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Girija Lal, Seema

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*'Making Lived Experiences Matter'*

VRIJE UNIVERSITEIT

**MAKING LIVED EXPERIENCES MATTER**

Understanding The Journey of Mothers Of Children with Autism In India

ACADEMISCH PROEFSCHRIFT

ter verkrijging van de graad Doctor of Philosophy aan  
de Vrije Universiteit Amsterdam,  
op gezag van de rector magnificus  
prof.dr. C.M. van Praag,  
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door

**Seema Girija Lal**

geboren te Trivandrum, India

promotor: prof.dr. J.G.F. Bunders-Aelen  
copromotoren: dr. E.V. Syurina  
dr. V. Gopikumar

*Account of the Chapters of the thesis*

Chapter	Title	Authors	Journal Submitted to
<b>Chapter 4</b>	Vulnerabilities prompting use of technology and screen by mothers of autistic children in India: Lived experiences and comparison to scientific literature	Seema Girija Lal ,Elena Syurina Laura Pilz González ,Esmee Bally Vandana Gopikumar, Bunders - Aelen, J.G.F.	Culture, Medicine and Psychiatry ,An International Journal of Cross-Cultural Health Research
<b>Chapter 5</b>	Experience of Indian mothers from a child's birth to the diagnosis of autism: Role of family and professionals	Seema Girija Lal ,Elena Syurina Laura Pilz González, Vandana Gopikumar, Bunders - Aelen, J.G.F.	Transcultural Psychiatry
<b>Chapter 6</b>	Coping with grief – experiences of Indian mothers after a diagnosis of their child's autism	Seema Girija Lal ,Elena Syurina Laura Pilz González, Vandana Gopikumar, Bunders - Aelen, J.G.F.	Journal of Child and Family Studies
<b>Chapter 7</b>	'Being mothers of such children, we always have to beg' A qualitative study on the barriers to and violations of inclusive education experienced by mothers of children with autism in India	Seema Girija Lal ,Elena Syurina Vandana Gopikumar, Bunders - Aelen, J.G.F.	International Journal of Inclusive Education
<b>Chapter 8</b>	A realist evaluation of together we can (TWC) – an advocacy group in Kerala: "From breaking of a bone to a breakthrough in policy change"	Seema Girija Lal ,Elena Syurina Vandana Gopikumar, Bunders - Aelen, J.G.F.	Journal of Evidenced Based Social Work

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DISCLAIMER:

Explaining the Semantic Contradiction:

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In this thesis one can find the interchanging use of the 'person first' language "child with autism" and 'identity first' language "autistic child" used interchangeably. We understand that words have power. It does have an impact on people and can influence and even change their approach towards a topic. It is with careful deliberation that the 'person first' and 'identify first' language has been used interchangeably as we respect the views and choices of everyone. In India, the Rights for Persons with Disabilities Act [RPD Act 2016] uses the 'person first' language in all documents. However, there are many self-advocates who oppose this. Taking into consideration the fact that the participants in the research too had diverse views we have retained both the terminologies. The mothers choosing the 'person first' language argued that it is their child first and then autism as autism influences each child differently. Mothers with 'identity first' language argued that they have accepted the autism in their child and it is part of their child's being and identity. We respect both views.

ABSTRACT

Lived experiences have become increasingly significant within research in mental health, particularly for working on service reforms from a human rights perspective. The vulnerabilities within which women are positioned in a patriarchal society is further deepened by the extensive responsibility placed on her as she navigates motherhood. While traversing this role, meeting the challenges of early parenting, in addition to balancing her authentic self and her choices with that of her attachment with the child and family, she is also expected to ensure that the child meets the norms of development as set by the society. In such a scenario, when the child gets a diagnosis of autism, - that comes with no known single cause or cure, and with myriad interventions and approaches, the experiences of mothers of children with autism stand out from that of other mothers.

Their experiences of vulnerability and of overcoming the same in the Indian context, along each phase of their journey with their child, forms the basis of this thesis. It aims to answer the question of how lived experiences of mothers of children with autism can be understood and supported so as to enable sustainable long-term solutions. The experiences were studied in four phases of her journey: From birth to noticing first differences, during the diagnostic process, early intervention, and further during the whole schooling phase.

Findings show how the experiential knowledge of mothers of autistic children, despite their importance and prominence, is often not included in the rehabilitation process, in the context of Southern India. It is shown how vulnerability is a construct that is compounded and acts within multiple layers which include the lack of knowledge and lack of coordinated and collective support systems. It shows how the existing support predominantly focus on fitting the child into a 'norm' that most often disregards the dignity of the mother and the child,

leading to human rights violations all through her journey. The thesis also emphasizes the disconnect of these experiences while framing policies that aim to improve her quality of life.

Maternal knowledge and how it can add value to the diagnostic and intervention process and aid agency in mothers is shown. It is also shown how the mother's agency, if not blocked by various societal barriers, has a strong potential for advocacy and social change, with mechanisms that can be replicated.

# CHAPTER 1.

## 1. INTRODUCTION

### 1.1 GENESIS OF THE THESIS

I have spent 23 years working in the care and rehabilitation of people with physical or mental disabilities, yet it is only in my later experience of this work that I have come to understand it in the holistic fashion within which I situate this thesis. Initially, the focus of such work was largely on rehabilitation in special schools, clinics or homes, where there was limited involvement or interaction with families and communities. What contact did exist was focused on brief conversations with the mother, but rarely with the father or other family members, who situated themselves as more passive observers of the intervention. This disconnected perspective only began to strike me as troubling when I gave birth in 2006 to a son whose communication difficulties put me in the shoes of such a mother, facing this struggle single-handedly and with no support. I began to focus my work more on listening to the mothers of

such children, in order to understand how to better support them in the myriad problems they faced in raising a child with a disability. I learned about the common instances of ill-treatment by the system, lack of understanding in the family or community, intimidation by professionals and, most significantly, the human rights violations to which the children are subjected and the mothers' impotence to do anything about it. This realisation reached boiling point on 23 March 2015 when a mother with whom I was working mentioned that her non-verbal autistic child had broken his arm during a therapy session. To this day we do not know precisely what happened in that session, as these routinely took place on a one-to-one basis with the therapist, so the child's mother had to wait outside. The distinctly problematic nature of this practice had never even been previously discussed. Therefore, I began collecting extensive evidence from several mothers whose children had experienced severe malpractice, and together with them, we filed a petition to the Kerala State Commission for the Protection of Child Rights asking for caregivers to be included in the therapy process. The response was striking: in a single phone call we were informed that despite our evidence, it was impossible for mothers to attend because "experts think otherwise", or, more specifically, because experts said that the mother would hinder or disrupt the therapy. We were at a loss as to how to show our perspective to the experts and the policy-makers they advised, as well as how to persuade them to consider mothers' experiences and knowledge in their decision-making process. From this point, the questions began to arise that would take full shape within this thesis.

This story does not stand alone in the landscape of academic research and knowledge; the association between mental illness and abuse is known across the globe, and forms the basis of a movement for human rights-based approaches in global mental health (Patel et al., 2011). While debates on the parents' association with the rights of the child are well researched, the potential role of parents in safeguarding the child's rights is rarely touched upon directly (Reynaert et al., 2009; Westman, 1999). The aim of this research is to attempt to reduce this

gap. Indeed, the complex constellation of interacting rights and obligations in relation to children, including the prerogative of parents, the role of the state, and the defining of the rights of each body, highlights the ways in which all *three* of these perspectives are essential to the true safeguarding of a child's rights (Westman, 1999). Therefore, work on understanding the rights, obligations, knowledge and abilities of mothers as caregivers presents a valuable perspective for study, especially considering the silence and isolation within which they find themselves. It is important to address how the baseline agency demonstrated by mothers in their efforts to support and protect their child might be further strengthened to the child's benefit and thus to that of the whole family. As such, the focus of this thesis is on understanding both the value of the knowledge and agency of mothers of children with autism, what processes and factors contribute to the fact that these remain untapped, and what the potential pathways could be towards a better integration of this kind of knowledge in policy and practice. This understanding is informed by lived experiences in varying levels of specificity, discussed through a gradual narrowing of scope described below.

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## 1.2 LIVED EXPERIENCES

Central to the question of valuing mothers' perspectives, as was demonstrated in the response to the petition, is what qualifies as valuable knowledge in society. In relation to health-related policy and care, the gold standard for knowledge is Evidence-based Medicine, established in the early 1990s, and the associated Evidence-based Practice (EBP) (Milewa & Barry, 2005; Ryan, 1998). Originally formulated as a way to improve medical decision-making, EBM has evolved into a way of thinking that places value on a knowledge hierarchy in which 'objective' Randomized Control Trials (RCTs) form the top value. All knowledge categorized as 'non-experimental' – including qualitative, experiential knowledge and narratives and personal experience – is seen as less objective and thus a less suitable basis for decision-making

(Geanellos, 2004). This ranking of knowledge is increasingly used in much health-related decision-making – not only for the medical care but also in choices regarding the allocations of funding for research activities, for instance. A result of such ranking of knowledge includes that acute care research is better able to mobilize funding than the more dynamically complex fields of chronic illness and mental health (Geanellos, 2004; Ryan, 1998). Despite its obvious use and importance for pharmaceutical research and practice, among other things, this approach has been the subject of some criticism in recent years. Among the common points raised is the fact that it is not possible, feasible or useful to conduct large RCTs for all clinical dilemmas and questions. Even within conventional medicine, it has been noted how within nursing the lack of space for individual narratives can lead to neglect of the human dimension, where, for instance, patients may want to hear about experiences of illness, treatment, recovery and death at a more personal level (Geanellos, 2004). This often can only be achieved with qualitative research, which is rarely included in the formulation of clinical guidelines. As such, critiques of EBM are common, in part due to this limitation, but also due to challenges in implementing what is essentially an ideal (Paley, 2006). It has been related to ‘an old epistemological issue resurfacing’ in that it relates to how we judge what is considered knowledge or, in this case, evidence, and therefore what is valued in practice (Mantzoukas, 2008). Ultimately, given the focus on human experience and human relationships inherent in mental health care, the definition of value underlying quantitative research is not always suited to tackling such issues (Kim, 2006). Indeed, it might also be questioned more generally whether the shifting of theoretical underpinnings to more dynamic approaches, such as systems thinking in which connection and relationships are central, might indicate the potential - or at least the potential need - for a paradigm shift (Wilkinson et al., 2018).

Beyond qualitative research, at the bottom of old hierarchies is situated the idea of ‘experiential knowledge’, which is an emotionally and contextually situated engagement in a certain act,

event or process (Denzin, 1985). It is a knowledge gained from having 'lived' something, and is often referred to as 'lived experience' (primarily in phenomenological and anthropological fields, but increasingly in broader fields of work). This is where we might situate the knowledge of the mothers whose value (and devaluing) we wish to understand. Within research on mental health, the significance of lived experience is increasingly being recognized with relevance to research priorities and outcomes, achieving service reform and commitments to human rights (Bellingham et al., 2021). Lived experience is derived from the Interpretative Phenomenological Analysis approach, which is concerned with the detailed study of personal lived experience (Eatough & Smith, 2008). Most often, 'lived experience' refers to patients' experiences, where their participation and inclusion is of newly recognized importance, such that their previous exclusion is seen as 'epistemological injustice' (ibid). It has gone so far that lived experience is being applied as a category or identity replacing the term 'patient' (Bellingham et al., 2021; Voronka, 2016). As Voronka notes in an extensive review of the merits and limitations of lived experience as expertise in mental health, "Experiences happen, but how we as individuals make sense of them matters, because it informs [...] our frameworks for meaning-making [...] and how we work through notions of truth" (Voronka, 2016). Ultimately, the precise use of the term varies greatly across fields and focuses, but its primary input in any field is to dislodge the hegemony of limited types of knowledge and broaden our understanding to consider real-world problems, complexity and relatedness. For the purposes of this thesis, it functions as a lens through which to understand the mothers' narratives in an effort to find commonality in their experiences and the key points that can be used to enable and support them. As a starting point, we must therefore consider the aspects of lived experience that they have in common.

---

### 1.3 LIVED EXPERIENCES OF MOTHERS

Mothering is a shared and yet ultimately unique experience with a significant impact on one's place within social systems. What it means to be a mother is a complex, socio-culturally specific construct, frequently situated within patriarchal structures that render them vulnerable (Jiao, 2019). The transformative responsibility experienced by mothers is framed as the logical conclusion of the female lifecycle and plays a significant role in forming women's sense of self (ibid). The identity of the mother is in turn shaped by ideals of motherhood that emphasize the virtues of compassion, nurturing and glorified self-sacrifice, resulting at times in problematic expectations of new mothers (ibid). This degree of responsibility centred on the mother in her assumed role of primary caregiver for the child or children does not always result in the leveraging of appropriate social resources, as despite the complicated impacts of early parenting, guidance for new parents is often limited to courses on the basics of childbirth and the physical acts of care (Barimani et al., 2018). The lack of guidance is coupled with clear expectations of family and community and the monitoring of health systems, which place responsibility on the mother to ensure the child meets the norms of development and behaviour (Bloemink, 2018). Reed and Osborne further suggest that deviation and disability on the part of the child can further be seen as a personal failing of the mother (2018). Interestingly, while lived experience frequently refers to patients in the current literature, research on lived experiences of the family of patients or individuals with a particular experience is well established (Kimura & Yamazaki, 2013; Murray, 1998). This is often conducted in relation to the individual effect of personal witnessing of illness, disability, treatment and death, and while this is of great value, no parallel work on 'experiential expertise' and inclusion has been identified (ibid). Indeed, work on the lived experiences, vulnerability, agency and experiential expertise of mothers of children with autism in particular is still relatively under-researched. The potential benefits of understanding this perspective and its value for research, policy and practice are little understood.



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#### 1.4 LIVED EXPERIENCES OF MOTHERS OF CHILDREN WITH AUTISM

Autism Spectrum Disorder (ASD) is a pervasive neurodevelopmental condition characterized by social and communication deficits that exert a negative impact on functioning without adequate support, training or accommodation (Elder et al., 2017). Notwithstanding ongoing research, there are no clear causes or origins of autism as yet, resulting in a lack of public awareness leading to issues with timely and decisive diagnosis (ibid). The lack of visibility of the condition might further contribute to complex parenting dynamics, given the responsibility that rests on the mother and the lack of early diagnosis or assistance (RS et al., 2015). These issues related to the timeline of diagnosis also have implications for the potential for early intervention, which is known to improve later outcomes for mother and child (Farooq & Ahmed, 2020). Furthermore, where the point of diagnosis has been associated with intense grief in the family, the particular ideals and responsibilities of motherhood have been known to have a negative impact on the mother's mental health (Krishnan et al., 2017; Reed & Osborne, 2018). Indeed, it has been suggested that autism may have greater impacts on family functioning than other forms of disability, with the stress of navigating systems for support and the marginalization and internalized stigma parents are likely to experience (DePape & Lindsay, 2014; Veeraraghavan et al., 2014; WWS & YTY, 2010). Despite the considerable barriers to mothers of children with autism established thus far, it can also be seen that mothers deploy significant agency for the sake of their child, raising the question of what they might be capable of under better circumstances (Farooq & Ahmed, 2020).

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#### 1.5 LIVED EXPERIENCES OF MOTHERS OF AUTISTIC CHILDREN IN INDIA

*An excerpt from a mother of a child with autism in India – Social media post:*

*'...Coming to terms with an autism diagnosis is hard. All of a sudden, everything you took for granted is no longer guaranteed: Your child going to school, your child having friends, your*

*child playing sports, your child participating in extracurricular activities, your child becoming independent, your child getting a job, your child having a career, your child getting married, your child having children, your child leading a conventionally successful life. It is like grieving the loss of a loved one, except, in this case, you're grieving the loss of your hopes, dreams, expectations and ambitions for your child. The grieving process, however, remains the same: denial, anger, bargaining, depression and acceptance. In my experience, the only way you can move on is to get through all the stages of grief. Every person has to take this journey alone but it helps to have people who understand and support you by your side...'*

The particular experiences of mothers of autistic children in India are characterized by sociocultural dynamics regarding patriarchal family structures, stigma and legislation. First, the established preference for male children based on assumptions of expected returns and the resulting female infanticide, coupled with the higher rates of autism in boys, can create a greater social and emotional burden given the expected future and social benefit of having a son (Bano, Beg, Kumari & Dahiya, 2021). This is further affected by the strong ties of the extended family, which can both provide much-needed social, cultural and financial support and contribute to marginalization through expressions of pervasive stigma related to mental health. This stigma is also largely influenced by the lack of clear estimates of the prevalence of autism in India and the resulting gap in knowledge, awareness and appropriate care (Mahomed, Stein, Chauhan, & Pathare, 2019; Jagan & Sathiyaseelan, 2016). In addition to this, the specific role of mothers is affected by expectations of care, whereby mothers often give up their job in order to better support their child, struggle to explain the issue to their support networks and thus rely increasingly on religion and spirituality to cope. Issues related to the period of schooling and integration of the child have also been identified, creating further barriers for the mother to overcome (Desai et al., 2012). Finally, the political context within which these struggles occur was characterized by the late recognition of autism as a condition in the 1999 'National Trust

for Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act.' Ultimately, it becomes evident how the mothers' experiences studied within this research are characterized by specific forms of vulnerability at many levels of establishing their identity. Their experiences of vulnerability, agency and expertise form a unique area of study that could make further contributions to filling research gaps on each of the levels identified. In order to best represent their specific lived experiences, this research approaches their narratives with the following research question:

How can the lived experiences of mothers with an autistic child be understood and supported so as to enable sustainable long-term solutions?

To further position this research question within the existing scientific knowledge and paradigm, in Chapter 2 we will provide an overview of the major theoretical frameworks that helped structure this investigation. We will also highlight and describe the most important concepts that were used in the studies constituting this work. In Chapter 3 the methodological approaches, data collection and analysis tools used in this research will be presented in more detail.

---

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# CHAPTER 2

## 2. THEORETICAL CONCEPTS

This chapter sets out the theoretical and conceptual base for the thesis. We begin by conceptualizing and contextualizing the complexity of the research field by showing different approaches that are, however, not mutually exclusive. As we were interested to understand both mothers' experiences and how these experiences can contribute to sustainable change, we start by describing the way we see the 'mother' and her child(ren) in the wider context, and how we believe that various actors and institutions interact with and influence each other's experiences. This also ties in with how we generally perceive the concept of "disability" and how best to address it in this thesis. We then narrow it down by providing models that help us investigate more specifically the experiences of mothers at different stages in their journey with a child diagnosed with autism, as well as which capabilities or vulnerabilities might have a unique influence on their journey. In the final section of the chapter, we will show how the main concepts are used throughout the thesis.

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### 2.1 CONCEPTUALIZING MOTHERS AS SITUATED IN COMPLEXITY

In order to operate on a conceptual level concerning the lived experiences of mothers of children with autism and how to support them, it is first necessary to address the topic of complexity in relation to their experiences. Parents, and therefore mothers, do not live in a vacuum, but live and act within various formal and informal networks of actors and events defined by the multifaceted issues that constitute their diversity and heterogeneity (Lightfoot, LaLiberte, & Cho, 2018). The way the institutions and actors in these networks function and how they interact greatly determine the conditions of children and parents at the centre of these

broader ecosystems. These include schools, work, playgrounds, and sports centres, and for children with disabilities may also include facilities for rehabilitation and therapeutic support. The way mothers perceive these institutions and gain a sense of support or alternatively a sense of frustration, anger and grievance from them, matters greatly (e.g. Woodgate, Ateah & Secco, 2008). This is especially important when the system actually works to make mothers feel more isolated and ignored by the very institutions and facilities that are intended to help their child, as Woodgate et al. (2008) also describe. Therefore, rather than understanding mothers' experiences as a series of disconnected problems, this work focuses on a holistic perspective on their multifaceted journeys.

Of course, this is not the first research to consider the need for alternative scientific approaches to grapple with the complexity; scholars have previously noted that such problems require creative thinking as well as complex, comprehensive and iterative approaches (Duboz, et.al. 2018). It requires an understanding of the way numerous stakeholders in a mothers' network function and encourage integration, which is an approach already practised in other studies on children with disabilities and in disability rights advocacy (Carpenter, 2000; McIntyre & Brown, 2018, Menken & Keestra, 2016). A significant contribution to the field of pedagogy was a model developed by Bronfenbrenner (2009), which continues to steer various studies on children. His Ecological Systems Theory was initially developed to capture the lived experience of children as being situated in a system of social layers, starting with the child itself (who has several characteristics and functions) as situated in a micro-level (first with the parents, but also contexts such as kindergartens and schools), and as indirectly influenced by the way these institutions interact with each other (meso level) also outside them, including the way parents feel about and interact with teachers, for instance. His theory explains how within and between each system there are two-way influences, which imply that relationships exert

an impact in two directions, both away from and towards the individual (ibid). Finally, the child is also influenced by the local politics, infrastructure and resources (exo level), as well as the cultural, legal, political and ideological state of the country in which they live (macro level). For instance, children growing up in a relatively deprived neighbourhood, or in a low-income country, will have different health outcomes than children who grow up in a wealthy setting in any country (e.g. Emerson & Hatton, 2007). Finally, the chrono level added to the model captures the ways in which systems change over time through historic events, capturing the individual life-course, and more direct alterations over the course of a child's life that affect their wellbeing (ibid).

