does interdependence have a role? *Journal of Intellectual & Developmental Disability, 23*(3), 219-228. doi:10.1080/13668259800033711.

Chacko, E. (2003). Marriage, development, and the status of women in Kerala, India. *Gender & Development*, *11*(2), 52–59. https://doi.org/10.1080/741954317

Chakravarti, U. (2008). Burden of Caring. *Indian Journal of Gender Studies*, *15*(2), 341–363. https://doi.org/10.1177/097152150801500207.

Chander, J. (2018). Disability Rights Law and Origin of Disability Rights Movement in India. In A. Ghai (Ed.), *Disability in South Asia: Knowledge & Experience*. Sage Publications.

Chan, K. K. S., & Leung, D. C. K. (2020). Linking Child Autism to Parental Depression and Anxiety: The Mediating Roles of Enacted and Felt Stigma. *Journal of Autism and Developmental Disorders*, *51*(2), 527–537. https://doi.org/10.1007/s10803-020-04557-6.

Chauhan, C. P. S. (2008). Education and caste in India. *Asia Pacific Journal of Education*, *28*(3), 217–234. https://doi.org/10.1080/02188790802267332

Chauhan, A., Sahu, J. K., Jaiswal, N., Kumar, K., Agarwal, A., Kaur, J., Singh, S., & Singh, M. (2019). Prevalence of autism spectrum disorder in Indian children: A systematic review and meta-analysis. *Neurology India, 67*(1), 100. https://doi.org/10.4103/0028-3886.253970

Chopra, T. (2013). Expanding the Horizons of Disability Law in India: A Study from a Human Rights Perspective. *The Journal of Law, Medicine & Ethics, 41*(4), 807-820. doi:10.1111/jlme.12091

Cidav, Z., Marcus, S. C., & Mandell, D. S. (2012). Implications of Childhood Autism for Parental Employment and Earnings. *Pediatrics*, *129*(4), 617–623. https://doi.org/10.1542/peds.2011-2700.

Clapton, J., & Fitzgerald, J. (1997). The History of Disability: A History of 'Otherness'. Retrieved from http://www.ru.org/index.php/human-rights/315-the-history-of-disability-a-history-of-otherness.

Clark, L., & Marsh, S. (2002). Patriarchy in the UK: The Language of Disability. https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/Clark-Laurence-language.pdf

Clarke, H., & McKay, S. (2013). Disability, partnership and parenting. *Disability & Society*, *29*(4), 543–555. https://doi.org/10.1080/09687599.2013.831745

Coleridge, P. (1993). Disability and development: the basics. In *Disability, Liberation, and Development* (pp. 64–82). Oxfam.

Cologon, K. (2016). "What is disability? It depends whose shoes you are wearing": Parent Understandings of the Concept of Disability. *Disability Studies Quarterly, 36*(1). doi:10.18061/dsq.v36i1.4448.

Courcy, I., & Rivières, C. D. (2017). "From cause to cure": A qualitative study on contemporary forms of mother blaming experienced by mothers of young children with autism spectrum disorder. *Journal of Family Social Work, 20*(3), 233-250. doi:10.1080/10522158.2017.1292184.

Creswell, J. W. (2003). *Research Design: Qualitative, Quantitative, and Mixed Methods Approaches*. Sage.

Crow, L. (1996). Including All of Our Lives: Renewing the Social Model of Disability [Review of Including All of Our Lives: Renewing the Social Model of Disability]. In C. Barnes & G. Mercer (Eds.), *Exploring the Divide: Illness and Disability* (pp. 55–72). The Disability Press.

Culham, A., & Nind, M. (2003). Deconstructing normalisation: Clearing the way for inclusion. *Journal of Intellectual & Developmental Disability, 28*(1), 65-78. doi:10.1080/1366825031000086902.

Dako-Gyeke, M. (2018). Courtesy stigma: A concealed consternation among caregivers of people affected by leprosy. *Social Science & Medicine, 196*, 190–196. https://doi.org/10.1016/j.socscimed.2017.11.030.

Daley, T. C., & Sigman, M. D. (2002). Diagnostic Conceptualization of Autism Among Indian Psychiatrists, Psychologists, and Pediatricians. *Journal of Autism and Developmental Disorders, 32*(1), 13-23. doi:10.1023/a:1017947922349.

Daley, T. C. (2004). From Symptom Recognition to Diagnosis: Children with Autism in Urban India. *Social Science and Medicine, 58*(7), 1323-1335.

Dalwai, S., Pillai, G., & Shah, Z. (2017). Intervention to Develop Social Skills in a Child with Autism with Lower Degrees of Impairment. *Journal of*

Pediatrics, Perinatology and Child Health, 01(01), 7-16. doi:10.26502/jppch.7405003.

Das, D., & Balasubramanian, A. (2017). The practice of traditional rituals in Naga Aradhana (snake worship): a case study on Aadimoolam Vetticode Sree Nagarajaswami Temple in Kerala, India. In *SHS web of conferences*, 33, 1-7.

Das, S., Das, B., Nath, K., Dutta, A., Bora, P., & Hazarika, M. (2017). Impact of stress, coping, social support, and resilience of families having children with autism: A North East India-based study. *Asian Journal of Psychiatry,* 28, 133-139. doi:10.1016/j.ajp.2017.03.040

Davidson, J. & Henderson, V. L. (2010) 'Coming out' on the spectrum: autism, identity and disclosure. *Social & Cultural Geography, 11*(2), 155-170, DOI: 10.1080/14649360903525240.

Davis, L. J. (1995). *Enforcing normalcy: Disability, deafness, and the body*. Verso.

Deb, S., Strodl, E., & Sun, J. (2015). Academic Stress, Parental Pressure, Anxiety and Mental Health among Indian High School Students. *International Journal of Psychology and Behavioral Sciences*, *5*(1), 26–34.

Desai, M. (2005). Indirect British Rule, State Formation, and Welfarism in Kerala, India, 1860–1957. *Social Science History,29* (3), 457-488. doi:10.1017/s0145553200013018

Desai, M. U., Divan, G., Wertz, F. J., & Patel, V. (2012). The discovery of autism: Indian parents' experiences of caring for their child with an autism spectrum disorder. *Transcultural Psychiatry, 49*(3-4), 613-637. doi:10.1177/1363461512447139

Devika, J., & Thampi, B. V. (2007). Between 'Empowerment' and 'Liberation.' *Indian Journal of Gender Studies*, *14*(1), 33–60. https://doi.org/10.1177/097152150601400103

Devika, J. (2010). Egalitarian Developmentalism, Communist Mobilization, and the Question of Caste in Kerala State, India. *The Journal of Asian Studies*, *69*(3), 799–820. https://doi.org/10.1017/s0021911810001506.

Devika, J., & Thampi, B. V. (2011). Mobility Towards Work and Politics for Women in Kerala State, India: A View from the Histories of Gender and Space*. *Modern Asian Studies, 45*(5), 1147–1175. https://doi.org/10.1017/S0026749X09000080.

Devika, J. (2019). Women's Labour, Patriarchy and Feminism in Twenty-first Century Kerala: Reflections on the Glocal Present. *Review of Development and Change, 24*(1), 79–99. doi: 10.1177/0972266119845940.

Dew, A., Llewellyn, G., & Balandin, S. (2013). Exploring the later life relationship between adults with cerebral palsy and their non-disabled siblings. *Disability and Rehabilitation, 36*(9), 756-764.