A helpful implementation of the model, such as the one seen in Melvin et al. (2019), resulting in the KiTeS (Kids and Teens at School) framework, is also adopted in this thesis, as it situates parents, children and schools together at the centre, thus merging the micro- and meso-level institutions. Through this combination, it is possible to situate mothers and their child (ren) in dimensions beyond the personal level or even extended family, yet still within institutional levels and even the policy aspects of the macro system. The KiTeS framework helps in considering various levels of influence on the mother when working with her autistic child (micro system), and at the same time analysing the experiences of their mothers, who are themselves also interacting with various stakeholders in each phase of their journey – for example, the actors involved during therapy and schooling (exo system) and how this translates in relation to existing policies and laws in India (macro system). At the same time, as we are interested in how mothers themselves experience their journey with a child with certain characteristics, who is also part of a broader complex world, we will place mothers at the centre of our analysis, and question what they can contribute in terms of resources and challenges that influence their inner journey. Figure 1 shows the KiTes framework, with some adaptations



made to emphasize the focus on mothers, and add the role of therapeutic and rehabilitation centres in the context of mothers of children with autism.

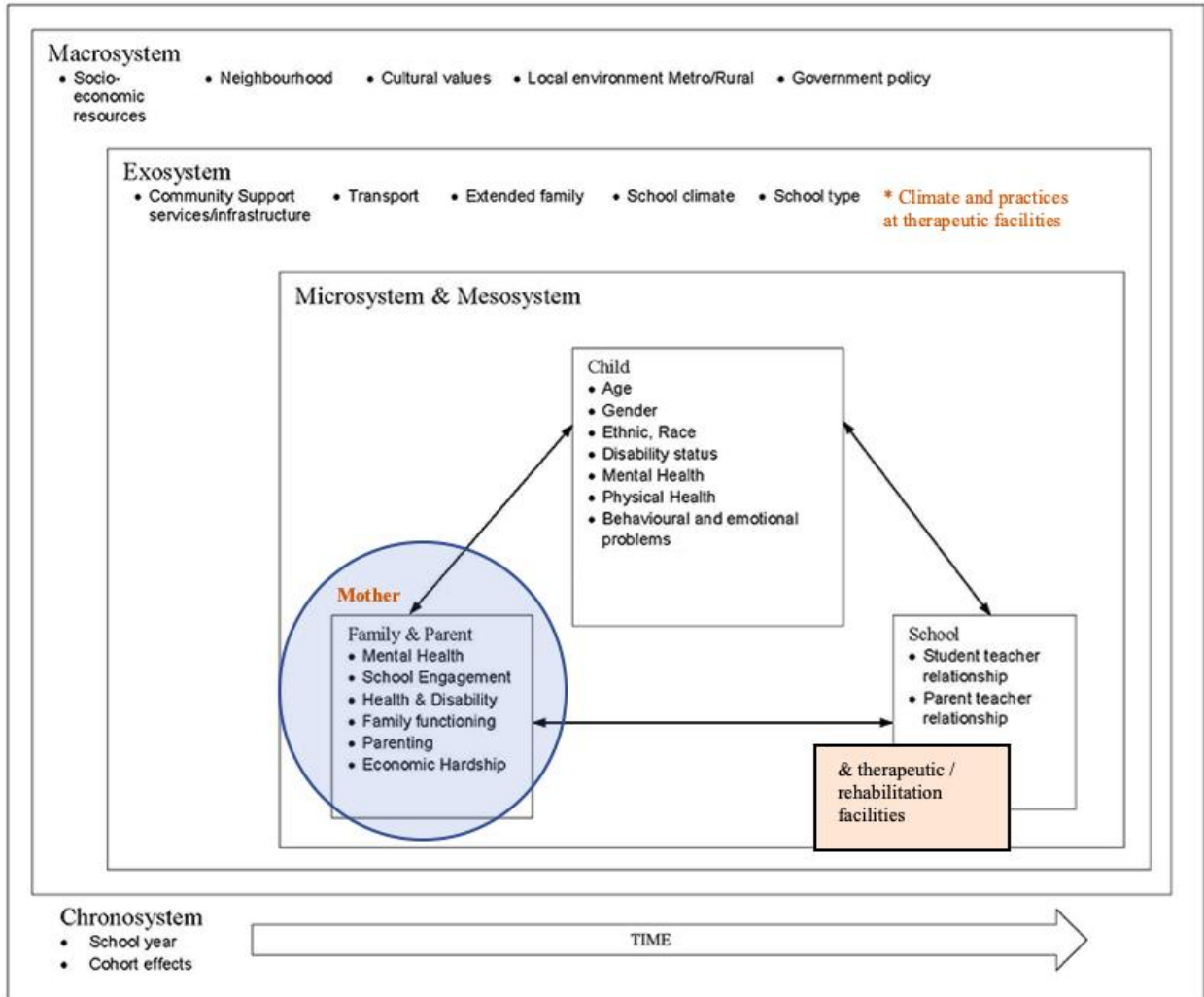


Figure 1. The KiTes framework (Melvin et al. 2009) adapted to fit the complexity of the context of mothers with a child diagnosed with autism

### 2.1.1 DISABILITY AS SOCIALLY CONSTRUCTED

Inherently connected to the notion that children are situated and build their experiences in a broader social context, we also perceive disability (as an expression) as a social construct. Bronfenbrenner also emphasized that children’s development, and their “biological” characteristics are shaped by their environment (e.g. Bronfenbrenner & Ceci, 1994). This

means that “development” and “disability” are more interwoven than is commonly thought (Rosenbaum, 2009). Given autism’s classification as a disability it is worth considering how the way in which disability is understood in a given context significantly affects the ways that a condition defined as a disability is treated, and the paths that they must navigate. As such, conceptualizations of disability give a sense of which epistemological approach this research adopts. Despite the common use of the term, its definition could fall under any number of historical ways of understanding it, including (but not limited to) religious models, medical models, charity models, social models, identity models and human rights models (Retief & Letšosa, 2018). Each of these a unique take on how disability should be approached in society. Religious models, which are among the oldest, often regard disability as an expression of divine punishment, implying the need for suffering and factoring out any empathy (ibid). Within this understanding, mothers might then be said to be experiencing the difficulties of their child “for a reason” (ibid). This can be compared to the more sympathetic “charity” model, which views disability in terms of victimhood, subject to able-bodied superiority and assistance, which simultaneously isolates the disabled body as needing “special” support, as with specific schools for certain types of disability (ibid). None of these approaches are mutually exclusive and serve or have served a purpose in different settings and circumstances.

By contrast, the more contemporary medical models generally understand disability in terms of individual ill-health, requiring a cure through intervention and rehabilitation and thus dependent on health professionals and distinguished from good health by medically defined diagnostic criteria (Siebers, 2006). The final three models of understanding disability originate in disability studies or disability rights work and are often developed precisely on the premise of reconfiguring social understandings of the term (ibid). Chief among these is the social model, which differentiates itself from treating disabled bodies as “machines” in need of repair,

where this supposedly objective view fails to acknowledge how such deviance is subjectively and socially determined, such that needing glasses does not result in the classification of disability (Siebers, 2006). It notes that individuals move through different phases of dependence throughout their lives, including the protected figure of the child and the “frail” figure of an elderly person (Siebers, 2013). Its main conclusion, then, is that rather than seeking to adjust the disabled individual as the medical model does, it may be necessary to adjust the environment that is *creating* the experience of disability by excluding the individual; in a world of wheelchair users, there would be no stairs. Thus, the situation of mothers of children with autism might be seen more to be defined by the actors and institutions around them than by the child’s differences. In an alternative critique of medical approaches, the identity model, while sharing the understanding of disability as socially constructed, is situated in a differential, positive understanding of disability, aiming to create recognition of a minority identity with its own values and distinctions (Retief & Letšosa, 2018). This might be best understood in relation to, for instance, movements of “deaf culture”, which has its own language and way of interacting that resists “repair” by cochlear implants (Pass & Graber, 2015). In our case, this would relate to the neurodiversity movement to explain the autistic spectrum (Cascio, 2012), which explains autism as a neuro-variation, rather than a “deficit”.

Finally, recognizing disability as a human rights issue notes the ways in which disability is associated with multi-modal human rights violations (Patel et al., 2011). It aims, much like the identity model, for a recognition of the marginalized voices of people with disabilities, but places this in a framework of dignity, participation and equal worth. For the mothers of this study, this would mean recognizing the challenges they face from a perspective of community or wider social responsibility. It should then be clear that the way in which different actors

perceive and construct definitions of disability has significant implications for the mothers' journeys.

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## 2.2 THE JOURNEY OF MOTHERS OF CHILDREN WITH AUTISM

We continue the theoretical foundation by narrowing our focus now on mothers, and specifically how we might define their development in parenting a child with autism. With regard to that development, we look particularly for ways to distinguish specific phases in their journey. It is often said that no child with autism is the same, so the same true for their mothers. Nevertheless, scholars have identified some general patterns (Gentles et al., 2019).

These multiple investigations show that parents (often mothers) are the first to notice and develop an image of “difference” (Gentles et al., 2019), in which some signs are noticed and picked up, such as particular difficulties in being comforted or being late in reaching certain “milestones” in child development. While these signs are often ignored for some time, at some point they are usually questioned and arouse the suspicion of one of the parents. It could be that at this stage parents are already looking for information online or through friends. Parents who are aware of the possibility of autism, as well as being emotionally ready to investigate further, indicate the source of the problem. This phase usually involves emotional adaptation and grief (ibid.). It is then that the parents can start to seek professional support to diagnose their child's perceived differences, and start coping with the idea that their child has autism.

Research shows that mothers are usually the first to notice any changes or idiosyncrasies in their children, and also the first to seek help that might result in a possible diagnosis (e.g. Kishore & Basu, 2011; Mackintosh, Myers & Goin-Kochel, 2005; McConkey, Truesdale-Kennedy & Cassidy, 2009; Ribeiro et al., 2017). The diagnosis itself, the search for which is

often being initiated by the mothers, is often described as a critical stage in the mothers' journey. Studies report that mothers often feel grief and anxiety, emotions which are also carried throughout the stages of adjustment and rehabilitation after the diagnosis (Lutz, Patterson & Klein, 2012; Mann, 2013; Russell & Norwich, 2012). Within clinical practice, the diagnosis of autism is typically followed by the provision of therapy, which much research has described as a step when mothers and their children face further challenges such as finding the right therapist, making a therapeutic plan and following progress (Bourke-Taylor, Howie & Law, 2010; Houser et al., 2014). Last but not the least in relation to these children, an important setting where a large volume of research has been conducted is the school setting (Larcombe et al., 2019). It has been shown that regardless of whether the child was referred to a special school or stayed in the mainstream, several important adaptations and changes were necessary (Bourke-Taylor, Howie & Law, 2010; Carrington & Graham, 2001; Hall & Graff, 2010). This might lead to further stress for the mothers. Bearing in mind earlier research and combining it with the initial findings of our pilot study, we decided to focus on the four distinct stages of the mothers' journeys: 1) from birth to diagnosis; 2) from receiving the diagnosis and coming to terms with it; 3) start and continuation of therapy; and 4) the school years (see Figure 2.)

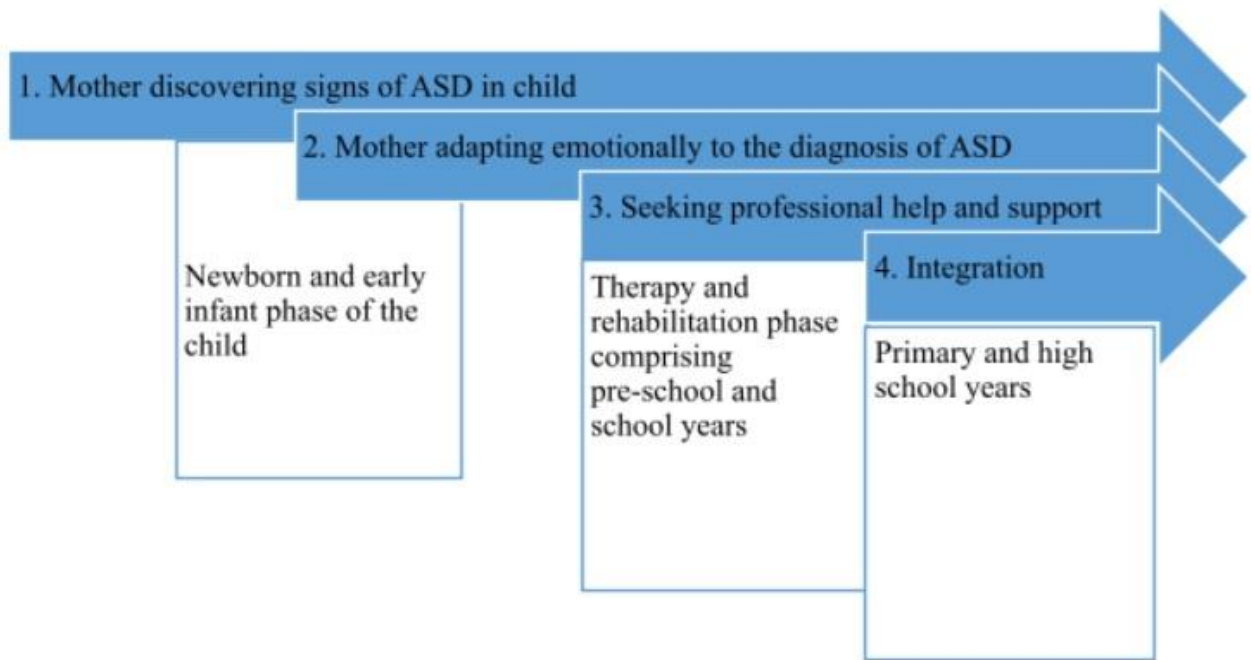


Figure 2. Visualization of phases in a mother's journey in relation to the child's diagnosis with autism

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## 2.3 RESOURCES AND CHALLENGES

To further narrow our focus on what actually goes on in the mothers' journeys, and how they also resist certain aspects of their environment, this section concludes by touching upon a few important concepts (Knowledge, Attitudes, and Practices (KAP), vulnerability and agency). These concepts help our understanding of the journeys in an actively analytical way, aiming to identify barriers and facilitators as experienced and used by mothers.

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### 2.3.1 KNOWLEDGE, ATTITUDES AND PRACTICES (KAP)

To structure our analysis, and to provide more attention to proactive, solution-oriented ideas of what mothers use to shape their world, this study uses the KAP model (Okobia et al., 2006). "Knowledge" in this context is seen as information the mother or another actor has that might have an influence on her journey, whether or not it is shared. For instance, knowledge about autism, child development, parenting or disability. "Attitudes" include how mothers and other actors perceive and value such knowledge or concepts, such as definitions of disability

and their implications for the mother's role. Finally, "practices" relate to the action taken on the basis of this knowledge and the perception of the knowledge (ibid). This model has been applied in numerous areas of health research, including cancer, epilepsy, food poisoning and antibiotics (Nicholson et al., 2018; Okobia et al., 2006; Radhakrishnan et al., 2000; Sharif & Al-Malki, 2010). As such, the support that various actors can offer mothers is largely contingent on their knowledge and attitudes about the central concepts in this journey. Similarly, the mothers' practices or actions may be defined by their knowledge, or their lack of knowledge, and attitudes in ways that limit or facilitate them. As such, the elements of KAP cut across the levels identified in the socio-ecological model and KiTes framework and define the roles of different actors and structures. A key aspect of KAP is that they are fluid and changeable elements of interactions, and so lead to different outcomes in different contexts.

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### 2.3.2 VULNERABILITY

Given that this research aims to understand mothers' inner journeys, it is important to consider their subjective states. In this regard, we consider the concept of vulnerability, which much like disability is understood by nature of its construction, recognizing both the disciplinary construct of the term in the literature and the social construct of the condition of being. In recent years, the term vulnerability has frequently been used in a variety of disciplines, such that even in its original field of disaster management there is no single, clear definition (Levine, 2004). Furthermore, despite the substantial differences in how it is used across various disciplines, definitions of the term are not always discussed before it is applied (McEntire et al., 2010; Spini et al., 2017). Where in psychology it might refer to factors of susceptibility based on genetic, biomedical and psychological predispositions in relation to cognitive stability, in disaster management Lei et al. find vulnerability relates to the socially determined characteristics determining the ability to anticipate, cope with, resist and recover from a major

event such as a catastrophic natural event (Lei et al., 2013). As such, the research decision to define vulnerability with regard to the social construction of disability, the safeguarding of rights and the role of mothers needs to be explicitly discussed. This thesis, then, understands vulnerability not from the outside, as an existing dynamic as psychology does, nor as a static set of conditions, but rather as a process. Given its emphasis on the individual journeys of mothers of children with autism, the concept is employed to understand barriers and facilitators within the mothers' life-course as they experience them. As such, vulnerability is defined for this purpose as a procedural experience of mothers related to social factors that diminish their capacity to anticipate, cope with and respond to the needs of their child.

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### 2.3.3 AGENCY AND EMPOWERMENT

Vulnerability and agency are two sides of the same coin, and both require equal consideration as concepts in this thesis. Much like vulnerability, agency is rarely defined clearly in the literature, as they are often both treated as an individual or collective characteristic without making this distinction explicitly (Gesser, n.d.; Ling & Dale, 2014). Some speak of agency as a personal characteristic, that you have or do not have (like a virtue), while others refer to it as a process, a series of actions, and, beyond that, numerous articles discuss agency as a collective property of groups of people or whole social systems (Benesch, 2018; Gesser, n.d.; Ling & Dale, 2014). Fields of focus range from nursing and care, to teachers and education, to development aid, and more theoretical work on ideology and defining agency as political in nature (Benesch, 2018; Benner, 2000; Hemmings & Kabesh, 2013; Ling & Dale, 2014). Furthermore, definitions of agency are often tightly linked to particular understandings of the nature of human freedom and self-determination based on an ideal of being unbound by a wider social context, which feminist scholars have determined to be unrealistic and limited (Abrams, 1998).



In the context of this research, then, mothers' agency is understood in terms of how mothers are socially embedded in networks of giving and receiving, both as individuals and as a group involved in collective action. As such, understanding their agency becomes deeply linked to the agency and actions of policy-makers, psychologists and educators in a way that requires a system-wide view. An example of agency, both individually (often as a start), but also collectively (as people come together in shared purpose) might be found, for instance, in the #Metoo-movement, in which collective action and mediation become central to any potential change (Ozkazanc-Pan, 2019).

To further inform both individual and collective agency, two additional models of understanding are used: realist evaluation and Harden's nursing education model (Harden, Sowden & Dunn, 1984). Realist evaluation is a theory-driven strategy that enhances the understanding of multifaceted processes and approaches of continuous reconstruction and interface that any movement striving for sustainable change must go through (Pawson, & Tilley, 1997). It is an emerging paradigm in social work practice, designed to understand complex processes of social change. It has the potential to not only understand outcomes, but also track and systematically evaluate the mechanisms that lead to these outcomes, as well as the context that generates these mechanisms (Kazi, 2003). At the individual level, the ways in which mothers navigate their pathways is understood in relation to enlightenment, empowerment and emancipation. Enlightenment once more addresses mothers' knowledge and understanding through which they gain clarity on how to move forwards. Empowerment addresses their awareness and confidence to act in their desired direction.

Finally, emancipation refers to action in relation to the process of becoming, which is only place in which this research specifies the ways in which emancipation is understood

individually, while the mothers acting on behalf of their children's needs have a different understanding of flourishing or becoming than might otherwise be assumed.

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#### 2.4 CONCEPTUAL FRAMEWORK

The concepts as discussed above are brought together in one conceptual framework that will help guide the structure of this thesis (Figure 3), which is based on the idea that social and medical models are not mutually exclusive, but should rather be utilised for mutual strengthening depending on the settings/circumstances at hand. It incorporates the levels as suggested by Bronfenbrenner (2009?) and adapted by Melvin et al. (2016). We have added to this a narrow focus on mothers' knowledge, attitudes and practices (KAP), which also shape their sense of vulnerability or, on the other side, agency in the struggle for better circumstances for children with autism. We look at these resources in particular stages of their lives as illustrated in Figure 2. The questions arising from this theoretical model, include broadly:

1. How do mothers experience their journey in discovering, and coping with their child's diagnosis, as part of India's broader social context?
2. What are their resources (including KAP) that help them navigate their journey with an autistic child in a way that drives change at any relevant level of society or the interaction between these?

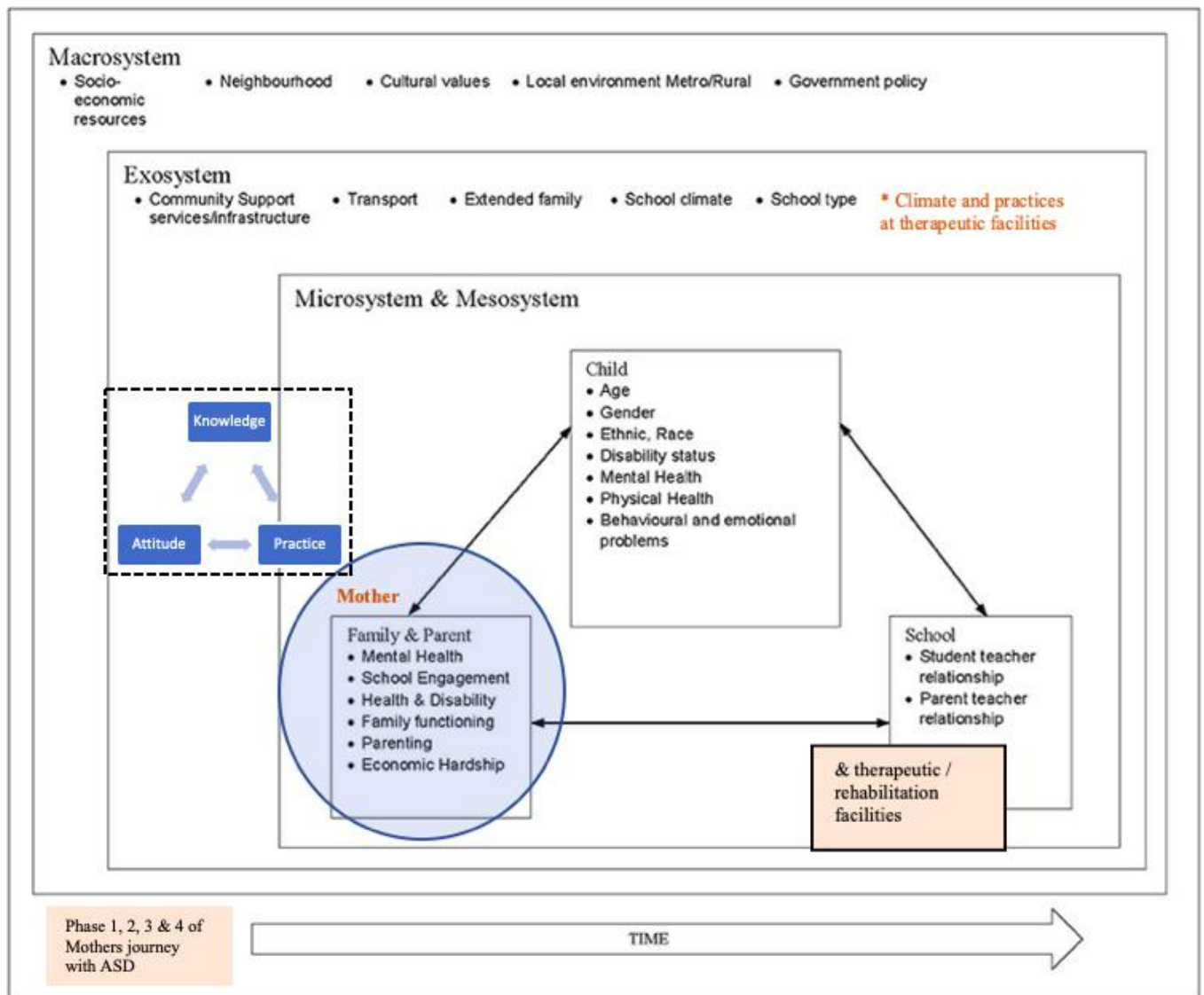


Figure 3. Final conceptual framework, including an ecological context in which mothers, including their knowledge, attitudes, and practices at different phases of their journey, are centrally positioned.

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# CHAPTER 3

## 3. RESEARCH DESIGN

In this chapter, we begin by reiterating the main research question, followed by a presentation of the research sub-questions and how they are addressed throughout the thesis. Next, we present the research approach chosen for investigation. We then explain the reason for deciding on a qualitative research approach was preferred to other methods, and clarify the exploratory and in-depth nature of the study. The setting in which the study takes place is described next, before moving to the data-collection tools, procedures and analysis. We conclude the section with the validity of the study and ethical considerations.

The main research question is how to understand the lived experiences of mothers of autistic children so as to support and enable long-term solutions, there was a need for both an exploratory and in-depth understanding of the field of research – “lived experiences”. Based on the theoretical models and concepts discussed in Chapter 2, combined with the known challenges in different phases of the mothers’ journey identified in earlier literature, the following sub-questions have been formulated:

1. How can we understand mothers’ lived experiences, their challenges and coping strategies from childbirth to noticing differences in their child?
2. How can we understand mothers’ lived experiences and the gaps in support from the time of noticing differences to reaching an early diagnosis of autism in their child?
3. How can we understand mothers’ lived experiences during the diagnostic process and early intervention stages – the facilitators of and barriers to her agency?

4. How can we understand the mothers' lived experiences from a rights perspective during their children's school years?
5. How can we understand the agency in a few mothers and the mechanisms they used to lead to policy change?

Given the structure of this thesis around five distinct articles, the models outlined above are applied differently in each chapter as appropriate. All models informed the methodological distinctions outlined in chapter 3. The Bronfenbrenner ecological model, KiTeS and KAP approaches summarized in Figure 1 form the basis of the contextually rich approach throughout the research, but are most apparent in chapter 4–7.

Disability constructs form the basis for the interviews and coding in chapters 5, 6, and 7. Knowledge, Attitudes and Practices (KAP) informs both data collection and analysis of the research in all chapters. Vulnerability is used as a concept used in the analysis of the data in chapters 5, 6 and 7, while agency and empowerment, including Harden's nursing education model, extends to the first and the final articles.

<b>MAIN RESEARCH QUESTION: HOW CAN MOTHERS' LIVED EXPERIENCES WITH AUTISTIC CHILDREN BE UNDERSTOOD AND SUPPORTED SO AS TO ENABLE SUSTAINABLE LONG-TERM SOLUTIONS?</b>					
<b>THEMES</b>	<b>CHAPTER 4</b>	<b>CHAPTER 5</b>	<b>CHAPTER 6</b>	<b>CHAPTER 7</b>	<b>CHAPTER 8</b>
<b>RESEARCH SUB QUESTIONS</b>	How can we understand mothers' lived experiences, their challenges and coping strategies from childbirth to noticing	How can we understand mothers' lived experiences, the gaps in support, from the time of noticing differences to reaching an early diagnosis of autism in their child?	How can we understand mothers' lived experiences during the diagnostic process and early intervention stages – the facilitators and	How can we understand mothers' lived experiences from a rights-based perspective during their children's schooling?	How can we understand the agency in a few mothers and the mechanisms they used to lead to policy change?



	differences in their child?		barriers in their agency?		
<b>Disability construct</b>		✓	✓	✓	
<b>Knowledge, attitudes and practices</b>	✓	✓	✓	✓	✓
<b>Vulnerability</b>		✓	✓	✓	
<b>Agency and Empowerment</b>	✓	✓	✓	✓	✓

Table 1. Overview of Research questions and concepts used in this thesis

### 3.1. QUALITATIVE EXPLORATORY RESEARCH APPROACH

With regard to the research approach this thesis takes and its implications for sub-question(s) and methodology, this section first discusses the concrete application of lived experiences, followed by the choice of a qualitative exploratory approach, in increasing specificity.

While the first chapter explains the reason for a focus on “lived experiences” and their relevance and Chapter 2 describes the various theories on how to best understand these lived experiences and describes their methodological implications. There is growing research of the term “lived experience” within social policy and related fields. For instance, it can be seen as both a method and approach in feminist literature and anthropological work (Mcintosh & Wright, 2018). There is ample evidence that deeper contemplation of “lived experience” provides new methodological connections and development. Among other things, it can positively expand research, writing and engagement in policy-making processes, by providing detailed descriptions about a phenomenon and providing perspective in evaluation (ibid). It has the scope to be immersed in the lives and concerns of people affected by and involved in policy processes and outcomes, including policy-makers and influential change agents, grassroots workers, and disempowered and vulnerable groups (ibid). Thus, lived experiences can be closely associated with qualitative longitudinal research, and the specific timeline of living

through various continuous changes, which gives insight into how agency is applied over time (ibid).

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### 3.1.1. QUALITATIVE APPROACH

A qualitative research approach was chosen to gain a rich and holistic overview of the journey of mothers of autistic children. It involved in-depth investigation of the mothers' lives and a naturalistic understanding of the various experiences specific to their context and setting. This was essential for the nature of the research questions, but also for the researcher's positionality, which was closer than that of an ethnographer, given the layered in-and-out-group roles of mother, professional and researcher. In this sense, the researcher is both an observer and engaged within the system as in classical participant observation, allowing for a depth of understanding and engagement that might otherwise be unachievable.

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### 3.1.2. EXPLORATORY APPROACH

Exploratory research is often used as a synonym for fieldwork, such that its scope helps to compensate for how qualitative research often focuses only on individuals and not on relationships and context (Stebbins, 2011). In the case of this research, knowledge about mothers' individual lived experiences functioned as the starting point, but in order to understand the interrelation of those experiences and generate research that effectively addresses those experiences as knowledge, exploration was required.

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## 3.2. SETTING AND CONTEXT

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### 3.2.1. SETTING

By using telephone interviews, the full scope of participants ultimately changed. Most of the participants were found within the study setting of Kerala, India. Kerala is the twenty-first largest Indian state by area and is bordered by Karnataka to the north, Tamil Nadu to the east and south, and Lakshadweep Sea to the west (Noble, 2020; Census 2011, n.d.)

It is divided into 14 districts with the capital being Thiruvananthapuram (Government of Kerala, 2018). Malayalam is the most widely spoken language and is also the state's official language (Noble, 2020). With 33 million inhabitants as the time of the 2011 census, Kerala is the thirteenth-largest Indian state by population. Kerala has the lowest positive population growth rate in India and in 2018 had the highest Human Development Index (HDI). The state has the country's highest literacy rate, life expectancy, and sex ratio (Human Development Indices (5.0), n.d.; Kerala population 2011-2021, n.d.; Noble, 2020). Kerala was also declared the first digital state, the second-least impoverished state, and the second-most urbanized state in India (Correspondent The Hindu, 2016; Ministry of Housing and Urban Affairs, 2021; Reserve Bank of India, 2015). The state also has India's highest media exposure with newspapers publishing in nine languages, although mainly in English and Malayalam (International Institute for Population Sciences (IIPS) and ICF, 2018). Hinduism is practised by more than half of the population, followed by Islam and Christianity (Noble, 2020).

There is a tradition of matrilineal inheritance in Kerala, where the mother is the head of the household. As a result, women in Kerala have a much higher standing and influence in society than in other states (Jeffrey, 2004). Opportunities for women, such as education and gainful employment, often translate into a lower birth rate, which, in turn, make education and employment more likely to be accessible and more beneficial for women (Nair, 2010). This creates an upward spiral for both the women and children that is passed onto future generations (Jeffrey, 2004). Factors like high rates of female literacy, education, work participation and life

expectancy, along with favourable sex ratio, contributed to this outcome (Jeffrey, 2004; Nair, 2010).

In line with the above, all the participants were well-educated; most of them employed at the time of the childbirth, which they had to give up afterwards. They were all married, their husbands contributed financially and the family was financially secure. Thus, the barriers faced by this group of mothers tends to be magnified compared to other mothers who become more vulnerable and marginalized, particularly if they are from families that cannot afford or access services and are not educated. None of the mothers mentioned the role of faith healing and other religious healing. This was probably due to being better educated than most mothers in the rest of the country, indicating the greater barriers to knowledge and support that might be experienced by mothers beyond Kerala.

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### 3.2.2. CONTEXT

The context of this research is of greater relevance given the series of events that affected the direction of study, starting with the initiating event of 23 March 2015, when a non-verbal autistic child broke his arm during occupational therapy. In April 2015, Together We Can (TWC) started a petition to KeSCPCR (Kerala State Commission for Protection of Child Rights) and to the Health Minister of the then ruling party. Based in the Ernakulam district, TWC functions primarily as a Facebook page and a WhatsApp group. The ruling party changed in June 2016. In August 2016, a landmark order was passed by the commission directing the state to frame guidelines to regulate and monitor therapy centres and make its practices more transparent, accountable, ethical and inclusive. However, since there was no follow-up, TWC filed PIL (Public Interest Litigation) in 2017, followed by a social media campaign. The exploratory, or pilot, phase of the study, its coding and the preparation of a research proposal

for the ethics committee occurred during 2016-17. In 2018 when the semi-structured interviews started – the in-depth phase took place until 2019, alongside data analysis. These events formed the backdrop for the research process, with the TWC's PIL progress in 2019 during data analysis resulting in a favourable court judgement and the drafting of new guidelines in June of 2020. While many of the articles were structured on the basis of the information available prior to 2019, the entire thesis, concluding discussion and analysis exists within the context of these developments and their implications for its findings.

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### 3.3. DATA COLLECTION AND ANALYSIS

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#### 3.3.1 STEPS OF RESEARCH

The research broadly comprised three phases: first, the pilot study, was conducted to scope the field and make preliminary assessments of the themes the mothers deemed important. Next, the data collection on several phases was undertaken. During the last step, the breadth of data was used for the realist evaluation synthesis.

##### 3.3.1.1 PILOT STUDY

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The exploratory phase, or pilot study, was conducted in 2016 and used to frame the interview guide for the next phase of the study. Eight mothers, who were known to the researcher and had experiences with their autistic child in Kerala and other regions of India, were randomly selected by using accessibility sampling. All interviews were unstructured and an open, informal conversational format was used when mothers were asked to narrate their life story from the time of childbirth. All interviews were done by phone and lasted for 45 minutes to an hour. The data analysis of the exploratory phase interviews consisted of a combination between open coding and thematic analysis, where open coding was used first to identify

main themes and concepts. These codes were then grouped and used for a more detailed thematic analysis. This resulted in an understanding of the mothers' journeys in phases, which were then labelled as:

Phase A: Phase before a diagnosis

Phase B: The phase of coming to terms with the diagnosis

Phase C: The therapy phase after the diagnosis

Phase D: The schooling phase

In addition, the coding process helped in identifying the main actors alongside their journey as family members, the professionals and the policy-makers. The mother's own knowledge and influence of her own personality were also found to be prominent.

#### 3.3.1.2. EXPLORATORY RESEARCH

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As the thesis aimed to dwell deeper into the lived experiences of the mothers of autistic children, it was important to use a more structured and focused interview method that also gave scope for some flexibility. Thus, in the second phase of the research, the narrowed lens of semi-structured interviews was used, using a frame developed in the initial interviews, to allow for data saturation on the particular points of interest. Semi-structured interviews allow for clearer direction while maintaining the necessary flexibility (Gray, 2013).

#### 3.3.1.3 REALIST EVALUATION

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Given the origin of this research relating to the human rights violations, an in-depth exploration of the journey of TWC relating to the experiences of the mothers was also given explicit focus in this research. Realist evaluation was used to understand the complex process and mechanisms of continuous transformation that TWC underwent in the five years from its

initiation to bringing about policy change. There was also a need to analyse the feasibility of applying these mechanisms to other contexts. The unique structure of realist evaluation was seen to be ideal due to its theory-driven strategy used to understand movements leading to sustainable change.

The data-collection methods included a document analysis of all social media post, emails, court cases related to TWC, minutes of meetings with various stakeholder groups, research notes, case studies, videos, photographs, write-ups on blogs and social media relevant to TWC. For the formulation of the initial programme theory, the core members of the TWC provided narratives explaining their journey and their perceptions about TWC’s journey. The audio narratives were transcribed and the parts in Malayalam were translated into English. This was followed by a realist interview between the scientific guide and knowledge partner, a key player in the journey, and the researcher who is also a core TWC member. The theories were then tested against other contexts in other causes that TWC supported.

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### 3.3.2 OVERVIEW OF METHODS AND CHAPTERS

Given the breadth of the methods used in each of the following chapters, we discuss the data-collection and analysis methodologies in detail below.

METHODS	STUDY					
	Pilot Study	Study 1 Chapter 4	Study 2 Chapter 5	Study 3 Chapter 6	Study 4 Chapter 7	Study 5 Chapter 8
Document Analysis	✓	✓	✓	✓	✓	✓
Research Notes	✓	✓	✓	✓	✓	✓
Unstructured Interview	✓					
Semi-Structured Interview		✓	✓	✓	✓	
Literature Review		✓				
Realist Interview						✓

Realist Evaluation							✓
Theory Testing							✓

Table 2. Overview of the methods used in this thesis

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### 3.3.2.1. DOCUMENT ANALYSIS

An extensive document analysis was conducted to understand the views of mothers based on their social media posts, blogs and other research notes. The search and analysis were performed iteratively in an unstructured way. Several social media and traditional media pages were identified as relevant due to the volume and frequency of relevant posts and these pages were revisited during the regular intervals (at least twice monthly). Views of multiple other stakeholder groups such as medical doctors, therapists, owners of therapy centres, media, disability rights activists, lawyers and the general public views and understanding of the issue was taken into consideration in framing the interview guide for the next phase.

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### 3.3.2.2. RESEARCH NOTES

By research notes as a method of data collection, we mean notes taken by the researcher while one of the other methods was being used. For example, notes were taken from the time of analysing the documents, making separate notes of any event that stood out, a strong emotion that was voiced and which could be missed out in transcription, or any other specific observations made by the researcher while interacting with the mothers in various contexts, even outside the research.

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### 3.3.2.3. INTERVIEWS

#### 3.3.2.3.1 UNSTRUCTURED INTERVIEWS

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Unstructured interviews were used in the first phase of the research in the pilot study as explained in the section on the pilot study.



### 3.3.2.3.2 SEMI STRUCTURED INTERVIEWS

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Participants for the semi-structured interviews were contacted by circulating digital posters explaining the nature of research and role of participants. This was distributed via the parent support and advocacy group Together We Can (TWC) based in Kochi and Kerala as well as from the Autism Club in Kerala. Given the sensitivity of the topic and the researcher's affiliation with these organizations, a combination of purposeful and convenience sampling methods was used. In order to reach more participants through the interviews, a snowballing technique was added to the sampling method. The respondents were all women with an autistic child. There were no explicit exclusion criteria beyond being proficient in English, Hindi or Malayalam.

In the semi-structured interview guide, the mothers were guided to speak about the influence of their knowledge, attitudes and practices (KAP) and also that of the family members and professionals. They were asked specifically to speak about the role of government and policy-makers as well. They were then asked to speak retrospectively about what they wished had changed and also to indicate any advice to future mothers. In the Phase A of the interview guide, the role of technology was specifically asked as it emerged as a relevant theme in the pilot study where mothers mentioned the pre-diagnosis experiences.