Dey, A. & Orton, B. (2016). Gender and Caste Intersectionality in India: An Analysis of the Nirbhaya Case, 16 December 2012. *Gender and Race Matter: Global Perspectives on Being a Woman* (*Advances in Gender Research*, *Vol. 21*) (pp. 87-105). Emerald Group Publishing Limited.

Dey, A., & Das, D. (2020). Motherhood in India: Myths, Theories and Literature [Review of *Motherhood in India: Myths, Theories and Literature*]. *Research Journal of English Language and Literature (RJELAL), 8*(3), 64–70. Retrieved from http://www.rjelal.com/

Dhanda, A. (2018). A Disability Studies Reading of the Law for Persons with Disabilities in India. In A. Ghai (Ed.), *Disability in South Asia* (pp. 383-400). New Delhi: Sage Publications.

Dhar, R. L. (2009). Living with a developmentally disabled child: Attitude of family members in India. *The Social Science Journal, 46*(4), 738-755. doi:10.1016/j.soscij.2009.05.009

Dickinson, R. (2018). Parenting a Child with Disabilities: the Intersection of Education and Cultural Perceptions in Southern India. *Journal of Human Rights and Social Work, 3*(2), 72–80. https://doi.org/10.1007/s41134-018-0053-8.

Dimech, K. (2014). Otherness and mothers of children with disability. *Malta Review of Educational Research*, *8*(2), 364-379.

Disabilities Affairs. (2021). Disabilityaffairs.gov.in. Retrieved from http://disabilityaffairs.gov.in/content/page/acts.php.

Dowse, L. (2017). Disruptive, dangerous and disturbing: The ‘challenge’ of behaviour in the construction of normalcy and vulnerability. *Continuum, 31*(3), 447-457. doi:10.1080/10304312.2016.1275148.

Duggal, C., Dua, B., Chokhani, R., & Sengupta, K. (2019). What works and how: Adult learner perspectives on an autism intervention training program in India. *Autism*, *24*(1), 246–257. https://doi.org/10.1177/1362361319856955

Eaton, S. (2020). Witchcraft and deformity in early modern English literature. *The Seventeenth Century*, *35*(6), 815–828. https://doi.org/10.1080/0268117x.2020.1819394.

Elwood, S. A., & Martin, D. G. (2000). “Placing” Interviews: Location and Scales of Power in Qualitative Research. *The Professional Geographer*, 52(4), 649-657. doi:10.1111/0033-0124.00253

Erevelles, N & Minear, A. (2011) “Unspeakable” offences: disability studies at the intersection of multiple differences. Chapter 3 in Erevelles, N. *Disability and Difference in Global Contexts: Enabling a Transformative Body Politic*. 95-120. 1st Edition. Palgrave Macmillan.

Etikan, I., Musa, S. S., Alkassim, R., S. (2016). Comparison of Convenience Sampling and Purposive Sampling. *American Journal of Theoretical and Applied Statistics*, *5*(1), 1-4. doi: 10.11648/j.ajtas.20160501.11.

Farrugia, D. (2009). Exploring stigma: medical knowledge and the stigmatisation of parents of children diagnosed with autism spectrum disorder. *Sociology of Health & Illness*, *31*(7), 1011–1027. https://doi.org/10.1111/j.1467-9566.2009.01174.x.

Findler, L. (2016). Grandparents of Children with Disabilities—The Parents' Perspective. (Grand) Parents Are Forever Parents. In O. T. Ben-Ari, S. B. Shlomo, & A. Noy (Eds.) *Grandparents of Children with Disabilities: Theoretical Perspectives of Intergenerational Relationships* (pp. 69–85). Springer.

Fine, M and Glendinning, C (2005). Dependence, independence or inter-dependence? Revisiting the concepts of 'care' and 'dependency'. *Ageing & Society*, *25* (4),601-621. https://doi.org/10.1017/S0144686X05003600.

Finkelstein, V. (1991). Disability: An Administrative Challenge. Disabling People and Disabling Environments. Retrieved from https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/finkelstein-Administrative-Challenge-1.pdf.

Francis, A. (2012). Stigma in an era of medicalisation and anxious parenting: how proximity and culpability shape middle-class parents' experiences of disgrace. *Sociology of Health & Illness, 34*(6), 927–942. https://doi.org/10.1111/j.1467-9566.2011.01445.x.

Ganjiwale, D., Ganjiwale, J., Sharma, B., & Mishra, B. (2016). Quality of life and coping strategies of caregivers of children with physical and mental disabilities. *Journal of Family Medicine and Primary Care*, *5*(2), 343-348. https://doi.org/10.4103/2249-4863.192360

Gaur, S., & Pandey, N. (2016). Coping Mechanisms and Parental Relationship in the Families of a Child with Autism Spectrum Disorder. *The International Journal of Indian Psychology*, *3*(3), 83-93.

George, M. (2011). In the Midst of a Storm. *Affilia, 26*(3), 304–313. https://doi.org/10.1177/0886109911417690.

George, B., Padmam, M. S., Nair, M. K., Leena, M. L., & Russell, P. S. (2014). CDC Kerala 14: Early Child Care Practices at Home Among Children (2–6 y) with Autism—A Case Control Study. *The Indian Journal of Pediatrics, 81*(S2), 138-141. doi:10.1007/s12098-014-1602-5

George, L., & Sakeer, S. (2015). Awareness about Autism among Parents. *International Journal of Science and Research, 4*(9), 1525-1530.

Ghai, A. (2002). Disabled Women: An Excluded Agenda of Indian Feminism. *Hypatia, 17*(3), 49-66. doi:10.1353/hyp.2002.0052

Ghai, A. (2015a). Conversations about Disability: The Cultural Landscape. In *Rethinking Disability in India* (pp. 20–71). Routledge.

Ghai, A. (2015b).Understanding Disability: Slippery Slopes. In *Rethinking Disability in India* (pp. 72-100). Routledge.

Ghai, A. (2015c). At the Periphery: Marginalized Disabled Lives. In *Rethinking Disability in India* (pp. 101-162). Routledge.

Ghosh, N., & Banerjee, S. (2017). Too Much or Too Little? Paradoxes of Disability and Care Work in India. *Review of Disability Studies: An International Journal, 13*(4), 1–20.

Giallo, R., Wood, C. E., Jellett, R., & Porter, R. (2011). Fatigue, wellbeing and parental self-efficacy in mothers of children with an Autism Spectrum Disorder. *Autism, 17*(4), 465–480. https://doi.org/10.1177/1362361311416830

Gill, J. & Liamputtong, P. (2011). Being the Mother of a Child with Asperger's Syndrome: Women's Experiences of Stigma, *Health Care for Women International, 32*(8), 708-722, DOI: 10.1080/07399332.2011.555830.

Goble, C. (2014). Dependence, Independence and Normality. In J. Swain, S. French, C. Barnes, & C. Thomas (Eds.), *Disabling Barriers- Enabling Environments* (pp. 31-36). Sage.

Goffman, E. (1963). *Stigma*. Alexander Street Press.

Goldkuhl, G. (2012). Pragmatism vs interpretivism in qualitative information systems research, *European Journal of Information Systems, 21*(2), 135-146, DOI: 10.1057/ ejis.2011.54.

Goodley, D. (2001). Learning Difficulties, the Social Model of Disability and Impairment: Challenging epistemologies. *Disability & Society*, 16(2), 207-231. doi:10.1080/09687590120035816.

Government of India Ministry of Law and Justice Legislative Department. (2020). The Constitution of India.