*'Making Lived Experiences Matter'*

Participated In					Year of birth of Child	Sex	Ordinal Position	Age of Diagnosis in years	Education	Age of Mother	Marital Status	Work Status	Family type	State
Pilot Study	Chapter 4	Chapter 5	Chapter 6	Chapter 7										
MP 1	3A	M3A	11B		2002	M	Single Child	1.5	PG	40	M	E	J	KL
MP 2	2A	M2A	13B	14C	2008	M	1st	4.5	G	36	M	UE	N	KL
MP 3				3C	2005	M	Single Child	2	PG	41	M	UE	N	KL
MP 4	MP 4				2008	M	2nd	2.2	PG	33	M	UE	N	KL
MP 5					2005	M	Twins	2.2	G	36	M	UE	N	KL
MP 6	1A	M1A		6C	1993	M	2nd	2.5	G	55	M	UE	N	KL
MP 7	10A	M10A		8C	2005	M	Single Child	3.6	G	54	M	UE	N	KL
MP 8	11A	M11A	15B		2009	M	Single Child	2	G	44	M	UE	N	KL
	4A	M4A	10B	4C	2001	F	2nd	2.5	G	50	M	E	J	KL
	5A	M5A		10C	2008	M	2nd	2.3	PG	38	M	E	N	KL
	6A	M6A	9B	13C	1999	M	2nd	3.3	PG	51	M	E	N	KL
	7A	M7A	5B	1C	2003	M	1st	2.10	PG	42	M	E	N	MH
	8A	M8A	8B		2009	M	1st	2	PG	35	M	UE	J	KL
	9A	M9A	14B		2005	M	Single Child	3.3	PG	46	M	UE	N	KA
	12A	M12A	3B	5C	2001	M	2nd	4	G	48	M	UE	N	TN
	13A	M13A	6B	12C	2007	F	2nd	2.7	PG	43	M	E	N	KA
	14A	M14A	7B		2012	M	Single Child	1.8	PG	36	M	E	N	KL
	15A	M15A	4B	15C	2001	M	Single Child	2.5	G	44	M	UE	N	KL
			1B		2010	M	Single Child	3.3	PG	38	M	UE	J	WB
			2B		2009	M	1st	2.6	G	36	M	UE	N	KA

*'Making Lived Experiences Matter'*

			12B	7C	1996	M	Single Child	2.5	PG	45	M	UE	N	HY
				2C	2004	M	Single Child	1.6	G	42	M	UE	N	DEH
				9C	2004	F	2nd	1.5	PG	43	M	E	N	KL
				11C	2009	M	1st	4.4	G	35	M	UE	J	KL

*Table 3. Demographic characteristics of the participants of the study: Sex: Male [M], Female [F]; Education: Graduate [G], Post Graduate [PG]; Marital Status: Married [M], Work Status: Employed [E], Unemployed [UE]*

The nature of the interviews was greatly affected by external events related to severe flooding in Kerala during the months of data collection. With work coming to a stand-still and the ongoing struggle with flooding, mothers opted for phone interviews, which coincidentally allowed for the incorporation of participants from outside the state. Each phase of the narrative had 15 interviews of 45 minutes, and while most spoke English, some interviews were conducted in Malayalam and translated after transcription. In total, 24 mothers were interviewed, most for more than one phase. Furthermore, to ensure data quality, all interviews were audio recorded, translated where necessary, and transcribed by students or other research assistants. The transcription was again checked against the audio tape to see if any interpretations were made while transcribing or if any parts were omitted or added. The transcription was then revised to produce verbatim transcripts. For each study, one randomly selected transcript was undertaken by two different transcribers and checked by the researcher for variance. Interpretations of the interviews and selections of themes were made with support from peer researchers using randomly selected transcripts. The themes were then compared and contrasted with those arrived at by the researcher. All identified codes and derived themes were agreed upon prior to reporting.

<b>Demographic Details</b>	<b>INTERVIEWS : Total No of mothers=24</b>
<b>Participated in</b>	Pilot Study=8, Chapter 4=16, Chapter 5=15, Chapter 6=15, Chapter 7=15
<b>Year of Birth of Child</b>	<2000=3, 2001 to 2004=7, 2005 to 2008=8, 2009 to 2012=6
<b>Gender</b>	Males=21, Females=3
<b>Ordinal Position</b>	First Child=5, Second Child=8, Single Child=10, Twins=1
<b>Age of Diagnosis</b>	1 to 3 yrs.=17, 3 to 5yrs=7
<b>Educational qualification</b>	PG=13, G=11
<b>Year of Birth of Mother</b>	<35=3, 36 to 40=7, 41 to 45=8, 46 to 50=3, >50=3
<b>Marital Status</b>	Married=24, Unmarried=0
<b>Employment Status</b>	Unemployed=16, Employed=8
<b>Family Type</b>	Joint=5, Nuclear=19
<b>State</b>	Kerala=16, Karnataka=3, West Bengal=1, Maharashtra=1, Tamil Nadu=1, Haryana=1, Delhi=1

*Table 4. Summarised key characteristics of the sample*

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#### 3.3.2.4. LITERATURE REVIEW

As many mothers in the pilot study mentioned great confusion regarding the use of technology when parenting, a systematic search of scientific literature was conducted to explore the positive and negative effects of screen media on children's language development. The literature search was conducted in November 2018 using the following three main databases: PubMed, EMBASE and PsycINFO. This resulted in 24 articles after removal of any that did not meet the inclusion criteria from a database search which resulted in 1119 publications. Subsequently, studies were grouped by associations found (positive, negative, no evidence) and age of the target study population (younger than three years or three years and older) to identify patterns across the paediatric age spectrum. The newly formed categories thus provided information on the kind of association or effect found and the age of the sample included. Due to their scarcity, articles including research on autism in relation to exposure to screen media and language development were analysed separately. To ensure the integration of different findings across multiple articles, a thematic content analysis was conducted with the support of a qualitative research programme (MAXQDA). First, a deductive coding method allowed us to see how the effect was established in one of the three categories: positive effect, negative effect or no effect. Moreover, the type of screen media exposure was coded. Second, an inductive approach was used to explore relevant concepts that triggered the effect and needed to be analysed in a broader perspective.

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#### 3.4. VALIDITY

Several strategies were applied to ensure the validity of the study. A great effort was made to ensure that the constructs identified as vulnerabilities in the mothers are indeed representative of the experiences of others in this population, within and outside the stakeholder group. To ensure this, discussion around the experiences of mothers started in 2015. A wide range of

discussions happened on the social media platform of Together We Can. Views of multiple stakeholders were taken into consideration, including local psychiatrists, psychologists, social workers, special educators, occupational therapists, speech and language therapists, therapy centre owners, special schools and mainstream schools, mothers from other states, lawyers, media professionals and policy-makers. It was clear that the problem addressed is indeed complex and needed a scientific approach that would include perspectives of all stakeholders from the lens of those whose quality of life is most affected – the mothers of the autistic children. This research also used an iterative process as described in Chapter 8. This was done by working from initial assumptions developed through, for instance, the exploratory pilot study, yet allowing for changes based on developments throughout the research journey through active reflection within the research team.

Furthermore, to ensure data quality, all interviews were audio recorded, translated where necessary, and transcribed by students or other research assistants. This was again checked against the audio tape to see if any interpretations were made while transcribing or if any parts were omitted or added. The transcribed work was then revised to produce verbatim transcripts. For each study, one randomly selected transcript was done by two different transcribers and checked by the researcher for variance. Interpretations of the interviews and selections of themes were done with support from peer researchers using randomly selected transcripts. The themes were then compared and contrasted with the ones arrived at by the researcher. All identified codes and derived themes were agreed upon prior to reporting.

As a South Indian woman, born and brought up in Kerala and knowing to how interact in three Indian languages – Hindi, Malayalam -and Tamil – there were no cultural or language barriers. However, as a qualitative researcher whose role is to interpret and understand the lived

experiences of the participants, overcoming the challenges of my own personal bias, or the influence of my knowledge of experiences of mothers before the research began, was minimized by using unstructured and semi-structured interviews, which gives greater scope for the mothers to speak openly. A snowball method of selecting mothers ensured a good spread of participants. There were participants from other states as well, but this led to no change in the main themes.

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### 3.5. ETHICS

Ethical clearance for the study was received in June 2018 by the independent ethics committee of The Banyan Academy of Leadership in Mental Health (BALM) in Chennai. Explicit informed consent was obtained from each participant in either a written (Email/WhatsApp) or oral form (recorded via phone recorder application or WhatsApp voice note recorder) before any form of data collection. The participants were informed about the aim and procedures of the research, its implications, their rights as participants, and the fact that participation was entirely voluntary and could be stopped at any point in time. Assurance was given that all data would be anonymised when participants are quoted either based on what was said during the interviews or what they wrote on public portals such as social media (Facebook/Blogs) or print and visual media. All data is stored with the researcher and only those approved by the university had access to it. All the audio recordings and transcripts are saved with the researcher.

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### 3.6. OUTLINE OF THESIS

Chapter 4 narrates the vulnerabilities of the mothers with new-born children, and coping with differences noticed, particularly through the use of technology. It is done through a scoping

literature review to understand the knowledge gap in scientific literature regarding the influence of technology on children as young as three years or below. Chapter 5 narrates the experiences of the mothers while attempting to seek help and the role of family and professionals in either enabling or blocking her agency towards early intervention. Chapter 6 aims to offer an in-depth insight into the grief of the mother post an autism diagnosis in their child (ren) and the influence of the manner of diagnosis disclosure and extent of individualized support towards early intervention. Chapter 7 explores the specific gaps in implementation of the RPwD 2016 in the schooling phase of the lives of the mothers with their autistic child and the various violations of the law and how she copes is narrated. Chapter 8 offers an overview of the entire journey of TWC and the mechanisms that worked while taking collective action towards a change in policy.

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# CHAPTER 4

VULNERABILITIES PROMPTING USE OF TECHNOLOGY AND SCREEN BY MOTHERS OF AUTISTIC CHILDREN IN INDIA

LIVED EXPERIENCES AND COMPARISON TO SCIENTIFIC LITERATURE

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## ABSTRACT

Journeys of mothers of autistic children are challenging. This research aims to explore mother's vulnerabilities focusing on the example of screen use.

This study combined semi-structured interviews with 16 mothers of autistic children in Southern India and a scoping literature review that resulted in 24 articles.

In both the interviews and the literature analysis, there is a clear split in evidence and opinions about influence of screen media on child's development. The literature refers to a positive influence when co-viewing together with the child, it predominantly highlights improvements in speech and not in language. On the other hand, the interviews revealed that screens were used as a means of support, learning or language development tool or as a calming technique. Nevertheless, when compounded with the stress and helplessness women face when being mothers of an autistic child, it resulted in a negative use of technology and screen-time for their children.

Mothers of autistic children have clearly shown their vulnerabilities and indicated the feelings of being lost without advice with regards to use of screen time. This suggests a need for more research into how they can be supported.

**KEYWORDS:** Mother –Vulnerability- Autism - Influence - Technology - Screen-Time

## 1. INTRODUCTION

Autism spectrum disorder (ASD) is one of the fastest-growing childhood neurodevelopmental disorders across the world with an exponential growth rate spurt in the past 20 years.

(Maenner, et al., 2020). Despite the lack of evidence available on the prevalence in the Indian context, autism is estimated to affect over two million people in the country. Nevertheless, this has been shown to be most likely an underrepresentation of the true prevalence (Raina, et al., 2017; Rudra, et al., 2017).

Autism mainly affects areas regarding social interaction, verbal and nonverbal communication, and the development of social and language milestones. (Baishya, et al., 2018). Such effects are often under-recognised until at least a year after birth, and are hence not emphasized at the time of birth neither by healthcare professionals nor by significant members in one's family. (Ozonoff, et al., 2018). Differences in social, emotional and language development in the child are noticed only when they are significantly deviant or delayed from available childhood developmental checklists (Koh, et.al, 2016) but this usually does not happen before the child reaches one year of age. (Flensburg-Madsen, et al., 2019).

It has been long known that the journey of a mother of a child who has to yet been diagnosed with autism, becomes one of the most challenging ones. The prolonged process of trying and disheartening assessment as well as the diagnostic process in itself is only a beginning of the exploration into uncharted facets of life ahead (Mulligan, et al., 2012). Soon after a diagnosis, mothers of autistic children go through an intensely emotional phase that gives way to unanswered questions such as "*why me?*" or "*what did I do to cause this?*", prompt their curiosity about the diagnosis and causes of autism.

Despite the relatively low number of studies researching the family context of autistic children in India, there is enough evidence stating that having an autistic child can lead to significant physical, psychological, social and environmental impairments in family

functioning (Das, et al., 2017). Such effects are even more prominent among mothers as they usually stand as the primary caregiver in Indian households, which in turn highlights their need for social and emotional support (Singh, et al., 2017).

One of the areas of much debate in the clinical practice within the Indian context is the use of screen and technology as a potential support medium in general and in early years of a child's life specifically (Kardaras 2016; Salame, et al., 2020).

Some studies associate intensive early screen exposure to negative effects on a child's attention span, language development, emotional regulation, and socialisation. (Sadeghi, et al., 2019). There have also been studies in the field of autism, showing the existence of symptom improvements after the parents stop screen exposure for a few months. Regardless of this split in the evidence, it has often been recommended to restrict screen time in families of autistic children (Harlé 2019; Krupa, et al., 2019). The core of studies showing a possible effect of screen time, lies in the possibility of using screen media as a learning tool through the content that is presented (Greenhow and Askari 2017). This conflict in opinions can be very confusing for mothers of autistic children and thus further affect their vulnerabilities and uncertainties.

To provide mothers with the support they need, it is important to review the source and the lived experiences of their vulnerabilities. By looking at their experiences and opinions regarding screen use before and after their child's autism diagnosis, we aim to gain a better understanding of their struggles by highlighting perceptions regarding the content viewed and the reasons why they used screen media. We also expect to provide some clarity to health professionals on how to counsel parents, specifically mothers, regarding screen time use in their homes.

## 2. METHODS

This research is a sub-study of a broader qualitative research project on factors contributing to the empowerment of mothers with autistic children in India. During the interview collection process, a seeming confusion and insecurity about the use of technology was noted from the side of the mothers. This sparked the pathway to investigate the link between the Evidence Based Medicine (EBM) knowledge, the transfer of this knowledge to the mothers and the real-life factors that influence the use of technology. The resulting study consisted of two sequential research branches, namely the interviews with mothers, whose children were diagnosed with autism and an additional review of current scientific literature.

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## 2.1 PHASE 1: QUALITATIVE INTERVIEWS WITH MOTHERS

The qualitative data collection was conducted in two steps. First, in the form of a pilot study to navigate the pathways to empowerment and vulnerabilities of the mothers was conducted. As previously mentioned, one of the main themes that emerged in this pilot study was the use of technology. Consequently, in the later 15 semi structured interviews that followed, the mothers were specifically asked about their perceptions on the use of technology in the phase from childbirth to getting their child's autism diagnosis. The total sample size of the actual interviews was 16 mothers of which one was from the pilot study. Prior to collecting data, ethical approval was received from The BALM, Chennai (The Banyan Academy of Leadership in Mental Health), that has an independent ethical committee. During the study, explicit informed consent was obtained from each participant in either a written or oral form before any form of data collection. The participants were informed about the aim and procedures of the research, its implications, their rights as participants, and the fact that participation was entirely voluntary and could be stopped at any point in time.

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### 2.1.1 DATA COLLECTION

A poster was made inviting participation in the research and was circulated mainly via social media. From there on, a snowballing technique for the further participant recruitment was used. The participants were given a choice on how they wanted the interview to take place: face to face, telephonic, or WhatsApp voice records. All 16 participants chose telephonic interviews.

The interviews were semi structured, using open ended questions with a focus on the participants' lived experiences and perceptions. Following questions were included: Did you use any screen media or technology for your child before getting the diagnosis? What medium was used and why? Did you find it helpful? Did you find any influence of the same in your child's development? What made you use the screen mediums? The telephonic conversations were recorded using a call recorder application and were later transcribed verbatim. The completed transcripts were checked against the tapes for accuracy with additional focus on changes in voice and tones.

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#### 2.1.2 DATA ANALYSIS

The data analysis consisted of a combination between open coding and thematic analysis. First, open coding was used to identify main themes and concepts. These codes were then grouped and used for a more detailed thematic analysis.

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#### 2.2 PHASE 2: LITERATURE REVIEW.

As many mothers mentioned a strong confusion regarding the use of technology when parenting, a systematic search of scientific literature was conducted to explore the positive and negative effects of screen media on children's language development.

The literature search was conducted in November 2018 using the following three main databases: PubMed, EMBASE and PsycINFO. The search syntax included following terms:

"screen media", "information technology", "mobile device", "video" as well as synonyms for these terms in combination with "language development", "speech development", "communication" and related terms. This search combination is connected to the study population including key words such as "young children", "infants" or "pre-schoolers". Different combinations including search terms, MeSH terms and phrases of these three "categories" were made (see box 1).

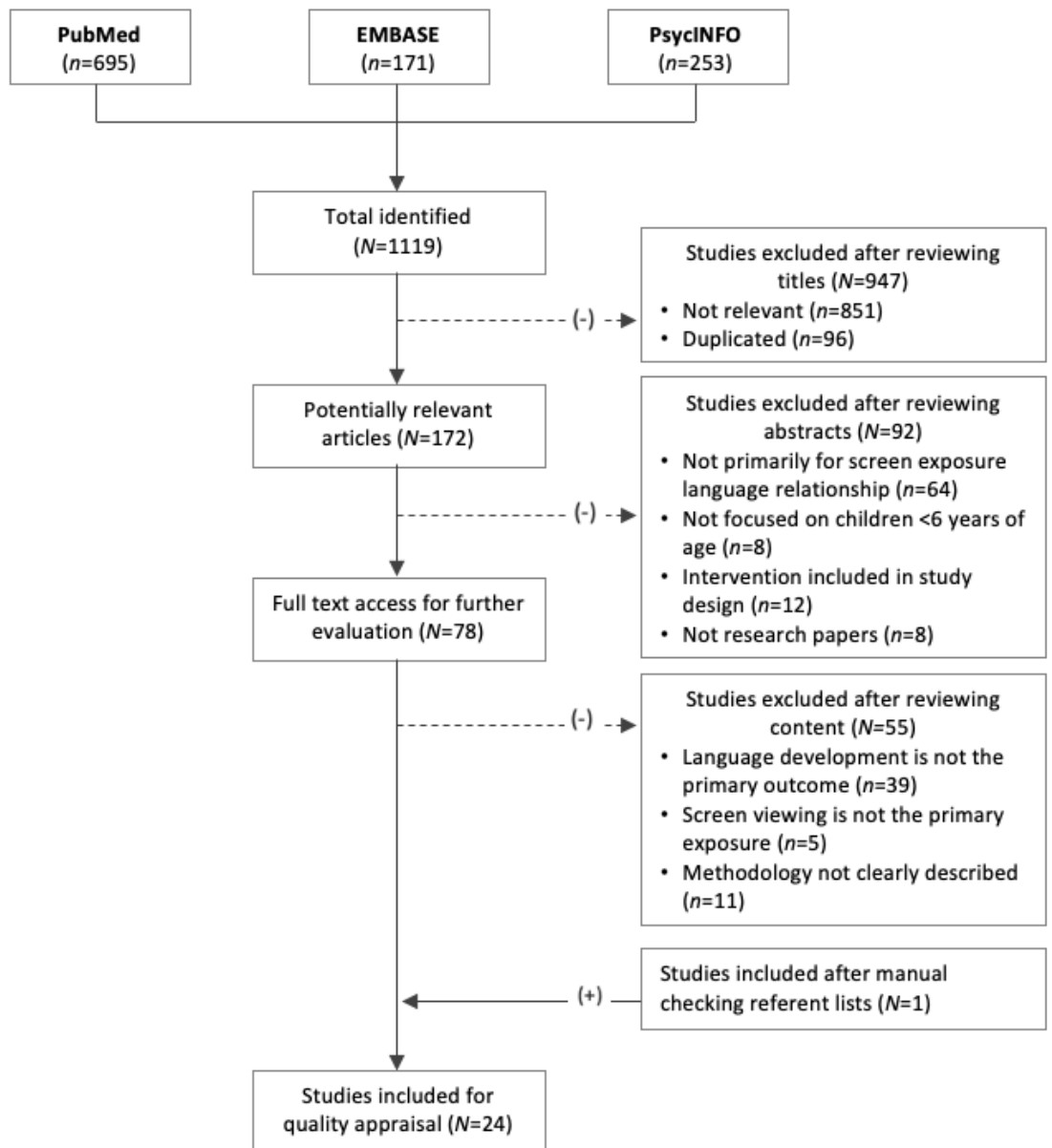
### 2.2.1 STUDY SELECTION

Identified studies were assessed based on the inclusion and exclusion criteria as seen in (Table 1). The database searches resulted in 1119 publications. After the removal of the duplicates, the titles and abstracts were screened. The full text of 78 articles was obtained for further review. This screening resulted in 23 articles meeting the inclusion criteria. In addition, one article was obtained through reference list searches of articles specifically focusing on the relationship between exposure to screen media and symptoms of autism. The full selection process can be seen in (Figure 1).

**TABLE 1 INCLUSION AND EXCLUSION CRITERIA IN THE APPRAISAL PHASE**

Inclusion		
Category	Criteria	Rationale for inclusion
Language	English	Mastered by author and common language among scientific publications
Type of publication	Peer-reviewed scientific article	Most reliable form of research dissemination (Pöschl, 2012). Authors are obliged to meet the high standards set by peers in their discipline
Time period	January 2008 – November 2018	Literature on technology use by young children emerged increasingly in recent years
Characteristics article	Full text available	Full text is needed to assess an article on quality, including design, study population, methods, etc.
Exclusion		
Category	Criteria	Rationale for exclusion
Language	Article not provided in English	-
Type of publication	Grey literature or research pending for publication	-

Time period	Articles published before - 2008	
Characteristics article	Article not available after request	
Content article	<ul style="list-style-type: none"> <li>• Article has an intervention design</li> <li>• Subjects (study population) older than 6 years of age</li> <li>• Article focused on cognitive and social development</li> </ul>	Articles with an intervention design alter the association between screen media and language development in children instead of presenting the current effects of screen media on children and are therefore excluded





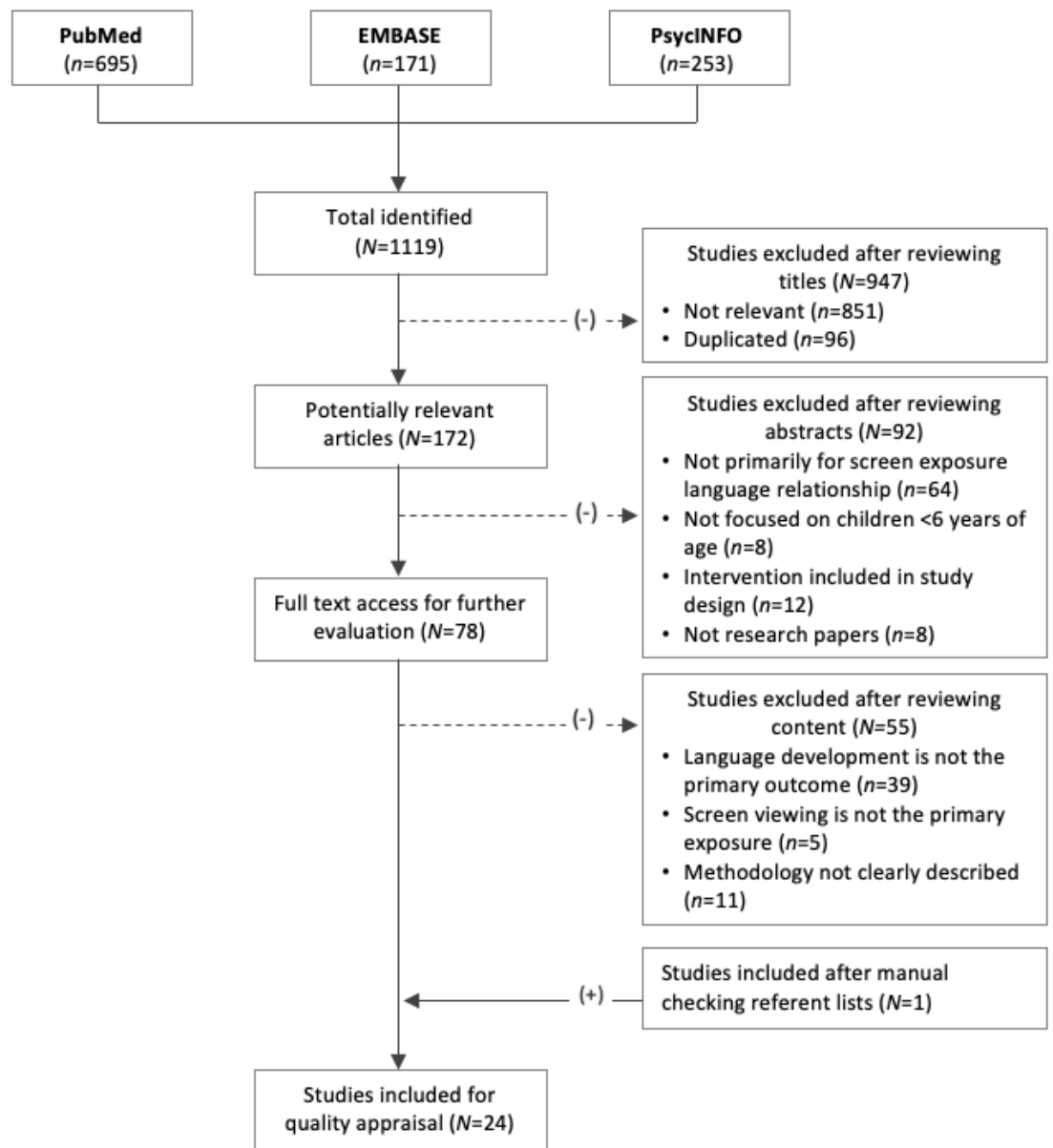


FIG. 1 SELECTION PROCESS OF INCLUDED STUDIES

### 2.2.2 DATA EXTRACTION AND ANALYSIS

An extraction table was used to assist the analysis of selected articles (Table 2). The extraction table contained several categories that helped to see similarities or conflicts between publications, but also to have an overview of all articles included. Subsequently, studies were grouped by association found (positive, negative, no evidence) and age of the target study population (younger than 3 years or 3 years and older) to identify patterns across

the paediatric age spectrum. The newly formed categories thus provided information on the kind of association or effect found and the age of the sample included. Due to their scarcity, articles including research on autism in relation to screen media exposure and language development were analysed separately.

To ensure the integration of different findings across multiple articles a thematic content analysis was conducted with the support of a qualitative research program (MAXQDA). First, a deductive coding method allowed us to see how the effect was established in one of the three categories: positive effect, negative effect or no effect. Moreover, the type of screen media exposure was coded. Second, an inductive approach was used to explore relevant concepts that triggered the effect and needed to be analysed in broader perspective.

**TABLE 2 CATEGORIES AND UNITS IN THE EXTRACTION TABLE**

<b>General</b>	Publication title
	First author
	Year of publication
	Country of study
<b>Research aim and focus</b>	Aim
	Type of screen media exposure
	Target study population
<b>Sample</b>	Sample size
	% of sample female
	Mean age in months
<b>Methodology</b>	Study design
	Study methods
	Predictor variable
	Confounding factors
	Outcome variable
<b>Findings</b>	Association found
	Main conclusions
	Negative association (yes/no)
	Positive association (yes/no)

### 3. RESULTS

### 3.1 QUALITATIVE INTERVIEW FINDINGS

This section describes the essence, themes, and sub-themes that emerged from the analysis of the experiences and perceptions of mothers of autistic children about the influence of technology and various types of screen on their children before they got the diagnosis of autism. The general demographics of the mothers who participated can be seen in Table 3.

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#### 3.1.1 DEMOGRAPHIC DETAILS

The final sample consisted of 16 mothers of autistic children. All the women were highly educated with 9 of them having a graduate and 7 of them a postgraduate degree. The participating mothers mostly had male children (n=14), who were born between 2000 and 2010. There were three outliers: two children were born before 2000, and one was born in 2012. The vast majority of children were diagnosed with autism before the age of 3 (n=11), while the rest (n=5) were diagnosed before the age of 5. Only one mother was living in a joint family, while the rest represented nuclear families. Given the convenience sample employed for the study, 15 of the mothers were living in South India, out of which 11 were living in Kerala.

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**TABLE 3 DEMOGRAPHIC DETAILS ABOUT PARTICIPATING MOTHERS**

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Total Number of Respondents	16 (6 were part of the pilot study as well)
Educational Qualification of the Mother	Graduates Post -graduates
Gender of Autistic child	Boys Girls

Year of Birth of Autistic child	: 2000 2000-2010 012
Ordinal Position of Autistic child	First born - Second born
Age of Diagnosis of ASD	Before 3 years After 3 years below 5
Type of Family	Nuclear Joint
Place of Residence	Kerala Karnataka Tamil Nadu Maharashtra

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### 3.1.2 TYPE OF SCREENS AND CONTENT USED

During the interviews, several types of screen devices and their use were mentioned. Among the most common ones were television and mobile phones (smartphones). None of the mothers mentioned the use of computers/laptops. Regarding the type of content, they mostly mentioned television advertisements, music videos, educational DVDs and cartoons.

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### 3.1.3 PROCESS OF SCREEN PROVISION

From the interviews, it became evident that there are several ways a child becomes exposed to the influence of screen devices. These ways vary in the level of intent for a child to get exposed to screens and the level of active engagement in doing so.

Some mothers noted that the child was not purposely exposed to screen mediums; it was just a coincidence that the television was on when the child was in the room. The mothers mentioned that the child initially started watching TV because the parents were doing so. In such cases, they did not recognize screen use as something out of routine as it was shown to

be embedded in their daily lives. *"They (referring to her children) used to watch the 'Thomas the Train' cartoon together. He (referring to autistic child) would come in front and watch it with great interest, laughing and playing...When he (referring to the husband) would come back home, he would watch TV instead of being with the children, so \_\_\_\_\_ (mentions the name of the child) would also do the same."*

On the contrary, other mothers mentioned that they purposely exposed their child to screens; thus, to either distract them or help them learn. The use of screen devices as a distraction tool was reflected in the active engagement of the mothers towards their children to use screens. While some mothers indeed relied on it to distract and entertain their child, others took a more engaging and interactive approach. *"I used to sit with him (referring to the child) and I would literally be explaining what is happening, to make it make more interactive. But if you ask me, yes! He had screen time, and he had a lot of screen time, but he preferred it and he was attracted to it"*

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#### 3.1.4 REASONS FOR SCREEN USE

In general, the main reasons for the use of screen devices were to calm the child, to use it as a distraction tool or to engage the child in learning. These reasons are often co-existent in the daily routines of the family environment.

Many mothers mentioned that they used screens due to the lack of time, energy and support of the others in their daily tasks. Even if the mothers themselves believed that screen exposure was not positive for the child, in the long run, they found themselves with no other tools in certain situations. For instance, when they still needed to finish work they often felt forced to allow for screen time. *"Most of the mothers satisfy the child's primary needs and then have to get back to their own household work or professional work. (...) I also did it (use screens), basically to finish off my work, especially when there is no support."*

Additionally, the use of screen media helped mothers under challenging situations often linked to social engagements. In such cases, the use of screen devices happened when alternative measures were either more complicated or seemed ineffective. The mothers then resorted to giving their child a screen, for example, their smartphone, to either calm them down or to distract them.

On another line, several mothers also mentioned that they felt the use of screen exposure as an optimal way to engage their child to learn as well as stimulate their interest in music. Here two different forms of the use of technology as a learning tool could be identified. The first one was as an actual resource for learning and the second one as a positive reinforcement reward. *"He (referring to the child) would not listen to what we say but he would listen to the TV advertisements. (...) He even learnt to clap hands by watching TV. Then, he started to imitate more things when we used the gadget as a reward. We will ask him to imitate something and if he did it, we would give (him) the gadget."*

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### 3.1.5 SCREEN USE AS A LEARNING RESOURCE

As mentioned above, there was a common belief that the use of technology resulted in the positive reinforcement of learning. While several domains were addressed with the use of screens as a learning tool, the most common one was regarding the language development of the child. Fourteen mothers mentioned that they used either special video materials, such as educational DVDs, or even common commercials in the attempt to expand the vocabulary of the child as well as increase and improve their speech production. *"I used TV as a learning resource. (...) The kid is not interested in real life, why can't we use his interest in TV into making him learn?"*

One of the mothers mentioned that she used the TV as a resource to teach her child to perform daily activities such as brushing or washing the hair. She noted that she had difficulties in explaining abstract skills to her child and managed to do so when using commercials in which people were performing said actions. Similar to this case, the use of screen devices for educational purposes was produced through a learning process of imitation. These imitations went as far as in one case, where a mother mentioned that her child was able to imitate the dialect and speech used in television. This ability declined and even disappeared after television time was excluded from the child's life.

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### 3.1.6 INCREASE IN THE USE AND ITS PERCEIVED CONSEQUENCES

Most mothers mentioned that they did not perceive screen use as a negative exposure as it was a daily routine in the household for others to use it. The exposure was not just for the child alone but also for the rest of the family environment. While it was shown that some children are more resilient to possible effects of screen use, others were more prone to them. Among the most commonly perceived adverse effects of the use of screen was the increasing dependency of the child to screen exposure. In some cases, this was even described by the mothers as a form of addiction. *"He wanted only that (gadgets) and started crying non-stop. When he didn't stop for half an hour, I was afraid and phoned my husband and said: I don't know why this child is crying for so long! That day, he cried for about one and half hours! It was on that day that we first noticed it (his addiction). He was really stubborn, and he only wanted that.... He wanted more gadgets."*

Even if mothers did not acknowledge the exposure as worrisome at first, it became evident when it was mentioned that the television was on most of the time in the household, even if the child was not directly watching or listening to it. Two mothers did not realize their child's addiction until they noticed unexpected and negative behaviours when screen time and

technology use was reduced. The mothers expressed such behaviours as them having difficulty to get the child to calm down or focus without the use of technology and crying for very long periods of time as well as tantrums when the screen was turned off. This new or unusual behaviour resulted in three mothers seeking professional help. *"When she (referring to the child) had the chickenpox she was full time in front of the TV as she could not do anything else. And after she recovered, we noticed a sudden change in her behaviour, she would not stop crying if we turned the TV off. That is when we took her to the doctor for consultation."*

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### 3.1.7 INSECURITY AND INNER CONFLICT (EXPLICIT AND IMPLICIT)

While all mothers indeed mentioned their child's use and access to technology via different forms of screens, most of them acknowledged regretting the excessive use of it in retrospect. Almost all of them mentioned the importance of being aware and informed of the possible effects of the use of technology and screen-time on children. *"I believe children nowadays are more addicted so mothers must know about the harmful effects (of technology)."*

Still, there were some mothers who perceived it as entirely positive and felt unsure about restraining the use of it. Although there were some differences in opinions in this regard, there was a general insecurity and confusion on whether the influence of screen use was indeed of positive or negative nature. *"I don't know about that ... I don't know if it was good or bad. I can only say it may be possible, because I don't know much, I don't know if it is right or wrong."*

However, when reflecting in retrospect on their experiences, mothers would not have known any other mechanisms on how to deal with stressful situations. Some mothers were judged by their relatives by being told that it was because of the use of screens that their child is autistic.



Regardless of the perceived external judgement from their social environment, the mothers mentioned that they would not have known how to cope with the lack of support and pressure on them and their role as mothers. *"Yes, I also thought, when we go somewhere, I need to talk to relatives and enjoy and so engage him in this... When we see the child's behaviour like this (inability to sit and play along with others) in front of others, we feel like we have gone a bit down in their eyes. So, he will not make any other issues. This is wrong, this is not right. That was all wrong. If we had dealt with the child without all these (gadgets and screens), it would have been better."*

When reflecting on their experiences, most of them mentioned that they would recommend future mothers to limit the use of screen devices or to find a balance to it. For instance, all mothers recommended an intermediate approach to the use of screens in which social interactions are actively engaged in the use of technology. They saw this as an intermediate approach to it, as they could not foresee a realistic withdrawal of their child's use and exposure to technology.

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### 3.2 LITERATURE REVIEW RESULTS

Out of the 24 studies included, ten reviews mentioned a positive association between exposure to screen media and language development (Ferguson and Donnellan 2014; Kirkorian, et al., 2016; Lee, et al., 2017; Lytle, et al., 2018; Myers, et al., 2017; Roseberry, et al., 2009; Roseberry, et al., 2014; Scofield and Williams 2009; Strouse, et al., 2018; O'Doherty, et al., 2011). These studies highlighted the importance of social interaction in the use of screen devices. Co-viewing with a parent and even video-chat were highlighted as viable options in which the exposure to screen goes hand in hand with social interaction. However, none of the studies presented an influence of screen use on receptive language but

rather only expressive language, which is the production of the sounds or repeating without understanding the meaning (Ferguson and Donnellan 2014).

The other ten studies showed a negative influence and mentioned the risk of a language delay in proportion with more hours of daily screen time (Byeon and Hong 2015; Chonchaiya and Pruksananonda 2008; Christakis, et al., 2009; Collet, et al., 2019; Duch, et al., 2013; Hermawati, et al., 2018; Lin, et al., 2015; Okuma and Tanimura 2009; Tomopoulos, et al., 2010; Zimmerman, et al., 2009). These studies specifically indicated that higher use of screen devices reinforces short attention and hyperactivity. It was also mentioned that screen inhibits conversational skills.

The remaining four studies did not mention any influence or effect of screen media on the language development of children (DeLoache, et al., 2010; Robb, et al., 2009; Taylor, et al., 2018; Richert, et al., 2010). Instead, one of the studies highlighted that only few of the words featured in the screen device were indeed learned, even with a substantial amount of exposure (DeLoache, et al., 2010; Robb, et al., 2009). Along with this, one of the studies even concluded that screen media has no real impact on the language and vocabulary size of children (Taylor, et al., 2018). These results are somewhat counterintuitive in relation to the other studies found.

#### **4. DISCUSSION**

In this paper, the authors explore the various facets mothers of autistic children underwent during the period between childbirth and the diagnosis of autism of their child. By looking at each mothers' experiential journey, the influence of screen media stood out. As such, the multiple reasons why mothers tend to use screen media with their children and their experiences with it were presented.

In line with additional literature on parenting autistic children, a blend of traditional, modern and creative resources, such as the use of technology, to manage and cope aspects of their child's disability is highlighted (John and Roblyer 2017). This paper shows that one of the biggest reasons why mothers tend to use screen media is the helplessness affecting their journey from childbirth to the diagnosis of autism of their child. The lack of awareness about how screen media influences a child's development and scarcity of "better" alternatives stand as crucial points in the increased use of screen media. This lack of awareness is compounded by the vulnerability women face, especially when being mothers of an autistic child. These two aspects negatively influence the maternal agency regarding taking action for their child's health.

The additional literature review conducted allowed us to place and contrast the results from the interviews to the broader body of evidence on the topic. Overall, the literature review did not show any conclusive evidence of either positive or negative effects of technology or screen media on children. Positive influences concerning language development were mostly about the enrichment of the child's vocabulary. However, the use of screen media was shown to not have any impact on the social communication skills among children which is primarily a deficit in autism (Ferguson and Donnellan 2014; Zimmerman, et al., 2009). Additionally, the conduction of the literature review highlighted that the limited evidence available predominantly focuses on Western countries. This gap in knowledge was even more profound on the experiences of autism and screen use.

The abovementioned split in opinions and evidence on the effects of technology or social media on autistic children were also prevalent in the interviews. While parent's help-seeking behaviour and coping mechanisms are strongly influenced by their beliefs about the disorder and the expectations about their child's future; often, when looking back in retrospect, they

realize the futility of their efforts too late as they see no real results from them (Juneja and Sairam 2018). This was also reflected when many mothers spoke about positive influences during their lived experience; however, they also spoke about them negatively when reflecting on them in retrospect. In line with the latter aspect, they advised future mothers to keep their children away from screens and technology exposure. In the broad sense, it meant that during their lived experience a lot of mothers did not see alternatives but in retrospect, they regretted their decisions. Even though they do not see it as a cause of autism they did feel there was an influence.

Many mothers linked the use of screen media to not only individual experiences, but broader family dynamics. They, therefore, mentioned relying on the use of screen-media to get daily routines with their child going on and be able to perform specific actions such as sitting their child down, feeding them or socially interacting with them as well as a teaching or learning tool. In line with this, Desai and colleagues (2012), highlight parents' and especially mothers' fundamental concerns when taking care of a child with autism. Such concerns lie in learning to meet new and unfamiliar challenges, caring for their child's basic needs, as well as finding engaging niches with a sense of belonging to their child in their everyday life (Desai 2012).

The interviewed mothers also mentioned that the lack of support they experience in taking care of their child, the household and most of them also professional work, plays as an enabler in the increased use of technology devices to cope with their child. While they highlighted multiple times that they were unsure about the possible effects of screen media on their child, they still relied on this option out of a lack of any other better means to cope with their child. Some of them even blamed themselves or their spouses when reflecting on it in retrospect. Literature on the vulnerability of parents of autistic children highlights the feelings of helplessness and uncertainty of parents when taking care of their child with autism

(Depape and Lindsay 2015). Indeed, becoming a parent calls for a change in roles that can be identified as a crisis. However, the birth and diagnosis of an autistic child adds a situational crisis that goes beyond the generic parental roles. Especially for mothers, this change in roles is even more drastic and traumatic, as the images and expectations of motherhood constructed by society are based on "healthy" children (Vidyasagar and Koshy 2010). In line with this, some mothers mentioned how they did not want to be judged as a "bad mother" for not being able to manage their own child, and hence resorted to screen media as a coping mechanism during social interactions or gatherings.

Most interviewed mothers stressed new-becoming mothers about the importance of knowing the possible effects of screen media on their child. Similarly, to the results of the literature review, mothers who mentioned positive influence were all talking about co-viewing or using it with ample social interaction as well. Additionally, most of them reached for the use of technology as an almost desperate attempt to find a solution as the child was not responding to conventional methods of teaching and learning. This clearly shows a lack of proper guidance on how best to work with the child or not knowing when to seek professional help. Nevertheless, proper structures or information sources that can support families and can be translated to the Indian context are missing (Juneja and Sairam 2018; Desai 2012; Divan, et al., 2012). Parenting and motherhood sharply differ depending on their societal and environmental context; for instance, Indian parenting is starkly different from the Western hemisphere (John and Roblyer 2017). The lack of support for parents and especially mothers as the primary caregivers of autistic children within the Indian context inhibits mothers to take their maternal role in a supportive and informed way. This lone caregiving occurs in the context of shared patriarchal parenting that is typical for the Indian family dynamics and context (John and Roblyer 2017). As shown through the experiences of mothers, they end up taking their own measures that they think are best for their child and situational context.