Government of Kerala (2019) Official Web Portal of the Government of Kerala. Retrieved from: **https://kerala.gov.in/**

Gray, D. E. (2002). "Everybody just freezes. Everybody is just embarrassed": felt and enacted stigma among parents of children with high functioning autism. *Sociology of Health & Illness, 24*(6), 734–749. https://doi.org/10.1111/1467-9566.00316.

Green, S. E. (2003). ''What do you mean 'what's wrong with her?''': Stigma and the Lives of Families of Children with Disabilities. *Social Science and Medicine*, *57,* 1361-1374.

Green, S., Davis, C., Karshmer, E., Marsh, P., & Straight, B. (2005). Living Stigma: The Impact of Labelling, Stereotyping, Separation, Status Loss, and Discrimination in the Lives of Individuals with Disabilities and Their Families. *Sociological Inquiry, 75*(2), 197-215. doi:10.1111/j.1475-682x.2005.00119.x.

Grugel, J., & Piper, N. (2009). Do rights promote development? *Global Social Policy*, *9*(1), 79–98. https://doi.org/10.1177/1468018108100399

Gudavarthy, A. (2012). Can We De-Stigmatise Reservations in India? *Economic and Political Weekly, 47*(6), 55-62.

Gulyn, L. M., & Diaz-Asper, C. (2018). Exploring Perceptions of Blame for Autism Spectrum Disorder. *Journal of Developmental and Physical Disabilities*, *30*(5), 587-600. doi:10.1007/s10882-018-9604-2.

Gupta, V. B., Mehrotra, P., & Mehrotra, N. (2012). Parental Stress in Raising a Child with Disabilities in India. *Disability, CBR & Inclusive Development*, *23*(2). https://doi.org/10.5463/dcid.v23i2.119

Gupta, A., & Singhal, N. (2004). Positive Perceptions in Parents of Children With Disabilities. *Asia Pacific Disability Rehabilitation Journal,15*(1), 22-35. Retrieved from http://english.aifo.it/disability/apdrj/apdrj104/positive-perceptions.pdf

Gupta, A., & Singhal, N. (2005). Psychosocial Support for Families of Children With Autism. *Asia Pacific Disability Rehabilitation Journal,*16(2), 62-83.

Gupta, Y. (2020). Narratives of Indian Parents of Children Diagnosed with Autism Spectrum Disorder, in (A. Ghai, Ed. pp. 1–88) [*Review of Narratives of Indian Parents of Children Diagnosed with Autism Spectrum Disorder*].

Guse, T., & Harvey, C. (2010). Growing up with a sibling with dwarfism: Perceptions of adult non-dwarf siblings. *Disability & Society, 25*(3), 387-401.

Hall, H.R. & Graff, J.C. (2012). Maladaptive Behaviours of Children with Autism: Parent Support, Stress, and Coping. *Issues in Comprehensive Paediatric Nursing, 35*(3)-(4), 194-214, DOI: 10.3109/01460862.2012.734210.

Hammell, K. W. (2006). Perspectives on Disability & Rehabilitation: Contesting Assumptions, Challenging Practice. W. Ross MacDonald School Resource Services Library.

Hapke, H. M. (2013). Theorizing Patriarchy: Development Paradoxes and the Geography of Gender in South Asia. *Gender, Technology and Development*, *17*(1), 1–29. https://doi.org/10.1177/0971852412472121

Haq, R., Klarsfeld, A., Kornau, A., & Ngunjiri, F. W. (2020). Diversity in India: Addressing caste, disability and gender. *Equality, Diversity and Inclusion: An International Journal, 39*(6), 585–596. https://doi.org/10.1108/edi-04-2020-0095

Harpur, P. (2012). Embracing the new disability rights paradigm: The importance of the convention on the rights of persons with disabilities. *Disability & Society*, *27*(1), 1–14. https://doi.org/10.1080/09687599.2012.631794

Hartley, S., & Muhit, M. (2003). Using Qualitative Research Methods for Disability Research in Majority World Countries. *Asia Pacific Disability Rehabilitation Journal, 14*(2), 103-114.

Hartley, S. L., Mihaila, I., Otalora-Fadner, H. S., & Bussanich, P. M. (2014). Division of Labor in Families of Children and Adolescents with Autism Spectrum Disorder. *Family Relations, 63*(5), 627–638. https://doi.org/10.1111/fare.12093.

Hartley, S. L., Papp, L. M., Mihaila, I., Bussanich, P. M., Goetz, G., & Hickey, E. J. (2017). Couple Conflict in Parents of Children with versus without Autism: Self-Reported and Observed Findings. *Journal of Child and Family Studies*, *26*(8), 2152–2165. doi: 10.1007/s10826-017-0737-1.

Hatzenbuehler, M. L., & Link, B. G. (2014). Introduction to the special issue on structural stigma and health. *Social Science & Medicine, 103,* 1–6. https://doi.org/10.1016/j.socscimed.2013.12.017

Hays, A., & Butauski, M. (2017). Privacy, Disability, and Family: Exploring the Privacy Management Behaviors of Parents with a Child with Autism. *Western Journal of Communication*, *82*(3), 376–391. https://doi.org/10.1080/10570314.2017.1398834.

Hillman, J. L., Wentzel, M. C., & Anderson, C. M. (2017). Grandparents' Experience of Autism Spectrum Disorder: Identifying Primary Themes and Needs. *Journal of Autism and Developmental Disorders*, *47*(10), 2957–2968. https://doi.org/10.1007/s10803-017-3211-4.

Hiranandani, V., & Sonpal, D. (2010). Disability, economic globalization and privatization: A case study of India. *Disability Studies Quarterly, 30*(3/4). https://doi.org/10.18061/dsq.v30i3/4.1272

History: Background of disability-inclusive development in the region. (n.d.). United Nations Economic and Social Commission for Asia and the Pacific Web site. Retrieved from https://www.unescap.org/disabilityhighlevelmeeting2017/history

Home Page. (n.d.). Retrieved from https://kerala.gov.in/

Home 2: Kerala Public Service Commission. Home 2 | Kerala Public Service Commission. Retrieved from https://keralapsc.gov.in/.

Horton, J., Macve, R., & Struyven, G. (2004). Qualitative research: experiences in using semi-structured interviews. In C. Humphrey, C & B. Lee (Eds.) *The Real Life Guide to Accounting Research: A Behind-the-Scenes View of Using Qualitative Research Methods* (pp. 339–350). Elsevier.

Hughes, R. (2010). The social model of disability. *British Journal of Healthcare Assistants*, *4*(10), 508–511. https://doi.org/10.12968/bjha.2010.4.10.79078

Hughes, B., & Paterson, K. (1997). The Social Model of Disability and the Disappearing Body: Towards a sociology of impairment. *Disability & Society*, *12*(3), 325-340. doi:10.1080/09687599727209.

Human Development Reports. Human Development Reports- India. (2020). Retrieved from http://hdr.undp.org/en/countries/profiles/IND.

Hunt, P., & Finkelstein, V. (2014). An Historical Overview. In J. Swain, S. French, C. Barnes, & C. Thomas (Eds.), *Disabling Barriers - Enabling Environments* (pp. 3-8). Sage.

Hurley-Hanson, A. E., Giannantonio, C. M., & Griffiths, A. J. (2020). Stigma of autism. In *Autism in the workplace: Creating positive employment and career outcomes for Generation A* (pp. 21–45). Palgrave Macmillan.

Jaarsma, P., & Welin, S. (2011). Autism as a Natural Human Variation: Reflections on the Claims of the Neurodiversity Movement. *Health Care Analysis, 20*(1), 20-30. doi:10.1007/s10728-011-0169-9.

Jacobson, D. (2004). Indian Society and Ways of Living: Organization of Social Life in India. *Asia Society*. Retrieved from https://asiasociety.org/education/indian-society-and-ways-living

Jaisoorya, T. S., Jacob, P., Srinath, S., G, S. K., L, M., GR, G., Robins, D. L., & K, T. (2018). Toddlers at risk for autism spectrum disorders from Kerala, India – a community-based screening. *Asian Journal of Psychiatry*, *31*, 10–12. https://doi.org/10.1016/j.ajp.2017.12.016

Jaiswal, N. (2018). Decline of Ayurveda in British India. *International Journal of Scientific Research in Science and Technology*, *4*(5), 493–497.

Jangir, S.K. (2013). Reservation Policy and Indian Constitution in India. American International *Journal of Research in Humanities, Arts and Social Sciences*, 3(1), 126-128.

Jeffrey, R. (2004). Legacies of Matriliny: The Place of Women and the "Kerala Model". *Pacific Affairs, 77*(4), 647-664.

Johansson, S. T. (2015). Parents Negotiating Change A Middle-class Lens on Schooling of Children with Autism in Urban India. *Contemporary Education Dialogue, 13*(1), 93-120. doi:10.1177/0973184915603175.

John, T., Subramanyam, A. A., & Sagar, R. (2018, January 5). Strength and Weakness of the Guidelines of Rights of Persons with Disabilities Act, 2016: With Respect to the Persons with Neurodevelopmental Disorders [Editorial]. *Indian Journal of Psychiatry, 60*(3), 261-264.

Jose, P., Sundaram, S., & Varma, R. P. (2021). Buffering Effect of Spousal Support on Stress Levels in Mothers of Children with a Diagnosis of Autism Spectrum Disorder in Kerala, India. *Journal of Neurosciences in Rural Practice 12*(3). 535–542. https://doi.org/10.1055/s-0041-1727559

Kabeer, N. (2015) Gender, poverty, and inequality: a brief history of feminist contributions in the field of international development. *Gender & Development, 23*(2), 189-205, DOI: 10.1080/13552074.2015.1062300.

Kalidasan, M., Geetha, S., & Sivakumar, I. (2019). Working mothers and parenting: health status in India. *International Journal of Applied Research*, *5*(9), 168–173.

Kalyanpur, M., & Gowramma, I. (2007). Cultural Barriers to South Indian Families' Access to Services and Educational Goals for Their Children with Disabilities. *Journal of the International Association of Special Education, 8*(1), 69-82.

Kannan, K. P., & Pillai, V. (2004). Development as a Right to Freedom: An Interpretation of the Kerala Model (pp. 1-61, Working paper No. 361).

Karmakar, S., & Saxena, V. (2015). Critical Analysis of Education Policies and Acts Related to People with Disability in India. *Journal of Indian Education, 41*(1), 5-18.

Kayama, M., Johnstone, C., & Limaye, S. (2019). Adjusting the “self” in social interaction: Disability and stigmatization in India. *Children and Youth Services Review, 96*, 463-474. doi:10.1016/j.childyouth.2018.11.047.

Kelley, S. J., Whitley, D. M., & Campos, P. E. (2011). Behavior problems in children raised by grandmothers: The role of caregiver distress, family resources, and the home environment. *Children and Youth Services Review, 33*(11), 2138-2145. doi:10.1016/j.childyouth.2011.06.021.

Khanlou, N., Mustafa, N., Vazquez, L. M., Davidson, D., & Yoshida, K. (2017). Mothering children with developmental disabilities: A critical perspective on health promotion. *Health Care for Women International*, *38*(6), 613–634. https://doi.org/10.1080/07399332.2017.1296841.

Khare, A. (2011). Impact of Indian Cultural Values and Lifestyles on Meaning of Branded Products: Study on University Students in India. *Journal of*

International Consumer Marketing, 23(5), 365-379, DOI: 10.1080/08961530.2011.602953.

Khokhar, T. & Serajuddin, U. (2015, November 15). Should we continue to use the term “developing world”? World Bank. https://blogs.worldbank.org/opendata/should-we-continue-use-term-developing-world

Kinnear, S. H., Link, B. G., Ballan, M. S., & Fischbach, R. L. (2015). Understanding the Experience of Stigma for Parents of Children with Autism Spectrum Disorder and the Role Stigma Plays in Families’ Lives. *Journal of Autism and Developmental Disorders, 46*(3), 942–953. https://doi.org/10.1007/s10803-015-2637-9.

Kishore, T. M., & Basu, A. (2011). Early concerns of mothers of children later diagnosed with autism: Implications for early identification. *Research in Autism Spectrum Disorders, 5*(1), 157-163. doi:10.1016/j.rasd.2010.03.005

Kodoth, P., & Eapen, M. (2005). Looking beyond Gender Parity: Gender Inequities of Some Dimensions of Well-Being in Kerala. *Economic & Political Weekly*, 3278-3286.

Krahn, G. (2021). Where is disability in Global Public Health? *Oxford Research Encyclopedia of Global Public Health*, 1–37. https://doi.org/10.1093/acrefore/9780190632366.013.287

Krcek, T. E. (2013). Deconstructing Disability and Neurodiversity: Controversial Issues for Autism and Implications for Social Work. *Journal of Progressive Human Services, 24*(1), 4-22. doi:10.1080/10428232.2013.740406.

Kudumbashree Story - BUDS School. (n.d.). Thekudumbashreestory.info. Retrieved July 28, 2021, from https://thekudumbashreestory.info/index.php/programmes/social-empowerment/buds-school.

Kumar, P., & Agarwal, P. (2016). Inclusive Education in India: Concern and Policy Perspective. *International Journal of Research in Humanities, Arts and Literature, 4*(1), 77-88. Retrieved from http://oaji.net/articles/2016/488-1456304078.pdf

Kumar, G., Roy, G., & Kar, S. (2012). Disability and rehabilitation services in India: Issues and challenges. *Journal of Family Medicine and Primary Care, 1*(1), 69-73. doi:10.4103/2249-4863.94458.

Kumar, A., Sonpal, D., & Hiranandani, V. (2012). Trapped between ableism and neoliberalism: Critical reflections on disability and employment in India. *Disability Studies Quarterly, 32*(3). https://doi.org/10.18061/dsq.v32i3.3235

Kutty, R. (2000). Historical analysis of the development of health care facilities in Kerala State, India. *Health Policy and Planning, 15*(1), 103-109. doi:10.1093/heapol/15.1.103.

Lakhan, R., Ekúndayò, O., & Shahbazi, M. (2015). An estimation of the prevalence of intellectual disabilities and its association with age in rural and urban populations in India. *Journal of Neurosciences in Rural Practice, 6*(4), 523-528. doi:10.4103/0976-3147.165392

Lang, R. (2001). The Development and Critique of the Social Model of Disability. 1-37. Retrieved from http://www.ucl.ac.uk/lc-ccr/lccstaff/raymond-lang/DEVELOPMMENT_AND_CRITIQUE_OF_THE_SOCIAL_MODEL_OF_D.pdf.

Laskar, M. H. (2010). Rethinking Reservation in Higher Education in India. *ILI Law Review, 1(1)*, p. 25-53. Available at SSRN: https://ssrn.com/abstract=1597863.

Lashewicz, B., Cheuk, S., & Shave, K. (2016). From roaring on the hilltop to weeping by the bedside: Protector personas of fathers raising children with autism spectrum disorder. *Families, Relationships and Societies, 5*(2), 299-312. doi:10.1332/204674315x14381836678571.