All of the above is indicative that we need more research on the effects of screens on young children. We also need more research into the sources of vulnerabilities of mothers of autistic children and how they can be addressed. The participating mothers of this study did not have enough knowledge about the influence of screen media which was reflected in both their perceptions and practices. Their sometimes even desperate turn to social media in order to cope with the lack of support - in raising their children, maintaining a home and being professionals - highlights their urgent need for support not only within the family, but also within the health structure. We need policies and guidelines for professionals to focus more on empowering mothers and thereby their families and children.

## **5. CONCLUSION**

The ultimate aim of the study was to gain a better understanding of the vulnerabilities of the mothers through their lived experiences regarding the use of screen and technology before they got a diagnosis of autism for their child. It was clear from the interviews that mothers did not have a lot of information or support when caring for their child, this resulted in stressful and uncomfortable situations in which the easiest methods, such as the use of technology to distract their children, were taken to protect themselves. Making matters even more confusing for them, is the absence of clear scientific guidance on the proper use of technology. This lack of evidence inhibits mothers to make informed decisions around the topic. The general advice given by both, the interviewed mothers and the available literature on the topic, has been to actively participate and co-watch when using screen media with a child. However, from the interviews, it was clear that this was done in a minority of cases. The reasons for this are partially due to the aforementioned lack of knowledge and opportunity for informed decision making, and partially due to the vulnerable position in which mothers are situated. Most mothers in retrospect regretted their decision for having used screen time the way they did and in their advice to future mothers was to use it wisely. It

is therefore highly recommended that there are more studies specifically to assess the influence of various types of screen exposure in children below 6 years.

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# CHAPTER 5

## EXPERIENCE OF INDIAN MOTHERS FROM A CHILD'S BIRTH TO THE DIAGNOSIS OF AUTISM: ROLE OF FAMILY AND PROFESSIONALS

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### ABSTRACT

Supporting an autistic child is demanding for families and especially mothers. The aim of the study was to review the experiences of mothers of autistic children in South India from birth to autism diagnosis in order to identify the gaps in support for these mothers, as well as make recommendations. Semi-structured interviews were conducted among 15 mothers in South India. The findings were analysed using a combination of open and thematic coding. Overarching themes emerged regarding knowledge of child development/autism, and trusting one's instinct. Additional themes were the role of significant others and their influence on the mother's agency when seeking help, as well as the role of health professionals in the diagnostic process and in health education. Mothers indicated feelings of being lost and powerless and a wish for more support in different areas. These can be used to create a more fitting support.

**KEYWORDS:** autism, Indian mothers, diagnosis, family, professionals

### 1. INTRODUCTION

Autism Spectrum Disorder (ASD) is a neuro-developmental condition that is increasingly diagnosed worldwide. In India, however, there is no official estimate of the prevalence or incidence of this disorder (Chauhan et al., 2019; Venkatesan, 2015). According to current research, autism prevalence in India could vary between 0.15% and 0.23%, although this is probably an underestimate (Raina et al., 2017; Rudra et al., 2017).

Although there are few studies on the family context of autistic children in India, there is enough evidence that having an autistic child can lead to significant physical, psychological, social and environmental difficulties for the family compared to families of children with other disabilities (Perumal et al., 2014). Having an autistic child has been shown to have a profound effect on the lives of these families (Woodgate et al., 2008), which in turn, affects the prospects of the child itself. The parents of children with various developmental disabilities have a greater risk of being overburdened and of social marginalisation, putting them at higher risk of internalised stigma (DePape & Lindsay, 2015; Mak & Kwok, 2010)

Despite the recognised importance of early intervention in autism for both the child and its family, the initial recognition of the symptoms of autism in India is rather later than in other countries (Daley, 2004; Mahapatra et al., 2019; Venkatesan, 2015). Previous research has found that local cultural beliefs may have a negative influence on families' help-seeking behaviour (Desai et al., 2012; Mahapatra et al., 2019). Parents' lack of awareness, knowledge, and understanding of autism are major factors that contribute to late recognition of symptoms, help-seeking behaviour, and final diagnosis; all of which eventually result in poor prognosis and complications for the child (Mahapatra et al., 2019). In order to address this, focus on the various experiences of Indian mothers during the critical period between giving birth and their child's official diagnosis of autism. By giving these mothers a voice, we aim to gain insight into their shared experiences with family members and health professionals regarding the period before diagnosis, through the lens of a family systems theory (Patterson, 1988). The model highlights empowerment as a helpful coping strategy that can assist in balancing the demands and pressures exerted on the family, as this has been associated with an array of positive outcomes for families with children with disabilities (Nachshen & Minnes, 2005; Patterson, 1988).

Such frameworks and models are based on non-Indian contexts and might, therefore, overlook the possible influence of certain cultural factors. The traditional forms of the family in the Indian context, as well as conservative gender roles, place women as the primary caregivers in the household, rendering them more susceptible to the negative effects of having a child with a neuro-developmental disorder (Bourke-Taylor & Jane, 2018; Brezis et al., 2015). Not only do women have to define themselves in the role of becoming mothers, but some also have to navigate being the mother of an autistic child. Thus, this study focuses on enlightenment as a concept that precedes empowerment. Enlightenment is seen as the first step of being aware of what is happening and why and what can be done about it. Empowerment is viewed as feeling confident and capable of using the knowledge and awareness gained during the enlightenment phase to change from where you are now to where you want to be.

## 2. CONCEPTUAL APPROACH

In order to capture the experiences of mothers of autistic children from giving birth to the diagnosis of autism, a holistic perspective of the complex and multifactorial environment of such mothers is needed. The Family Adjustment and Adaptation Response Model (FAAR), a family systems theory, offers a relevant framework for analysing and understanding the environment of families with autistic children, as empowerment has been found to be a supportive coping approach (Patterson, 1988). Empowerment is defined as “an intentional, ongoing process through which people lacking an equal share of valued resources gain greater access to and control over those resources” (Nachshen, 2005).

Family systems theories maintain that what affects one family member will directly and/or indirectly affect all other family members within the same environment (Bowen, 1966). This model examines only the dynamics within the family’s personal and interpersonal environment. Mothers of autistic children are not only influenced by their family environment,

but also by the perceptions, opinions, and actions of a broad range of people in addition to their immediate family, such as extended social relations (i.e. friends and neighbours) and health professionals. Bronfenbrenner's (Bronfenbrenner, 1992) socio-ecological approach situates these mothers within an even broader dimension beyond the family.

Bronfenbrenner's model is similar to the FAAR in looking at both the personal level, namely the mothers, and the interpersonal level, such as their families and extended relations. It also emphasises the institutional level – in this case, health professionals and institutions – and the external level, which highlights policy aspects. Although this model makes it possible to examine the different levels and the interactions between them, it does not account for the individual's experience within them.

In contrast, the Knowledge, Attitudes and Practices model (KAP) attends to its role and influence on individual experiences on the person affected, their social contexts and health professionals (National Academies of Sciences and Medicine, 2016). The KAP of these actors can influence the child's development and the autism diagnostic and intervention process. For the purposes of this paper, "knowledge" refers to facts, information and skills gained through experience or education and therefore understanding an issue or phenomenon. "Attitudes" relate to cultural beliefs, and "practices" refer to the behaviours or approaches the actor takes (National Academies of Sciences and Medicine, 2016). We placed these key aspects of the KAP model as cross-cutting factors throughout all levels of Bronfenbrenner's socio-ecological model in order to show the role and influence of the various actors and structures within the layers of the model.

In addition, to specifically navigate and understand the mother's experiences from childbirth to diagnosis, this paper also refers to Harden's nursing education model to follow mothers in their individual process of "enlightenment" and "empowerment" to "emancipation" (Harden,

1996). In the context of our research, enlightenment means understanding the role as mothers as "who they are and their own frame of reference"; empowerment means to allow them to change who they are as mothers and who they want to become for the benefit of their child by critical self-questioning, their frames of reference and their situation. Finally, the whole process is characterised as emancipation, referring to the actions that helped them "become" who they want to be. Harden's model strongly focuses on empowerment through knowledge and education and can, therefore, be closely linked to how the KAP and the ecological environments influence women's experiences from the birth of a child to its autism diagnosis.

### 3. METHODOLOGY

This qualitative study presents the findings from 15 semi-structured interviews with mothers of autistic children in India, mainly from state of Kerala as well as Tamil Nadu and Karnataka. All mothers had at least one child who had been diagnosed with autism.

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#### 3.1 SAMPLING PROCEDURE

Participants of this study were contacted through the parent support and advocacy group 'Together We Can', based in Kochi and Kerala, and from the Autism Club in Kerala. Digital posters were created and posted on the social media sites of these groups in order to disseminate information about the study and recruit participants. Given the sensitivity of the topic and the main author's affiliation with these organisations, a combination of purposeful and convenience sampling methods were used. In order to reach more participants through the interviews, a snowballing technique was added to the sampling method.

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#### 3.2 RESPONDENTS

The respondents were all mothers with an autistic child. There were no explicit exclusion criteria, except for being able to speak in English, Hindi or Malayalam.

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#### 3.3 DATA COLLECTION

The data collection began in 2016, with seven mothers known to the researcher and who gave consent to participate in a pilot study. The mothers were asked to share their experience from the time their child was born to the present. This study provided insights on using Bronfenbrenner's socio-ecological model, and enabled us to frame the interview guide with open-ended questions where mothers were asked to speak about their own personality and knowledge, and their experiences with significant family members, professionals and government agencies.

For both the pilot and the current study, all mothers were offered a choice of either an in-person or a phone interview. Mothers who consented to reveal personal details sent them via email or WhatsApp text messages.

An interview guide was developed for the current study following insights from the pilot study. A total of 15 mothers gave their consent, which was recorded during the interview and via email or WhatsApp. All interviews were conducted by phone. Of the 15 mothers who participated in this study, five also participated in the pilot study.

The interview guide included open-ended questions where the mothers were encouraged to share their thoughts about the role of individual factors, significant family members, professionals, and the government agencies, in acting as facilitators or barriers to reaching an early intervention and diagnosis of their child. Mothers were also asked to provide examples from their own lives on both the positive and negative influences of each factor, as well share their wishes in retrospect.

In addition, the following demographic details were collected from the mothers: age of mother and autistic child, age of the child at the time of diagnosis, mother's education, employment and marital status, details of siblings, type of family, and residential address.



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### 3.4 DATA ANALYSIS

The interviews were transcribed verbatim. The analysis had several stages: first an open-coding analysis was conducted, during which several themes emerged separately for each stakeholder: the individual, the significant family, professionals, and the institution. During the initial stage, it was noted that several recurrent themes pertained to the roles of each of the stakeholders, namely: knowledge, opinions and perceptions, and behaviour. We thus decided to perform the second step of the analysis, namely applying the Knowledge, Attitudes and Behaviour approach during a thematic analysis. The outcomes of both analyses were compared and combined as the final results.

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### 3.5 ETHICAL CONSIDERATIONS

Prior to the start of the data collection, ethical approval was received from The BALM (The Banyan Academy of Leadership in Mental Health) in Chennai, whose members constitute the Indian Ethical Committee. During the study, explicit informed consent was obtained from each of the participants in either written or verbal form before any form of data collection. The participants were informed about the goals and procedures of the research, its implications and their rights as participants, as well as of the fact that participation was entirely voluntary and could be stopped at any point.

## 4. RESULTS

After presenting the main characteristics of our sample, we discuss the paths towards the diagnosis and how the mothers experienced them. First, the reflections on the start of their journey to *redefining their role as mothers* is explained, which begins with them *noticing differences* in their child. Second, the reflections on what happened when they sought *support from family members* is explained. The following section explains their experiences when *seeking professional help* and the process leading up to the diagnosis. Section four explains what they feel the government could do to make a positive difference to these experiences

and thereby *help future mothers*.

4.1 DEMOGRAPHICS

4.1.1 TABLE DESCRIBING DEMOGRAPHIC DETAILS OF MOTHERS WHO PARTICIPATED IN THE STUDY

Age of mother (years)	Education level of	Working status	Marital status	Location	Nr. of children in the family	Nr. of children with autism in the family	Ordinal position of the child with autism	Age of the child (years)	Age at the time of ASD diagnosis (years/months)	Gender of child	Type of family
56	Graduate	Professional	Married	Kerala	2	1	2 <sup>nd</sup>	26	2y6m	Male	Nuclear
37	Graduate	Professional	Married	Kerala	2	1	1 <sup>st</sup>	11	4y6m	Male	Nuclear
42	Post-graduate	Professional	Married	Kerala	1	1	Only child	16	1y6m	Male	Joint
51	Graduate	Professional	Married	Kerala	2	1	2 <sup>nd</sup>	17	2y6m	Female	Joint
39	Post-graduate	Professional	Married	Karnataka	2	1	2 <sup>nd</sup>	11	3y	Male	Nuclear
52	Post-graduate	Professional	Married	Kerala	2	1	2 <sup>nd</sup>	19	3y3m	Male	Joint
42	Post-graduate	Professional	Married	Maharashtra	2	1	1 <sup>st</sup>	16	2y10m	Male	Nuclear
36	Post-graduate	Professional	Married	Kerala	2	1	1 <sup>st</sup>	10	2y	Male	Joint
47	Post-graduate	Professional	Married	Karnataka	1	1	Only child	14	3y3m	Male	Nuclear
44	Graduate	Homemaker	Married	Kerala	1	1	Only child	14	3y3m	Male	Nuclear
45	Graduate	Homemaker	Married	Kerala	1	1	Only child	10	1y9m	Male	Nuclear
49	Graduate	Professional	Married	Tamil Nadu	2	1	2 <sup>nd</sup>	18	4y6m	Male	Nuclear

*'Making Lived Experiences Matter'*

<b>44</b>	Post-graduate	Professional	Married	Karnataka	a	2	1	2 <sup>nd</sup>	12	2y6m	Female	Nuclear
<b>37</b>	Graduate	Professional	Married	Kerala		2	1	2 <sup>nd</sup>	7	1y8m	Male	Nuclear
<b>45</b>	Post-graduate	Professional	Married	Kerala		1	1	Only child	18	2y6m	Male	Nuclear

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#### 4.1.2 MAIN CHARACTERISTICS

The study sample came from four locations in southern India: Kerala, Karnataka, Maharashtra, and Tamil Nadu. The age of the respondents varied between 36 and 56 with the average of 44 years. It is important to note that due to the convenience sample, all study participants had a graduate or postgraduate level of education, and only two were full-time mothers. All 15 mothers were married and had biological children except one, who adopted the child at seven months of age. Only four mothers were part of a joint family, while the rest lived in nuclear families.

All of them had only one autistic child. The majority of participants had two children, only one of which was autistic. For half of the mothers, the autistic child was their first child and for the other half, the child was their second. Of the autistic children, only two were girls and the rest were boys. There were no significant differences mentioned in the experiences of mothers with an autistic daughter or son. At the time of the interview, the autistic children were between seven and 26 years old, with an average age of 15. All of the children were diagnosed with autism diagnosis no later than the age of four and a half and most a year earlier. Further details can be found in Table 4.1.1

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#### 4.2 THE START OF THE JOURNEY: (RE) DEFINING THE ROLE AS MOTHERS – NOTICING DIFFERENCES

We start the journey of the mothers at the turning point, marked by the recognition and understanding that their child's development is "different" from others. While speaking about their experiences, most mothers started with how they first noticed differences in their child. Almost all of them mentioned delayed or abnormal social and emotional development. Some spoke about the child not making eye contact and social smiles, while others mentioned a

lack of connection while trying to interact or play with their baby. In some cases, these first symptoms were noticed as early as three months, while in others, it was when someone else pointed them out to them a year or two later: “[...] when he was three months old [...] the baby was not giving eye contact when we would pamper him [...] and whatever I would do, he would not respond [...] He would not look at our face[s] and respond.” (M8A)

Many mothers attributed first attributed these differences to a hearing difficulty. This led to confusion as generally hearing seemed to be fine, which led them to keep guessing what was wrong. None of the mothers could pinpoint exactly the area of difficulty and they mentioned observations such as: “*something is amiss*”, “*it felt different*” or “*something was wrong somewhere*”. MP6: “[...] When we would call him [the child], he would not respond. We knew he could hear because when we would play music, he would run to the front of TV, so there was nothing wrong with his hearing. But we knew something wrong somewhere.”

In general, all mothers spoke about a lack of knowledge of what to expect in terms of social and emotional child-development skills. Initial symptoms were not recognised as such, as they were not perceived as delays or deviances. This resulted in them not seeking help and just continuing in their routines: “*I did not know that interactions and such things are significant. I did not even know it is a milestone [...] he [the child] never looked at the face, but I thought that was okay*” (M3A).

When mothers had previous knowledge of the basic milestones of child development and how to work around them, they felt that they could quickly identify the differences in their child. Such knowledge was mentioned as coming from various sources, either from experience of having another child, or from secondary information like reading materials, the Internet, or opinions from family members or professionals: “*I had registered [on] a site online and there they say your child should have certain features during a specific age, so I knew where he was delayed.... All those helped me*” (MP2).

What stood out in most of the statements was: *"if only they had told me,"* or: *"had I known earlier,"* which mirror the lack of knowledge that led to their experiences. Most mothers identified their lack of knowledge on the topic as the most prominent and negative influence on their experience from giving birth to their child's autism diagnosis.

The form of knowledge most highlighted concerned child development, specifically the emotional, social, and language milestones. They explained how, due to the lack of knowledge about the importance of interacting and providing the child with an emotionally and socially stimulating environment, they missed certain early-warning signs, which would have enabled them to act earlier: *".....I did not know that it was important to tell all this to the doctor...Maybe if I had known a bit more I would have done something about it earlier ..."* (M2).

Most mothers regretted having focused mainly on the main motor developmental milestones, as they were not as aware of the child's social and emotional development needs. They wished they had been educated about it earlier, which would have enabled them to identify any differences in their child early on: *"...his hands and legs are growing well., we don't feel anything is wrong...we did not know any symptoms..."* (M15A).

Mothers spoke about the need for having some knowledge about autism. They had different views on autism based on aspects that were mostly mentioned in their informal information sources. Autism was mostly portrayed as a child meticulously lining up toy cars or struggling with changes in the daily routine. Overall, a lack of awareness of autism and its various manifestations delayed mothers from seeking help and, therefore, also diagnosis and early intervention.

Most mothers said that they had never heard of autism before they received the diagnosis, while others were familiar with it due from television or magazines, but did not relate this

information to their own child: “... I [hadn't] even heard that word before. When it came on a TV programme, I heard about it. My child was around three years [old] then, yet I didn't recognise it. An illness called autism is all that I thought. I thought it was a disease...” (M2).

Continuing from this phase of confusion and apprehension, mothers then spoke about their experiences when they attempted to voice their concern and seek support from significant family members.

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#### 4.3 SEEKING SUPPORT - ROLE OF SIGNIFICANT FAMILY MEMBERS

Many mothers raised their concerns with their social support network, starting with family members. Though most mothers interviewed lived in a nuclear family, all of them spoke about both positive and negative experiences with significant family members –mostly their husband, parents, or in-laws. Some spoke about siblings or other relatives of their own or their husband.

Despite mothers having noticed differences and understanding the need for intervention, they described how they could not proceed because of resistance from other family members. Not only did they battle with their own uncertainties, but they also had to struggle to convince others around them: “... I would have started early intervention if I had not waited for my husband also to agree so we waited another six months to start...” (M13A).

Many participants spoke about how their family members brushed aside their worries and anxieties, albeit with good intentions. The mothers said that although they felt consoled, they felt that nobody trusted their intuition. Many mentioned how they respected their own parents' guidance, but in retrospect they felt that they should rather have trusted their own instincts: “When I used to express my doubts, the elders used to say he doesn't have any



*problem[s] as you think...so I also felt that... the grandparents are people who have already brought us up as children and are experienced..." (MP2).*

Some mothers said that family members blamed them for not paying enough attention to their child. Others mentioned that their work schedules or even their effectiveness as a mother were questioned: *"...when I was working from home at that time... everyone said: 'see you are working from home, you are always busy sitting at the computer and that is why he is like this...he is not speaking...you are not spending time with him...' "(M12A).*

Some mothers disclosed that their careers and choices made during pregnancy were blamed. Some even added that when they found the strength to voice their concerns and take action, they were further blamed as being the one needing help: *After three months I noticed something was amiss... but every time I kept telling, everybody said my brother was also like this ...or some or the other reasons were given... but at two years finally I insisted that we should show the child to a doctor... then my relatives considered me to be in a depressed state. They felt that I had some problem... (M8A).*

In contrast to this, other mothers had positive experiences with family members: immediate relatives were first to notice the difference and urged them to seek help. Some mothers described how a few family members were forthcoming with support, and took the lead in opposing family members who did not understand the issue. The mothers felt that this was a great relief and saved them from the dual struggle of not understanding her own child and also defending their position with their own close family members: *"... My husband's brother, on seeing my anxiety daily....told me to read about autism ...he was the one who finally suggested and he talked to my husband first and convinced him and that is how we went to the doctor first" (M2A).*

Most mothers described the lack of support from their direct environment as very discouraging and negatively affecting their self-confidence and intuition. Examples were mostly given in relation to family members. Lack of support in the household, alongside poor awareness of the importance of spending quality time with the children, led to resorting to using screens such as television, mobiles or computers in order to keep the child engaged instead of interacting with them: *"...they [family members] should spend a lot of time with the child and avoid TV as much as possible... If the family is with us, we can move from there [kitchen] a bit..."* (MP1).