Larkin, P. J., Casterlé, B. D., & Schotsmans, P. (2007). Multilingual Translation Issues in Qualitative Research. *Qualitative Health Research, 17*(4), 468-476. doi:10.1177/1049732307299258.

LeBel, T. P. (2008). Perceptions of and Responses to Stigma. *Sociology Compass, 2*(2), 409–432. https://doi.org/10.1111/j.1751-9020.2007.00081.x.

Levesque, J., Haddad, S., Narayana, D., & Fournier, P. (2005). Access to health care in urban Kerala: Emerging inequalities across the public-private divide. 2-15. Retrieved from http://citeseerx.ist.psu.edu/viewdoc/download?doi=10.1.1.129.6861&rep=rep1&type=pdf.

Lien, K., Lashewicz, B., Mitchell, J., & Boettcher, N. (2020). Blending Traditional and Nurturing Fathering: Fathers of Children With Autism Managing Work and Family. *Family Relations, 70*(1). 264-281 doi:10.1111/fare.12472.

Lilley, R. (2013). It’s an absolute nightmare: Maternal experiences of enrolling children diagnosed with autism in primary school in Sydney, Australia. *Disability & Society, 28*(4), 514-526. doi:10.1080/09687599.2012.717882.

Linneberg, M. S., & Korsgaard, S. (2019). Coding qualitative data: a synthesis guiding the novice. *Qualitative Research Journal, 19*(3), 259-270. https://doi.org/10.1108/QRJ-12-2018-0012

Llewellyn, G. (1997). Parents with Intellectual Disability Learning to Parent: The role of experience and informal learning. *International Journal of Disability, Development and Education, 44*(3), 243-261.

Loja, E., Costa, M., E., Hughes, B. & Menezes, I. (2013). Disability, embodiment and ableism: stories of resistance, *Disability & Society, 28*(2), 190-203, DOI: 10.1080/09687599.2012.705057.

Longhurst, R. (2003). Semi-structured interviews and focus groups. In N.J. Clifford, M. Cope, T.W. Gillespie & S. French (Eds) *Key Methods in Geography* (pp. 103–115). Sage.

Lopez, J.P., & Gillespie, K. (2016) A love story: for ‘Buddy System’ research in the academy. *Gender, Place & Culture, 23*(12), 1689-1700, doi: 10.1080/0966369X.2016.1249354.

Major, B., & O'Brien, L. T. (2005). The social psychology of stigma. *Annual review of psychology, 56*, 393–421. https://doi.org/10.1146/annurev.psych.56.091103.070137.

Majumder, P. P., & Basu, A. (2014). A Genomic View of the Peopling and Population Structure of India. Cold Spring Harbor. *Perspectives in Biology, 7*(4), 1-10. doi:10.1101/cshperspect.a008540.

Mantovani, N., & Thomas, H. (2013). Stigma, intersectionality and motherhood: Exploring the relations of stigma in the accounts of black teenage mothers ‘looked after’ by the State. *Social Theory & Health*, *12*(1), 45–62. https://doi.org/10.1057/sth.2013.19

Marks, D. (1997). Models of disability. *Disability and Rehabilitation, 19*(3), 85-91. doi:10.3109/09638289709166831.

Mason, J. (1996). *Qualitative Researching*. Sage.

Mason, J. (2002). *Qualitative Researching*. 2nd Edition. Sage.

Meekosha, H. (2011). Decolonising disability: Thinking and acting globally. *Disability & Society*, *26*(6), 667–682. https://doi.org/10.1080/09687599.2011.602860

Mehrotra, N. (2008). Women and Disability Management in Rural Haryana, India. *Asia Pacific Disability Rehabilitation Journal*, *19*(1), 38-49.

Mehrotra, N. (2011). Disability Rights Movements in India: Politics and Practice. *Economic and Political Weekly*, *XLVI*(6), 65–72.

Mehrotra, N. (2013). Disability, gender and caste intersections in Indian economy. *Disability and Intersecting Statuses, Research in Social Science and Disability, 7*. 295-324. https://www.researchgate.net/publication/290052340_Disability_gender_and_caste_intersections_in_Indian_economy

Minhas, A., Vajaratkar, V., Divan, G., Hamdani, S. U., Leadbitter, K., Taylor, C., Rahman, A. (2015). Parents’ perspectives on care of children with autistic spectrum disorder in South Asia – Views from Pakistan and India. *International Review of Psychiatry, 27*(3), 247-256.

Mishra, L. C., Singh, B. B., & Dagenais, S. (2001). Ayurveda: a historical perspective and principles of the traditional healthcare system in India. *Alternative Therapies in Health and Medicine, 7*(2), 36–42.

Mitchell, J. L. & Lashewicz, B. (2019) Generative fathering: a framework for enriching understandings of fathers raising children who have disability diagnoses. *Journal of Family Studies, 25*(2), 184-198, DOI: 10.1080/13229400.2016.1212727.

Mitra, A., & Singh, P. (2007). Human Capital Attainment and Gender Empowerment: The Kerala Paradox. *Social Science Quarterly, 88*(5), 1227–1242. https://doi.org/10.1111/j.1540-6237.2007.00500.x

Mohajan, H. K. (2018). Qualitative Research Methodology in Social Sciences and Related Subjects. *Journal of Economic Development, Environment and People*, *7*(1), 23–48. https://doi.org/10.26458/jedep.v7i1.571.

Muir, K., & Strnadová, I. (2014). Whose responsibility? Resilience in families of children with developmental disabilities. *Disability & Society*, *29*(6), 922–937. https://doi.org/10.1080/09687599.2014.886555

Mukhopadhyay, S. (2015). The Intersection of Gender, Caste and Class Inequalities in Child Nutrition in Rural India. *Asian Population Studies, 11*(1), 17–31. https://doi.org/10.1080/17441730.2015.995150.

Munyi, C. W. (2012). Past and Present Perceptions Towards Disability: A Historical Perspective. *Disability Studies Quarterly, 32*(2). https://doi.org/10.18061/dsq.v32i2.3197.

Nair, M. K., Sumaraj, L., Padmamohan, L., Radhakrishnan, R., Nair, V. R., George, B., & Kumar, G. S. (2007). Parenting practices in Kerala: A cross-sectional study. *Vulnerable Children and Youth Studies, 2*(1), 71-79. doi:10.1080/17450120601122646.

Nair, M. K., Russell, P. S., George, B., Prasanna, G. L., Bhaskaran, D., Leena, M. L., Mammen, P. (2014). CDC Kerala 9: Effectiveness of Low Intensity Home Based Early Intervention for Autism Spectrum Disorder in India. *The Indian Journal of Pediatrics, 81*(S2), 115-119. doi:10.1007/s12098-014-1474-8.

Narayana, D. (2008). High Health Achievements and Good Access to Health Care at Great Cost: The Emerging Kerala Situation. In E. Baris, S. Haddad, & D. Narayana (Eds.), *Safeguarding the Health Sector in Times of Macroeconomic Instability: Policy Lessons for Low- and Middle-income Countries* (pp. 199-225). International Development Research Centre.

Narayan, C. L., & John, T. (2017). The Rights of Persons with Disabilities Act, 2016: Does it Address the Needs of the Persons with Mental Illness and their Families. *Indian Journal of Psychiatry, 59*(1), 17-20. Retrieved from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5419007/.

Nash, J. C. (2008). re-thinking intersectionality. *Feminist Review, 89*(1), 1–15. https://doi.org/10.1057/fr.2008.4.

National Portal of India (n.d.) *Culture And Heritage - Lifestyle Values And Beliefs*. Retrieved from https://knowindia.gov.in/culture-and-heritage/lifestyle-values-and-beliefs.php**.**

Neely-Barnes, S.L., Hall, H.R., Roberts, R.J. & Graff, J.C. (2011) Parenting a Child With an Autism Spectrum Disorder: Public Perceptions and

Parental Conceptualizations, *Journal of Family Social Work*, *14*(3), 208-225. DOI: 10.1080/10522158.2011.571539.

Newman, K. S., & Thorat, S. (2007). Caste and Economic Discrimination: Causes, Consequences and Remedies. *Economic and Political Weekly, 42*(41). 4121-4124.

Nikarthil, D. S. (2015). Economic Evolution of Kerala Health Model. *SSRN Electronic Journal*. https://doi.org/10.2139/ssrn.2548902

NITI Aayog. (2020, September 7). Press Note on Global Multidimensional Poverty Index and India. Retrieved from https://pib.gov.in/PressReleasePage.aspx?PRID=1651981#:~:text=According%20to%20Global%20MPI%202020,(2015%2F16)%20data.&text=As%20the%20Nodal%20agency%20for,Index%20Coordination%20Committee%20(MPICC).

Oliver, M. (1990). The Individual and Social Models of Disability. Retrieved from https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/Oliver-in-soc-dis.pdf.

Oliver, M. (1996a). Defining Impairment and Disability: Issues at stake. *Disability and Equality Law,1*-19. doi:10.4324/9781315094861-2.

Oliver, M. (1996b). *Understanding Disability: from theory to practice*. Macmillan Press.

Oliver, M., & Barnes, C. (2010). Disability studies, disabled people and the struggle for inclusion. *British Journal of Sociology of Education, 31*(5), 547-560. doi:10.1080/01425692.2010.500088.

Oliver, M. (2013). The social model of disability: Thirty years on. *Disability & Society, 28*(7), 1024-1026. doi:10.1080/09687599.2013.818773.

Orb, A., Eisenhauer, L., & Wynaden, D. (2001). Ethics in Qualitative Research. *Journal of Nursing Scholarship*, *33*(1), 93-96. doi:10.1111/j.1547-5069.2001.00093.x

Padmanabhan, N. (2011). Formation of Kerala Society and Culture [PDF]. Kannur.

Pal, G. (2011). Disability, Intersectionality and Deprivation. *Psychology and Developing Societies, 23*(2), 159-176. doi:10.1177/097133361102300202.

Panjrath, Y., & Mishra, S. (2018). Parenting a Child with Autism: The Lived Experiences. *The International Journal of Indian Psychology,6*(4), 61-74.

Parchomiuk, M. (2014). Social context of disabled parenting. *Sexuality and Disability, 32*(2), 231–242. https://doi.org/10.1007/s11195-014-9349-5

Patton, M. Q. (2002). *Qualitative Research & Evaluation Methods* (3rd ed.). Sage.

Patwardhan, K., Gehlot, S., Singh, G., & Rathore, H. C. S. (2011). The Ayurveda Education in India: How Well Are the Graduates Exposed to Basic Clinical Skills? *Evidence-Based Complementary and Alternative Medicine*, 2011, 1–6. https://doi.org/10.1093/ecam/nep113.

Perumal, V., Veeraraghavan, V., & Lekhra, O. (2014). Quality of life in families of children with autism spectrum disorder in India. *Journal of Pharmacy Research, 8*(6), 791-797.

Pilcher, J., & Whelehan, I. (2017). Domestic Division of Labour. In *Key Concepts in Gender Studies* (pp. 34–37). Sage.

Power, E. M. (1999). An Introduction to Pierre Bourdieu’s Key Theoretical Concepts. *Journal for the Study of Food and Society, 3*(1), 48–52. https://doi.org/10.2752/152897999786690753.

Prendeville, P., & Kinsella, W. (2018). The Role of Grandparents in Supporting Families of Children with Autism Spectrum Disorders: A Family Systems Approach. *Journal of Autism and Developmental Disorders, 49*(2), 738–749. https://doi.org/10.1007/s10803-018-3753-0

Priestley, M. (2010). *Disability: A Life Course Approach*. Polity Press.

Rabiee, P. (2012). Exploring the relationships between choice and independence: Experiences of disabled and older people. *British Journal of Social Work, 43*(5), 872–888. https://doi.org/10.1093/bjsw/bcs022

Rahman, S. (2016). The Advantages and Disadvantages of Using Qualitative and Quantitative Approaches and Methods in Language "Testing and Assessment" Research: A Literature Review. *Journal of Education and Learning, 6*(1), 102-112. doi:10.5539/jel.v6n1p102

Rajan, A. M., & John, R. (2017). Resilience and impact of children's intellectual disability on Indian parents. *Journal of Intellectual Disabilities, 21*(4), 315–324. https://doi.org/10.1177/1744629516654588

Rajivlochan, M. (2019, July 1). Reservation has failed to address social inequities, create opportunities for all. *The Indian Express*. https://indianexpress.com/article/opinion/columns/reservation-caste-discrimination-quota/

Raman, K. R. (2009). Asian Development Bank, policy conditionalities and the social democratic governance: Kerala Model under pressure? *Review of International Political Economy, 16*(2), 284-308. doi:10.1080/09692290802454620

Ramkumar, G. S. (2015). Mental Health Provisions in Schools of Kerala: A Narrative Overview of Programs and Interventions. *Kerala Journal of Psychiatry, 28*(1), 82-93.

Ravindran, N., & Myers, B. J. (2011). Cultural Influences on Perceptions of Health, Illness, and Disability: A Review and Focus on Autism. *Journal of Child and Family Studies, 21*(2), 311-319. doi:10.1007/s10826-011-9477-9.

Reeve, D., (2004). Psycho-emotional dimensions of disability and the social model. In C. Barnes & G. Mercer (Eds.) *Implementing the Social Model of Disability: Theory and Research* (pp. 83–100). The Disability Press.

Reindal, S. M. (2010). Independence, Dependence, Interdependence: Some reflections on the subject and personal autonomy. *Disability & Society, 14*(3), 353-367.

Research Ethics Committee Application Form- University of Leeds. 1-13

Retief, M. & Letšosa, R., 2018, 'Models of disability: A brief overview', *HTS Teologiese Studies/Theological Studies 74*(1), a4738. https://doi.org/ 10.4102/hts.v74i1.4738

Richard, B. O. (2014). Families, well-being, and inclusion: Rethinking priorities for children with cognitive disabilities in Ladakh, India. *Childhood, 21*(3), 308-323. doi:10.1177/0907568214526264.

Robinson, S., Weiss, J. A., Lunsky, Y., & Ouellette-Kuntz, H. (2015). Informal Support and Burden among Parents of Adults with Intellectual and/or Developmental Disabilities. *Journal of Applied Research in Intellectual Disabilities, 29*(4), 356–365. https://doi.org/10.1111/jar.12184

Rohwerder, B. (2018, May 09). Disability stigma in developing countries (Rep.). Retrieved from https://assets.publishing.service.gov.uk/media/5b18fe3240f0b634aec30791/Disability_stigma_in_developing_countries.pdf.

Roy, V. (2018, July 14). The Misogyny in the Matrilineal Malayali Society. The Hindu. Retrieved from https://www.thehindu.com/opinion/columns/when-in-kerala-cherchez-la-femme/article24409582.ece.

Rudra, A., Belmonte, M. K., Soni, P. K., Banerjee, S., Mukerji, S., & Chakrabarti, B. (2017). Prevalence of autism spectrum disorder and autistic symptoms in a school-based cohort of children in Kolkata, India. *Autism Research, 10*(10), 1597-1605. doi:10.1002/aur.1812.