The mothers who said they trusted their instinct and acted upon it felt empowered, while those who did not spoke about how they wished they had done so. On the contrary, reactive attitudes like a lack of trust in one's instincts were closely linked to low self-confidence, poor support, and the absence of trusting relationships with their immediate environments. Those who had a reactive attitude were unable to seek help immediately, and it took them longer to realise and accept the fact that there was a problem, and that their child needed help. They highlighted the lack of knowledge among the family members too, which made it difficult for them to offer the necessary support to the mother: *"...Yes, for me. At that time, nobody seemed to understand me. I was stressed. My doubts went on increasing. I was afraid, because the features were so matching... Some said 'this is because you are reading such things'"* (M2).

In addition, when their anxieties were not allayed and delays or deviances in their child's development appeared to increase, they spoke about seeking professional help, which ultimately led to a diagnosis.

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#### 4.4 THE PROCESS OF RECEIVING THE DIAGNOSIS: SEEKING HELP – ROLE OF PROFESSIONALS

As most of the mothers were asked to “give it more time”, they all waited approximately six months to a year from when they first observed differences in their child’s development to seeking professional help. Here, we focus on the event triggering them to seek professional help and receiving an actual diagnosis. We also discuss the experiences of the mothers in this process.

One of most recurrent and common themes that came from all mothers when speaking about professionals was that they had to consult multiple professionals before receiving some clarity of how to move forward, whether to obtain the diagnosis or start some intervention. Mothers spoke about how professionals either dismissed their doubts, confidently denied any difficulty in the child, or spoke vaguely about why the issues were present. They also spoke about the strong cultural beliefs and stereotypes that influenced others to dismiss the fact that there was a genuine need for intervention. The final conclusion was that the mothers did not have a choice but to go ‘doctor shopping’: *One paediatrician said the child’s father talked late, so maybe that is why and also because he is a boy, so boys tend to talk late... I went to another paediatrician but she didn't diagnose it as autism though I had my own doubts, but she clearly said no, so then I too was in denial and waited another 3 months and went for the next opinion ... (M9A).*

Almost all mothers mentioned that the first professionals they consulted were paediatricians, who almost never asked them about social and emotional milestone development in any of the visits. Mothers stated that their worries were not considered seriously, though they were proved right later on. However, they did mention that if the paediatricians were unsure or needed more clarity, they referred them to other specialists such as neurologists, psychologists or speech and language therapists. Some were referred to developmental paediatricians, too. A few mothers described how the first symptoms were noticed by pre-school teachers, but how this was conveyed to the mothers made a significant difference in

whether or not the mother would seek help. Mothers also admitted that they sometimes did not want to hear the truth, as it was painful. Thus, it was important for professionals to be extremely empathetic and tactful in addressing concerns about young children to their mother: *"...the madam [preschool teacher] told me "my child is simply sitting in a place and he does not interact with other children and he likes to sit alone always...this was one week after he was admitted... I felt sort of angry towards her...and took him to the previous school. Even now I feel guilty about what I have done..." (MP2)*

In some cases, professionals mentioned the term 'autism', but only as a vague doubt, with no clear direction on what to do next. The suggestions offered by professionals were often highly general, such as: "enrol in a school" or "talk more to the child", which did not provide them with much clarity. As a result, they came back with little or no concrete idea about how to intervene and work with their child: *"...at one and a half years but we came off from there saying nothing is wrong, and we went back after three years. If there was that awareness, maybe we could have started early..." (M1A).*

Mothers spoke about the lack of knowledge not only of themselves and family members, but also of professionals. They remarked that especially paediatricians, with whom they regularly consulted, did not guide them adequately. Despite regular consultations in the early years, they felt they were asked to educate paediatricians about their child's social and emotional development. They would have liked such checklists to be mandatory and that paediatricians ask and offer better guidance, paying attention to reaching developmental milestones and giving appropriate advice in the event of delayed or unusual development. They also mentioned that if paediatricians were not equipped to handle cases of autism appropriately, they should refer mothers to other professionals rather than completely dismissing their worries....*It would be better if they have a scale to measure social and emotional*

*milestones too. I used to take him every month, but nobody told me. They could have given me a hint at least...I think some of the doctors say foolish things like it is 'over anxiety' of the mother. No practical solutions were given (MP2 referring to her visits to a paediatric clinic).*

The tedious referral process extended for months or even years until they finally obtained the diagnosis. Many mothers attributed this to their lack of knowledge about autism as many had not previously heard of it. Some mothers described how often up to three years were lost, as professionals failed to explain in detail what can be done: ....*one doctor did many tests... he asked us to go back and put him in school..., and let us just wait and watch... later another doctor said it would be infantile autism but did not explain what it meant... We were also hearing the term for the first time. And because it was not told forcefully, we didn't take it seriously and we came back... (MP6).*

Many mothers acknowledged that they first learnt about the term 'autism' not from clinicians, but from educational material in the hospital waiting area before obtaining their child's diagnosis: "*...we were waiting outside... reading all the posters put up outside the clinic and almost all symptoms and features mentioned were similar to what my child was showing. That is when we first heard the word 'autism' "* (MP1A).

All the mothers said that there was extensive delay in intervention due to the lack of knowledge both among themselves and among professionals, in combination with clinicians' inability to guide them in a timely and appropriate fashion towards an early intervention and/or diagnosis.

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#### 4.5 WHAT CAN THE GOVERNMENT DO?

Despite limited interactions with government agencies, mothers wished that such agencies had been more involved in awareness programmes on various aspects of child development:

*"The government can spread awareness maybe through newspapers because paper is one*

*which reaches [the] most [people], and TV ads... like information during pregnancy time itself on what to take care of..." (M3A).*

They would have liked more active early screening at primary health centres and that paediatricians to be adequately trained to identify early signs, especially regarding child development milestones. Mothers also wished that government agencies were more accessible and provided adequate and more affordable services: *"...they can have fully equipped centres...in hospitals [they could have] one unit accessible to everybody and affordable also...so we don't have to go and wait for hours to get a diagnosis and to get an evaluation done. ..."* (M1A).

They would also have liked the government to take up active training for *anganwadi* – preschool teachers – to identify high-risk children and suggest interventions to the mothers early on: *"I think the 'anganwadi' teachers should be trained.... before two and a half years [of age] the children are sent there. So, for them to have knowledge about all these, they can fix the children early enough"* (M4A).

In addition, they felt there was an urgent need to create simple educational and informative material on autism and basic child development and make it accessible during pregnancy: *"... If heard repeatedly on [the radio] or TV, it will create more awareness. They can stick posters in hospitals and we will read it for sure. Other health essentials are read by all mothers who go to any hospitals and so they may also read this..."* (MP2).

Despite most of them being socially privileged as educated and financially stable, participants found the help-seeking and diagnosis process tedious. Thus, it is especially important for the government to consider policy-level changes, in order to reach women who are from less privileged backgrounds.

## 5. DISCUSSION

In this paper, the authors explored the various paths Indian mothers followed from the birth of their child and the autism diagnosis, and thus provides a snapshot of such experiences. By examining each mother's experience, it was also possible to gain insight into the shared experiences with their family members and health professionals in the period leading up to their child's diagnosis.

This paper showed that one of the biggest barriers affecting the period from childbirth to diagnosis is the poor awareness of how to work on basic child development skills, especially social and emotional skills. This lack of awareness acted as a barrier to the mothers noticing the differences in their own child's development, which they recognised only once these had become prominent. This negatively influenced maternal agency with regard to taking action on their child's health.

The participating mothers underwent a number of negative and positive experiences before seeking help and receiving a final diagnosis. Similar to other studies which focus on mothers' experiences of having an autistic child in non-Western countries, the participants in this study perceived negative experiences as those giving them no sense of direction or clarity (Gobrial, 2018; Omar et al., 2017; Weiss et al., 2015). Such experiences were when family members dismissed the mother's initial "gut feeling" that something was "wrong" with their child, clearly highlighting the important role of family members in the mother's agency and decision to seek help. In some instances, a lack of support resulted in family members blaming the mother for the child's delayed or abnormal development. Conversely, positive experiences afforded them a sense of direction and clarity on how to move forward. These experiences were again based on the perceived support from their family members, especially when trusting the mother's instincts and supporting her in seeking help rather than blaming her.

Further complicating the matter is the late recognition of autism. Especially common in low- and middle-income countries, this paper showed that even if mothers, family members or health professionals noticed first symptoms of a child's delayed or abnormal development, there was a persistent focus on diagnosing such behaviour rather than finding a way to work with such delays in child development (Chauhan et al., 2019; Jain et al., 2013). The lack of awareness of autism and other neuro-developmental disorders, as well as the current trend of binary biomedical diagnostics, clearly delayed the mothers' sense of agency in pursuing their own instincts regarding their child's development and health.

Current research has shown that trends in epidemiological diagnostics are constructed around Western standards, not allowing for proper diagnosis in other contexts (Chauhan et al., 2019; Jain et al., 2013; Venkatesan, 2015). The main problem with such diagnostic approaches is that they ignore the contextual and socio-ecological dynamics and follow a binary approach to diagnosis by listing and counting somatic symptoms (Heer et al., 2015; Sarrett, 2015). As Daley (Daley, 2004) mentions, "norms about child development are of cultural and social nature and have, therefore, an impact on how and when a symptom is recognized as problematic". The wish that the mothers participating in our study communicated about including milestones in child development as part of any medical check-up is supported by findings from similar studies. For instance, an article by Sarrett (Sarrett, 2015) highlights the importance of proper diagnostic tools, which should focus on the dynamics of existing symptoms and non-somatic ones, especially milestones in child development and even family dynamics and social norms.

## 6. LIMITATIONS

First, it is important to mention that the mothers who participated in the study were mostly recruited from only one geographic area in India, namely Kerala. Second, the main author is affiliated with the parent support and advocacy group 'Together We Can' and could therefore



be influenced by being more closely connected with the participating mothers. Third, the study sample reflects a well-educated and financially secure population and it is therefore important to recognise that the experiences the mothers described are unlikely to be representative of the majority of the Indian population. Further research is needed on the topic, especially in lower socio-economic settings in the country.

This paper reflects the life experiences and stories of mothers of children with autism in India during a critical period, namely between childbirth and diagnosis, making it a unique study. By examining these experiences through the lens of the theoretical framework developed, it was possible to recognise the important role mothers play as agents of action throughout the whole diagnostic process – not only at an individual level, but also within different levels of society. Their stories can serve as a guide for improving and providing more suitable services for children with neuro-developmental conditions and empowering women as mothers in embarking on this new and challenging path.

## 7. FUTURE DIRECTIONS

Currently, there is a strong focus on parents' education and training as means of promoting the children's development and the empowerment of parents (mothers), as it has been shown to be an effective method of support (Dababnah et al., 2018) . However, such programmes have mostly been developed for a Western context. As shown in the literature, parents, and especially mothers in low- and middle-income countries, have little or no opportunity to gain information about neuro-developmental disorders in any formal way (Samadi & McConkey, 2011). Small-scale examples in India clearly show the success of such interventions (Dababnah et al., 2018; Samadi & McConkey, 2011). This points, therefore, to an increasing need for not only adapting diagnostic techniques, as mentioned above, but also adapting interventions in more culturally sensitive and contextual ways (Samadi & McConkey, 2011). Literature from

both Western and non-Western contexts has shown that by empowering parents through education and awareness on autism, there can be a stronger link established between early intervention and diagnosis, generating better outcomes for the development of the child and their family (Casagrande & Ingersoll, 2017; Dababnah et al., 2018; Daley, 2004; Jain et al., 2013; Samadi & McConkey, 2011). What needs to be explored further is what happens soon after mothers receive a confirmed diagnosis and how this knowledge acts as a facilitator or barrier to early intervention. The experiences of mothers after this diagnosis, both immediately and acting on it subsequently, need to be studied further.

## 8. CONCLUSION

The overarching themes that emerged among the participating mothers regarded a lack of enlightenment in specific crucial areas – a poor knowledge and awareness of child development and autism, as well as a need for empowerment, which helps people to trust their instinct and not wait for a diagnosis to begin intervention. Additional themes emerged regarding the role of significant others –family and friends – and their influence on mothers' empowerment and on their agency in seeking help, as well as the role of health professionals in the diagnostic process by contributing to their enlightenment through health education. Through exploration of the mothers' experiences, it was possible to reflect on the process they underwent from childbirth to diagnosis of autism, especially in navigating their new role of having to care for an autistic child and taking agency to generate action to benefit their child's health. Various recommendations emerged from the mothers' perspectives: they strongly highlighted the importance of focusing on interventions based on basic child development skills as opposed to waiting for a diagnosis. Such interventions need to be more holistic and take all child development milestones into account. Thus far, the focus of current interventions has first been on diagnosis and then on early intervention. This study explains how interventions could have

begun significantly before diagnosis, provided that the mothers were appropriately enlightened and empowered. Additional recommendations that emerged were to promote awareness of such development milestones among the general population, to be referred to proper interventions, and to have affordable services.

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# CHAPTER 6

## COPING WITH GRIEF – EXPERIENCES OF INDIAN MOTHERS AFTER A DIAGNOSIS OF THEIR CHILD'S AUTISM

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### ABSTRACT

The study from south India aims to understand the experiences of mothers of autistic children from the diagnosis of autism to early intervention.

Fifteen semi-structured interviews with mothers of autistic children were conducted and analysed via a combination of open and thematic coding.

Themes regarding the struggles mothers faced from the time of diagnosis overlapped with those of the grieving process and this delayed early intervention. The struggles continued as they moved towards intervention.

The themes related to overcoming the struggles indicated that a family- child-centred approach to disclosing the diagnosis and a seamless start of early intervention that treats mothers as equal partners in the process, empowers the mothers and helps them better to cope with the diagnosis.

**KEYWORDS:** Autism, Diagnosis, Indian Mothers, Grief, Coping

### 1. INTRODUCTION

Autism spectrum disorder (ASD) is a pervasive neuro-developmental condition that is usually detected in late infancy or early childhood, and is characterised by social and communication deficits that inhibit functioning in daily life without adequate support, training or accommodations. Despite extensive research and greater public awareness, autism has an unclear origin and no known cure, making it problematic to gain a precise and timely diagnosis (Elder et al., 2017). With respect to India in particular, there is no official estimate on the prevalence or incidence of this disorder (Chauhan et al., 2019; Venkatesan, 2015). Studies also show that the assumed prevalence may be an underestimate (Raina et al., 2017;

Rudra et al., 2017). Even the latest research in India shows a lack of a comprehensive nationwide evaluation of the burden of autism in India by evaluating the effectiveness of evidence-based interventions (Patra & Kar, 2020).

In analysing the role of paediatricians in India, some studies highlight an early diagnosis as a prerequisite to early intervention and also as a first step towards integrating the child with autism into a therapeutic programme that addresses delayed or abnormal development (Manohar et al., 2019). Once an autism diagnosis is made, parents find it difficult to navigate the healthcare system and determine the efficacy and appropriateness of interventions. A growing body of evidence supports the value of early diagnosis and evidence-based treatment, which can significantly improve the quality of life of individuals with autism as well as that of their caregivers and families. Particularly noteworthy are early interventions that occur in natural surroundings that can be modified to address age-related goals throughout the life of the autistic person (Elder et al., 2017).

Coping with an autism diagnosis has been much discussed in India, where it is clear that the diagnosis affects not just the child but the entire family and particularly the mother as the primary caregiver. Stress was evident as most such mothers have to give up their job, struggle to obtain support from family and friends and resort to avenues such as religion or spirituality as a means to cope (Das et al., 2017). Several studies highlight the negative impact of the diagnostic process on parental health, which can have negative consequences on the child's prognosis, thereby underlining the need to develop a better understanding of the impacts of diagnostic practices and the mother's experiences following a diagnosis (Reed & Osborne, 2019). Much is known about how a child's diagnosis can strongly affect parents, the most common reactions cited being anxiety, depression and parental stress. Studies have outlined the factors in the pre-diagnosis stage that enable mothers to have a meaningful and productive

relationship with the autistic child (Reed et al., 2019). However, not much has been studied about where difficulties in accepting the diagnosis can further delay early intervention and if so how to work towards overcoming these.

A focus group study in India found the same findings – that parents' grief-related experiences in autistic children is an ongoing process and cyclical since there is no real end, no closure, as there is when a child dies. The relentless search for the cause of the condition, frustrations resulting from the child's relative changelessness, the toll on emotional and financial resources, lack of emotional reciprocity and communication all contribute to their state of chronic sadness (Krishnan et al., 2017). While several studies have compared the mother's experience of grief after a diagnosis to that of loss of a child, little has been studied on what contributes to how she copes and the role of family and professionals in this. Despite ample knowledge about the grief process following a diagnosis of autism, it is important to understand why some mothers cope with their grief sooner and start early intervention, while others slide into depression. Do the mothers have to go through stages of grief such as shock, denial, anger and isolation and if so how do they cope with it? (Fernández-Alcántara et al., 2016). Other Indian studies that draw insights from parental experiences suggest that grief is a process that causes disruption, and the diagnosis of autism acts as the trigger (Rasmussen et al., 2020). There are also several cultural differences in terms of the support systems and various influences on mothers after a diagnosis, such as their support network that includes family members and professionals. Their own personality and knowledge also influence how they cope with the struggles.

This study tries to fill the knowledge gap by studying the stages of grief after a diagnosis of autism and by exploring how the family and professionals support access to evidence-based

care. Further, it examines factors that influence the process of empowerment and/or disempowerment during the early intervention process.

## 2. CONCEPTUAL FRAMEWORK

In order to understand in depth the experiences of mothers of autistic children in their journey from the diagnosis of autism to moving to early intervention, there is a need for a comprehensive perspective on the complex interplay between various actors and the grief process that influences the mother's agency. When evaluating a mother's reactions of grief to her child's diagnosis of a disability, it is the Kubler- Ross model of grief (Kubler, n.d.) lens that has been widely used, which refers to five stages: denial, anger, bargaining, depression and acceptance. These stages are experienced by the mothers not in a vacuum and it is in relation to the family and beyond. The socio-ecological approach outlined by (Bronfenbrenner, 1992) situates these mothers within an even broader dimension outside the family. Bronfenbrenner's model looks at both the personal level, namely the mothers, and the interpersonal one, such as their families and extended relations. It also emphasises the institutional level, in this case, health workers and institutions (Härkönen, 2001). To specifically navigate and understand the mother's experience from diagnosis to early intervention, this paper also refers to Harden's nursing education model (Harden, 1996) to follow mothers in their individual process of "enlightenment" and "empowerment" to "emancipation" (Harden, 1996). In the context of our research, enlightenment means the understanding of the role as mothers: "who they are and their own frame of reference"; empowerment means allowing them to change who they are as mothers and who they want to become for the benefit of their child, through critical self-questioning, their frames of reference, and their situation. Finally, the whole process is characterised as emancipation, meaning the actions which helped them "become" who they want to be. Hence Harden's model is used to understand both the barriers and facilitators to a mother's agency, in the



context of this article, as the mother navigates the early intervention phase soon after receiving a diagnosis.

### 3. METHODOLOGY

This qualitative study presents the findings from 15 semi-structured interviews with mothers of autistic children in India, mainly from Kerala and other parts of southern India and a few from the north of the country. All mothers had at least one child diagnosed with autism.

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#### 3.1 SAMPLING PROCEDURE

Participants were contacted through the parent support and advocacy group Together We Can (TWC) based, Kochi in Kerala as well as from the Autism Club in Kerala. Digital posters were created and posted on social media sites of these groups in order to disseminate information about the study and recruit participants. Given the sensitivity of the topic and the main author's affiliation with these organisations, a combination of purposeful and convenience sampling methods was used. In order to reach more participants through the interviews, a snowballing technique was added to the sampling method.

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#### 3.2 RESPONDENTS

The respondents were all women with an autistic child. There were no explicit exclusion criteria beyond being proficient in English, Hindi or Malayalam.