Runswick-Cole, K. & Ryan, S. (2019). Liminal still? Unmothering disabled children, *Disability & Society, 34*(7)-8, 1125-1139, DOI: 10.1080/09687599.2019.1602509.

Runswick-Cole, K. (2014). ‘Us’ and ‘them’: The limits and possibilities of a ‘politics of neurodiversity’ in neoliberal times. *Disability & Society*, *29*(7), 1117-1129.

Russell, F. (2003). The expectations of parents of disabled children. *British Journal of Special Education,30*(3), 144-149.

Ryan, S., & Runswick-Cole, K. (2008). Repositioning mothers: Mothers, disabled children and disability studies. *Disability & Society*, *23*(3), 199-210. doi:10.1080/09687590801953937.

Sabatello, M. (2014). A Short History of the International Disability Rights Movement. In M. Sabatello & M. Schulze (Eds.) *Human Rights and Disability Advocacy*. 13-24. University of Pennsylvania Press.

Saikia, N., Meh, C., Ram, U., Bora, J. K., Mishra, B., Chandra, S., & Jha, P. (2021). Trends in missing females at birth in India from 1981 to 2016: Analyses of 2·1 million birth histories in nationally representative surveys. *The Lancet Global Health*, *9*(6), 813–821. https://doi.org/10.1016/s2214-109x(21)00094-2

Salem, S. (2016). Intersectionality and its discontents: Intersectionality as traveling theory. *European Journal of Women’s Studies*, *25*(4), 403–418. https://doi.org/10.1177/1350506816643999.

Sangha, J. K. (2014). Contextualizing South Asian Motherhood. In A. O’Reilly (Ed.) *Mothers, Mothering and Motherhood Across Cultural Differences: A Reader* (pp. 413-427). Demeter Press.

Sankaran, S., Sekerdej, M., & von Hecker, U. (2017). The role of Indian caste identity and caste inconsistent norms on status representation. *Frontiers in Psychology, 8*. 1-14. https://doi.org/10.3389/fpsyg.2017.00487

Sarrett, J. C. (2015). “Maybe at Birth There was an Injury”: Drivers and Implications of Caretaker Explanatory Models of Autistic Characteristics in Kerala, India. *Culture, Medicine, and Psychiatry, 39*(1), 62-74.

Sauvaget, C., Ramadas, K., Fayette, J. M., Thomas, G., Thara, S., & Sankaranarayanan, R. (2011). Socio-economic factors & longevity in a cohort of Kerala State, India. *The Indian journal of medical research*, *133*(5), 479–486.

Saunders, V. (2018). What does your dad do for a living? children of prisoners and their experiences of stigma. *Children and Youth Services Review*, *90*, 21–27. https://doi.org/10.1016/j.childyouth.2018.05.012

Saxe, A. (2017). The Theory of Intersectionality: A New Lens for Understanding the Barriers Faced by Autistic Women. *Canadian Journal of Disability Studies, 6*(4), 153-178. https://doi.org/10.15353/cjds.v6i4.386.

Scambler, G., & Hopkins, A. (1986). Being epileptic: Coming to terms with stigma. *Sociology of Health and Illness*, *8*(1), 26-43.

Scambler, G. (2009). Health-related stigma. *Sociology of Health & Illness*, *31*(3), 441–455. https://doi.org/10.1111/j.1467-9566.2009.01161.x.

Scambler, G. (2020). *A Sociology of Shame and Blame: Insiders Versus Outsiders*. Palgrave Macmillan.

Scaria, S. (2017). Caste and Gender in Relation to Health Inequality. *South Asia Research*, *37*(1), 1–18. https://doi.org/10.1177/0262728016663273.

Series, L. (2020). Disability and Human Rights. In N. Watson & S. Vehmas (Eds.), *Routledge Handbook of Disability Studies* (pp. 72–88). Routledge.

Shyman, E. (2016). The Reinforcement of Ableism: Normality, the Medical Model of Disability, and Humanism in Applied Behavior Analysis and ASD. *Intellectual and Developmental Disabilities*, *54*(5), 366–376. https://doi.org/10.1352/1934-9556-54.5.366

Silberman, S. (2015). *Neurotribes: The legacy of autism and how to think smarter about people who think differently*. Allen & Unwin.

Silverman, D. (2004). *Qualitative Research: Theory, Method and Practice* (2nd ed.). Sage.

Singal, N (2011). Disability, poverty and education: implications for policies and practices. *International Journal of Inclusive Education, 15*(10), 1047-1052, DOI: 10.1080/13603116.2011.555065.

Singh, M., Chauhan, A., Sahu, J., Jaiswal, N., Kumar, K., Agarwal, A., Singh, S. (2019). Prevalence of Autism Spectrum Disorder in Indian Children: A Systematic Review and Meta-Analysis. *Neurology India, 67*(1), 100-104. doi:10.4103/0028-3886.253970

Singh, V., & Ghai, A. (2009). Notions of self: Lived realities of children with disabilities. *Disability & Society, 24*(2), 129-145. doi:10.1080/09687590802652363

Singh, P., Ghosh, S., & Nandi, S. (2017). Subjective Burden and Depression in Mothers of Children with Autism Spectrum Disorder in India: Moderating Effect of Social Support. *Journal of Autism and Developmental Disorders, 47*(10), 3097-3111.

Skarstad, K. (2018). Human rights through the lens of disability. *Netherlands Quarterly of Human Rights, 36*(1), 24–42. https://doi.org/10.1177/0924051917753251

Sloper, T., & Beresford, B. (2006). Families with disabled children. *BMJ (Clinical research ed.), 333*(7575), 928–929. https://doi.org/10.1136/bmj.39017.633310.BE.

Song, J., Mailick, M. R., & Greenberg, J. S. (2018). Health of parents of individuals with developmental disorders or mental health problems: Impacts of stigma. *Social Science & Medicine, 217,* 152–158. https://doi.org/10.1016/j.socscimed.2018.09.044.

Spears, D. (2016). Caste and Life Satisfaction in Rural North India. *Economic and Political Weekly*, 51(4), 12–14. https://www.jstor.org/stable/44003099.

Sriram, R., & Sandhu, G. K. (2012). Fathering to Ensure Child's Success. *Journal of Family Issues, 34*(2), 159–181. https://doi.org/10.1177/0192513x12461136.

Stalker, K., & Connors, C. (2004). Children's Perceptions of Their Disabled Siblings: 'She's Different but it's Normal for Us'. *Children and Society, 18,* 218-230.

Standard Rules on the Equalization of Opportunities for Persons with Disabilities. (n.d.). United Nations Department of Economic and Social Affairs Disability Web site. Retrieved from https://www.un.org/development/desa/disabilities/standard-rules-on-the-equalization-of-opportunities-for-persons-with-disabilities.html

Staples, J. (2020). Decolonising Disability Studies? Developing South Asia-Specific Approaches to Understanding Disability. In N. Mehrotra (Ed.) *Disability Studies in India: Interdisciplinary Perspectives* (pp. 25-41). Springer.

Steur, L. (2009). Adivasi Mobilisation: 'Identity' versus 'Class' after the Kerala Model of Development? *Journal of South Asian Development, 4*(1), 25-44. doi:10.1177/097317410900400103

Stienstra, D. (2012). Race/ethnicity and disability studies: towards an explicitly intersectional approach. In N. Watson, A. Roulstone, & C. Thomas (Eds.) *Routledge Handbook of Disability Studies* (pp. 376-389). Routledge.

Stone, E. & Priestley, M. (1996) Parasites, pawns and partners: disability research and the role of non-disabled researchers. *British Journal of Sociology, 47*(4), 699-716.

Stone, E. (1999). Disability and development in the majority world. Chapter 1 in E. Stone (Ed.) *Disability and Development: Learning from action and research on disability in the majority world* (pp 1-18). The Disability Press.

Stone, S. D. (2003). Disability, Dependence, and Old Age: Problematic Constructions. *Canadian Journal on Aging / La Revue Canadienne Du Vieillissement, 22*(1), 59-67. doi:10.1017/s0714980800003731.

Strand, L. R. (2017). Charting Relations between Intersectionality Theory and the Neurodiversity Paradigm. *Disability Studies Quarterly, 37*(2). doi:10.18061/dsq.v37i2.5374.

Sukhramani, N., & Verma, S. (2013). Disability as Diversity: The Indian Perception. In R. Lutz (Ed.) *Diversity and Respect. Problems of Perception in the Global Agenda for Social Work* (pp. 109-122). Paulo Freire Verlag.

Sultana, A. (2012). Patriarchy and Women’s Subordination: A Theoretical Analysis. *Arts Faculty Journal, 4*, 1–18. https://doi.org/10.3329/afj.v4i0.12929.

Susman, J. (1994). Disability, stigma and deviance. *Social Science & Medicine*, *38*(1), 15–22. https://doi.org/10.1016/0277-9536(94)90295-x.

Swain, J., & French, S. (2000). Towards an Affirmation Model of Disability. *Disability & Society*, *15*(4), 569–582. https://doi.org/10.1080/09687590050058189.

Swain, J., French, S., Barnes, C., & Thomas, C. (Eds.) (2014). *Disabling Barriers - Enabling Environments* (3rd ed.). Sage.

Terzi, L. (2004). The Social Model of Disability: A Philosophical Critique. *Journal of Applied Philosophy*, *21*(2), 141–157. https://doi.org/10.1111/j.0264-3758.2004.00269.x.

Thawani, A. (2013). Anxiety Level of Parents Having Autistic Children. Research in Psychology. Vista Publication. https://papers.ssrn.com/sol3/papers.cfm?abstract_id=2664761

Theerasilp, U., & Sherer, P. (2014). Contestation with the Bio-Power in Normalizing Process: The Life Experiences of Families with Autistic Children. *Kasetsart Journal - Natural Science, 35*(3), 497-505.

Thomas, C. (1999). Disability and the Social Self. In *Female forms: experiencing and understanding disability*. Open University Press.

Thomas, C. (2004a). Developing the Social Relational in the Social Model of Disability: A theoretical agenda. In Barnes, C., & Mercer, G. *Implementing the Social Model of Disability: Theory and Research* (pp. 32-47). The Disability Press.

Thomas, C. (2004b). How is disability understood? An examination of sociological approaches. *Disability & Society, 19*(6), 569–583. https://doi.org/10.1080/0968759042000252506.

Thomas, C. (2004c). Rescuing a social relational understanding of disability, *Scandinavian Journal of Disability Research, 6*(1), 22-36.

Thomas, C. (2014). Disability and Impairment. In J. Swain, S. French, C. Barnes, & C. Thomas (Eds.), *Disabling Barriers - Enabling Environments* (pp. 9-16). Sage.

The Union of the Physically Impaired Against Segregation and the Disability Alliance discuss fundamental principles of disability: Being a summary of the discussion held on 22nd November, 1975 and containing commentaries from each organisation. (1976). London: Union of the Physically Impaired Against Segregation.

Thresia, C. U. (2014). Social Inequities and Exclusions in Kerala's 'Egalitarian' Development. *Monthly Review, 65*(9).

Travis, M. A. (2014). Disabling the Gender Pay Gap: Lessons from the Social Model of Disability, (*91)*4 Denver University of Law Review 893.

Tyler, I., & Slater, T. (2018). Rethinking the sociology of stigma. *The Sociological Review*, *66*(4), 721–743. https://doi.org/10.1177/0038026118777425.

Vaid, D. (2014). Caste in Contemporary India: Flexibility and Persistence. *Annual Review of Sociology*, 40(1), 391–410. https://doi.org/10.1146/annurev-soc-071913-043303.

Vaidya, S. (2016a). *Autism and the Family in Urban India: Looking back, looking forward.* Springer.

Vaidya, S. (2016b). 'More than a Mother': Autism, motherhood discourse and lived experience. In A. Aneja & S. Vaidya (Eds). *Embodying Motherhood: Perspectives from Contemporary India* (pp. 107–133). Sage.

Van Patten-Walsh, C. M. (2013). *The impacts of autism: having a child with autism and the formation of mother's identity.* [Master's Thesis-Humboldt State University].

Vera-Sanso, P. (2012). Gender, Poverty and Old-Age Livelihoods in Urban South India in an Era of Globalisation. *Oxford Development Studies, 40*(3), 324–340. https://doi.org/10.1080/13600818.2012.710322

Vinod, A. U., Kalam, B. R., Mohan, L. S., Kunnath, S. K., S, S., B, S. K., & B, R. (2013). Correlation of Indian Scale for Assessment of Autism (ISAA) with Childhood Autism Rating Scale (CARS) and Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5) among Children with Autism (pp. 88-95, Rep.). Thiruvananthapuram, Kerala.

Véron, R. (2001). The "New" Kerala Model: Lessons for Sustainable Development. *World Development, 29*(4), 601-617. doi:10.1016/s0305-750x(00)00119-4.

Waltz, M. M. (2015). Mothers and Autism: The Evolution of a Discourse of Blame. *AMA Journal of Ethics, 17*(4), 353-358. doi:10.1001/journalofethics.2015.17.4.mhst1-1504.

Ward, N. (2011). Care ethics and carers with learning disabilities: A Challenge to dependence and paternalism. *Ethics and Social Welfare, 5*(2), 168–180. https://doi.org/10.1080/17496535.2011.571066

Waterfield, B., & Whelan, E. (2017). Learning disabled students and access to accommodations: socioeconomic status, capital, and stigma. *Disability &*

Society, 32(7), 986–1006. https://doi.org/10.1080/09687599.2017.1331838.

Watson, N. (2012). Theorising the Lives of Disabled Children: How Can Disability Theory Help? *Children & Society*, *26*(3), 192–202. https://doi.org/10.1111/j.1099-0860.2012.00432.x.

Weiss, J. A., Wingsiong, A., & Lunsky, Y. (2013). Defining crisis in families of individuals with autism spectrum disorders. *Autism, 18*(8), 985-995. doi:10.1177/1362361313508024.

Werner, S., & Shulman, C. (2014). Does type of disability make a difference in affiliate stigma among family caregivers of individuals with autism, intellectual disability or physical disability? *Journal of Intellectual Disability Research*, *59*(3), 272–283. https://doi.org/10.1111/jir.12136.

Whyte, S. R., & Ingstad, B. (1995). *Disability and culture*. University of California Press.

Wilder, L. K., Dyches, T. T., Obiakor, F. E., & Algozzine, B. (2004). Multicultural Perspectives on Teaching Students With Autism. *Focus on Autism and Other Developmental Disabilities, 19*(2), 105-113. doi:10.1177/10883576040190020601

World Bank Group - International Development, Poverty, & Sustainability. (2019). Retrieved from https://www.worldbank.org/.

World Health Organization. (2020). *10 facts on disability*. Retrieved from https://www.who.int/news-room/facts-in-pictures/detail/disabilities