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#### 3.3 DATA COLLECTION

The data collection began in 2016, with seven mothers known to the researcher and who gave consent to participate in a pilot study. The mothers were asked to share their experience from when their child was born to the present. This study gave insights on using Bronfenbrenner's

socio-ecological model, and enabled us to frame the interview guide with open-ended questions where mothers were asked to speak about their own personality and knowledge, and their experiences with significant family members, professionals and government agencies.

For the pilot study and the current study all mothers were given a choice of a face-to-face or a phone interview. All chose phone interviews for the pilot study. Mothers who agreed to reveal personal details sent them via email or WhatsApp text messages.

An interview guide was developed for the current study after the insights from the pilot study. A total of 15 mothers gave consent which was recorded during the interview and also via email or WhatsApp. All interviews were conducted by phone. Out of the 15 mothers who participated in this study, six mothers participated in the pilot study as well.

The interview guide, framed after the pilot study, included open-ended questions where the mothers were encouraged to share their experience about the role of individual factors, significant family members, professionals, and government agencies, in acting as facilitators or barriers to reaching an early intervention. Mothers were also asked to give examples from their own life on both the positive and negative influences of each of the factors, and also share their wishes in retrospect.

In addition, the following demographic details were collected from the mothers: age of mother and the autistic child, age of the child at the time of diagnosis, mother's education, employment and marital status, details of siblings, type of family, and residential address.

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#### 3.4 DATA ANALYSIS

The interviews were transcribed verbatim. The analysis had several stages: first an open-coding analysis was performed during which several themes emerged separately for those they perceived as struggles and those they perceived as overcoming struggles. Within each

theme the interplay of the role of either the family or the professional in acting as a facilitator or barrier to the mother's agency was analysed.

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### 3.5 ETHICAL CONSIDERATIONS

Prior to collecting data, ethical approval was received from The BALM, Chennai (The Banyan Academy of Leadership in Mental Health), that has an independent ethical committee. During the study, explicit informed consent was obtained from each participant in either a written or oral form before any form of data collection. The participants were informed about the aim and procedures of the research, its implications, their rights as participants, and the fact that participation was entirely voluntary and could be stopped at any point in time.

## 4. RESULTS

After presenting the main characteristics of our sample (see Table 1), we explain how the pathways of the mothers after getting a diagnosis resemble that of the grief process and go further as well. We then present the table (Table 2) that summarises the two sections of the results – the struggles and the overcoming. They are presented in an order for purpose of clarity. Not all mothers followed the same order or experienced all of the barriers and all of the facilitators. Following this each of themes within the struggles and the overcoming is explained in detail.

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### Table 1: TABLE OF DEMOGRAPHICS

Demographics of sample: Some of the key characteristics of the sample was that all the mothers were educated with all of them having a graduate degree, and with a majority of them being post graduates. Though all the mothers expect for one mother were gainfully employed before

Table 1

<b>Total number of Respondents</b>	<b>15</b>
<b>Age of mother</b>	Between 30–39 ( 6 ) ; Between 40–49 (7) ; Between 50–55 (2)
<b>Marital status</b>	Married (15)
<b>Educational qualification of mother</b>	Graduate (4) Postgraduate (11)
<b>Employment status of mother before the phase</b>	Paid employment (14) Homemaker (1)
<b>Employment status of mother during the phase</b>	Paid employment (4); Disability-related work Paid (1); Voluntary (3); Homemaker (7)
<b>Sex of the child with autism</b>	Boys (12) Girls (3)
<b>Age of the child at the time of interview</b>	5–10 (6) 11–9 (7) 20–25 (2)
<b>Ordinal position of child with autism</b>	1 (9) 2 ( 6)
<b>Age of diagnosis of autism</b>	Under 2 (3); 2–3 (7) Aged 3–4 (4); Over 4 (1)
<b>Type of Family</b>	Nuclear (13) Joint (2)
<b>No of children in the family</b>	One (5) Two (10)
<b>No of autistic children in the family</b>	One (15)

<b>Place of Residence</b>	Kerala (9); Karnataka (3); Maharashtra (1); Haryana (1); West Bengal (1)
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the diagnosis, it is noteworthy that only four continued in their employment post the diagnosis, and most either turned homemakers or switched to voluntary or disability related work. All but one were from nuclear families and predominantly based in Kerala. All of them received the diagnosis by the time the child turned three or earlier.

Each of the results is based on the lived experiences narrated by mothers of a child with autism and their journey as they cope with grief until they learn to live with it, moving to a phase of acceptance and hope. They face repeated grief, depending on interactions with various actors. Though a diagnosis is perceived as being as definite as death, the grief is ongoing and cyclical as there seems to be no end to it, analogous to the death of a child. The process of grieving was not linear or the same for each mother, but there were a lot of similarities in the experiences in terms of themes that emerged following the diagnosis of their child's autism. The results are analysed through the lens of the grief process following Kubler-Ross model (Kubler, n.d.), alongside the influence of the family and professionals who in their own ways either act as a barrier or a facilitator to the mother's agency. It also highlights the different intensity and impact of grief for different mothers. Some were able to cope with it and soon moved to early intervention. Some were totally devastated, and an early diagnosis did not lead to early intervention; rather, they took longer to cope with their grief. In this section we go through each of the stages of grief as commonly understood and then further analyse the additional stages of struggle before the mothers were able to take efficient action. Each stage is separately described from the perspective of the mothers and their interaction with themselves, family members or professionals. The stages as narrated can be broadly divided into two – the **struggles** and the **overcoming**. It is, however, important to

note that not all mothers followed this same order in their journey and not all of them go through all of the stages. It has been analysed in this manner only to better understand all the struggles the mothers go through and how they work towards overcoming these. Each struggle and facilitator was as a result of either the mother's own knowledge, attitude and practices (KAP), or that of their significant other or the professional.

TABLE 2 – TABLE OF THEMES

THEMES and SUB THEMES			
The Struggles	Description	The Overcoming	Description
Shock	The suddenness with which the diagnosis is revealed	<b>Cognition</b>	Gaining enough understanding about autism
Denial	The disbelief that this is true as it does not totally seem so	<b>Confidence</b>	Knowing that one has the skills to do what is necessary or knowing where and how to seek support
Depression	Extreme sadness while attempting to accept the diagnosis	<b>Control</b>	Knowing one has a choice
Confusion	Not having clarity on what the diagnosis is all about	<b>Child Centred Comprehension</b>	Understanding autism as it influences their child
Isolation	Feeling alone with all the overwhelming feelings and nobody to understand	<b>Communication</b>	Being able to communicate assertively with all other stakeholders
Blame	Feeling pained when criticised for something over which she had no clarity on	<b>Connection</b>	Being able to connect and feel heard by other stakeholders
Indecision	Inability to reach a course of action and finalize the same	<b>Contribution</b>	Being an equal participant in the therapies
Lack of Direction	Not knowing who to trust and what do next	<b>Collaboration</b>	Working together and learning together with other stakeholders
Intimidation	Feeling overpowered by those who are attempting to guide or help her	<b>Coordination</b>	Unified support from all stakeholders
Dependency	Feeling totally submissive	<b>Co-creation</b>	Their knowledge too being valued and used towards helping the child

Burn out	Exhaustion of taking care of everything all at once with limited support		
Going Back and forth	Going through it all across the phase randomly		

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## 4.2 STRUGGLES

### 4.2.1 SHOCK AND DENIAL

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Dealing with shock and denial was one of the first struggles most mothers faced as they explain their reactions to getting a diagnosis. This was because of the suddenness of the revelation, the insensitive manner in which they were told, or because of the overwhelming thoughts of how and why this happened.

Many mothers who were not so convinced about their child’s difficulties went ahead with the consultation with professionals because of the insistence of family members. Most mentioned that they had no prior knowledge about autism or had even heard the term before or understood anything about it. So, when the diagnosis of autism was suddenly disclosed, it came as a shock to almost all of them. M11B said: *“...reading all the posters put up outside the clinic...almost all symptoms and features mentioned were similar to what my child was showing. That is when we first heard the word Autism. It was a shocker...”*

Many mothers also spoke about not understanding entirely what had been said to them due to the shock, and how the awareness and the impact sunk in slowly, as the overwhelming feeling was of numbness from the shock of getting the diagnosis. M9B said: *“....the seriousness of it did not strike us...we were all in a shock, what is this, how did this happen, such was the feeling at that time...”* Denial is explained here as the mother’s difficulty in accepting the diagnosis, which delayed her ability to move ahead with effective early intervention. Many mothers spoke of a denial phase, which led to “doctor shopping” as they

sought a second or third opinion before starting intervention. They also spoke about how they regretted being in denial and wasting crucial years for early intervention. M4B: *"...he was 2 years when he got the diagnosis...I was totally not willing to accept and it took me one more year.... I did not agree... that one year I still regret..."* Some mothers spoke about not acting upon the diagnosis as they did not want to accept it and believed that the child would soon outgrow their difficulties with time. They mention also being anxious in their denial. Some mentioned the denial phase as a rejection and regression in which an individual totally rejects the truth and is unwilling to accept and unable to even think about early intervention. M9B: *"...it was an emotional phase. There was rejection...there was a waste of time. That is regression. You go into that rejection phase. You are not able to accept..."*

#### 4.2.2 DEPRESSION AND CONFUSION

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Depression and breakdown can be explained as the struggle that mothers experienced where they felt everything had come to a standstill. This struggle was perceived as something that pulled the entire family backwards instead of forwards in terms of life in general. Thinking about it even years later brought strong feelings of regret and remorse for having not acted immediately. The diagnosis had not given clarity on a way forward and the painful tears seemed to be more from an anxiety of being pushed into embarking on an unknown and uncertain journey. M1B: *"...when the doctors said your son has autism, I just cried...quite hard, because it's a huge... It's also money...really tough... so I cried...How I can try to support him..., how can I find all the money...how can we do that?"*. Many mothers mentioned sadness, despair and lack of clarity on how to move ahead. Some of them even talked about having thought about suicide as they could not see a way forward. M10B: *"At the time he was diagnosed, those were the days when we even felt like committing suicide..."*



The lack of clarity and confusion was manifold. They had to make many life changes and choices. They did not know what to expect next and such overwhelming feelings impeded effective early intervention.

Many mothers mentioned being in a state of confusion about where to go and who to contact. Though all of them realised sooner or later that therapies were the way forward, they did not know what to expect as the outcome of the therapies and how long they had to be continued.

MP4: *"...we did not get a written record and so what I thought was if we do some speech therapy he will be fine.... We did not realise or understand the seriousness... we were not clearly told what to do at home so we continued as usual..."* According to many mothers, what added to this confusion was how professionals gave the diagnosis without spending time to explain it and discuss a way forward. The confusion was also because they sometimes received too much information and had too many choices so they were unclear about which to choose. M12B: *"... It was too much. Too much of the therapies. Too much advice.... I tried to make him normal, but ... I took almost 18 years to accept..."*

#### 4.2.3 ISOLATION AND BLAME

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Mothers explained this struggle as one that made them feel alone and lonely in their journey. The mother not only had to gain clarity about the diagnosis, but also had to be equipped to explain this to their significant others and to society at large. Some said the husband blamed them, which was the most difficult to cope with. M9B: *"... My husband did not support me at all... blamed it totally on the me...that it is a mistake from my part...worst of all, he started neglecting me..."*. Some isolated themselves so much that they delayed seeking therapeutic interventions and felt this led to more isolation as they did not know how to work with their child or explain the situation to anyone else. M4B: *"... people have told that to my face...that he is mad...that kept hurting me a lot... so I made sure that I don't take him anywhere, I used*

*to keep him inside only. And without doing anything and thinking why it happened?"* In addition to not understanding why this happened to her child, she was being bombarded with questions about her role in causing it, and this lack of support, they said, was a devastating experience. As a result, early intervention was not possible until the mother got a grip on herself before attempting to work with her child. M5B: *"...I had huge tremendous pressure from my in-laws' side and everybody until he was 10 years they did not want me to take him anywhere or let anybody know..."*

#### 4.2.4 INDECISION AND LACK OF DIRECTION

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At some point the mother had to prepare to decide to do something about the diagnosis. A few were pushed back to the blame and isolation phase but some were able to convince their family. M4B: *"...I was lucky enough to convince my parents...they accepted it too. We ourselves have to be open about it..."* The mothers had to also prepare themselves to take on this new role in addition to their other responsibilities. Some mothers decided that it would be better to continue with their career and saw that as a stress buster. They found it healthy to focus on things other than the child. M6B: *"...if you are 24/7 only focusing on this one thing, you can go insane. So unless you get a hold on yourself, you can't really work with your child and you can't give the child quality time and attention..."* But many other mothers felt that it was important to take a career break because they had now to take the child to all the therapy sessions and also learn from the therapist and work on it at home. Most mothers did, however, stress that they had to be willing to take out some time for themselves too, whether by pursuing hobbies or through a career they love. M7B: *"...I reduced my working time...When this therapy and everything is happening, the mothers should allocate time for themselves because then only we will get some relaxation..."*

#### 4.2.5 INTIMIDATION AND DEPENDENCY

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Everything began to happen so fast in a mother's life immediately after the diagnosis that there was hardly any time for her to introspect and think for herself what is in the best interest of her child. So, in good faith mothers placed blind trust in the professionals. Some got lucky and met good professionals from the start, but most had to meet several professionals who were intimidating. They spoke about how they felt totally helpless even when they knew what was being done was not right and yet could not find the voice to resist and speak up for their own child. M4B: "*... another person hits my child and goes off, and I cannot say anything about it...I was depressed....it was their style of teaching...*"

Many mothers did not feel it was appropriate to question what the professionals were doing as they felt it was in the best interest of the child that they listen to them and do just as they say. M10B: "*...now I think... so much of leave was wasted, so much of money was wasted... on therapy....*" Following the lead of a professional without much understanding or insight into what was being done to their child, was neither enlightening nor empowering to many mothers. They felt sorry for their child too as they would get attached to one professional and then take a lot of time to settle down with a new one. This lack of continuity in therapy was mentioned as a reason why therapies often did not work well. M12B: "*our kids take time to settle with a new person. After 6 months, they just resign.... constructive teaching literally actually stopped happening....*"

#### 4.2.6 BURN-OUT AND GOING BACK AND FORTH STAGES

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All mothers spoke about a stage of emotional or physical exhaustion. A mother mentioned that she was drained by trying to accommodate all her daughter's needs. M10B: "*... I would not be having a single paisa in my hand. Her auto rickshaw, her therapy, she being taken to town, taken to park, taken to the beach, after all this... I will not have anything at hand...*"

This burn-out and frustration was also exacerbated by significant others when they interfered with the goals she had set of the child. M8B: *"...my son was packing his bag on his own. His grandmother interfered saying – so sad, he is packing his bag on his own and she offered to help him in that, whereas I struggled so much to get him to do that on his own..."*

This need for respite increased among mothers who were living alone with their children and if their husband was not around to offer physical or emotional support. M12B: *"... There was no support here because. My husband was travelling... I was all alone with my son and I was like a zombie. Because you expect a miracle...You get frustrated, irritated, depressed..."*

Though at the time of interview the mothers had long moved on from all these stages and their children were teenagers, some continued have difficulty in accepting their diagnosis, hoping that one day the child would not be labelled. M10B: *"... To tell the truth, even now it is difficult to feel 100% okay. To tell the truth, sometimes, we feel that we have not yet accepted it...we feel helpless at times..."* They spoke about themselves as both weak and strong and how the whole experience was not linear and they would swing back and forth through all their feelings and had to muster the courage to remain strong. M5B: *"There was a contradiction there, I was a strong mother and I was a weak mother too....I will decide to do what they tell me to do, but slowly tell myself "maybe he doesn't have autism".*

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## 4.3 THE OVERCOMING

### 4.3.1 COGNITION, CONFIDENCE AND CONTROL

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One of the biggest turning points was when the mothers educated themselves and started to gain more understanding and to comprehend the diagnosis and how therapies work. Most mothers resorted to reading informative material from various sources and this slowly gave them the confidence and command to not only interact with the professionals but also question them if necessary.

M14B: *"...Unless you unlearn the things, you won't learn the new things...as a mother what I did was I read up a lot. Rather than just limiting to listening to what therapists tell us..."*

Mothers who were well-read or took on the role of educating themselves or asking the therapist questions were better able to cope and feel more confident to take on this phase.

Mothers used various kinds of sources to learn – books, the internet, watching the professionals work with their child, attending seminars and workshops or by doing a special education course themselves and making a career change and establishing contact with other mothers in the same plight. M1B: *"....I have learned from the therapist. I try to do it at home and then I take it – try to learn from the book... I did a workshop also ..."*

#### 4.3.2 CHILD-CENTRED COMPREHENSION

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Mothers who understood autism more in the context of their own child and learned how to apply what they had learnt to their child at home were better able to cope. These mothers could think for themselves and did not blindly follow any intervention strategy that they read or heard about. Some mothers who were appropriately guided to work with their child, starting with where the child had difficulty and equipping them to work with the child, mothers began to gain confidence and understanding of their child and were able to follow the therapies at home. M13B: *"... I was struggling to make him sit, everything else I know I can do easily. So that trainer was telling ten seconds. And he started sitting... After that, I never felt that much difficulty. I got a grip somewhere, if I sit with him, he will... So I started reducing the therapies..."* Mothers mentioned how this understanding of the child extended to the rest of the family, and with the help of professionals many more positive changes took place. M15B: *"... Some programmes will ask the counsellor to come to talk to the family, like how can they go about with the child.... That will at least boost the morale of all the people at home like we are working towards an improvement".* They felt that when the

goals were set realistically and meaningfully to cater to the needs of the child they were much better able to follow up at home. M6B: *"I think that relevant and realistic goals are what are required, self-help skills...which helps the child in the long term..."* Mothers slowly became open to learning from all sources – other parents, therapists, and other children too – and then adapt to use with their own child. M7B: *"... whichever way it works for the child...for the therapist and also for the mother, the main goal should be making the kid independent"*.

#### 4.3.3 COMMUNICATION, CONNECTION AND CONTRIBUTION

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When there was effective communication and partnership between the mothers and the professionals and other significant family members, mothers felt equipped to move forward. Letting the mother know that she is not alone and, through counselling, reassuring her that support is always around seemed to be essential. M15B: *"Counselling to the mother, psychologically knowing what the child is going to have and going to go through... then definitely the mental trauma would be very [much] less"*. Some mothers said when they went to places which had residential programmes for the entire family, where both parents and the child would live together for some time without being judged and also be trained to understand the child better, the family could connect better with each other. M14B: *"... they have a parent training programme and we stayed for 3 months and of course we did get knowledge about autism that is there but more importantly ...we were there as mother, father and a child in an environment where nobody was judging, nobody was offering advice and that helped us a lot in connection ...."*

Mothers spoke extensively about the contribution of other significant people around them. They needed others to connect with them and received support from different people in different ways. While some mentioned family members like their own mother, husband or mother-in-law, others mentioned peer groups and even other parents who were undergoing

the same experience. The support they needed ranged from lending a hand with household work to supporting therapies and working with the child, and also financial and emotional support. A mother speaks about how her husband could contribute to the household work and not expect things he can do for himself to be done for him. M2B: *"...Not waiting for the wife to bring the dinner, clean. He can do it for himself, because he can look after himself..."*

Another parent mentions that her own mother contributed by just being there, providing both emotional and moral support. M14B: *"...The only person who occasionally would come and stay is my mother. And she has come with me for therapies.... I have shown her how I read with him...she has sat and read with him... the emotional support has always been there..."*

Connection with a peer group was mentioned as a source of support. Some parents changed their peer group to mothers with the same experience where they felt more connected, while some mothers preferred to stay in touch with their old friends. M6B: *"I have found the most solace in peers, friends who have children with autism and face similar issues. They would be able to relate to you better...These sort of discussions you can't have with typical parents..."*

#### 4.3.4 COLLABORATION COORDINATION AND CO-CREATION

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When professionals worked in collaboration with them, the mothers they found it more meaningful. This coordination and collaboration was not just about effective communication and connection but also about how both professionals and mothers co-created a programme that was in the best interest of the child. Joint efforts made mothers feel the journey they were experiencing was both empowering and rewarding. M5B: *"It takes a joint partnership. The guidance will come from the therapist, but the actual work has to be done by the parents"*. Mothers said they found it easier when they could start off with professionals who focused more on training them rather than taking it all upon themselves to work with the child and keep the mother away. And when this happened in the early stages, this saved the mother

considerable time and energy and she would see the results of early intervention sooner.

M10A: *"We understood what to do and how to change the child's behaviour and we got training and it was not necessary to go to another place"*. Some mothers also mentioned how both professionals and mothers might have different understanding of the child as they each work with the child in a different setting, so both had to share information and coordinate their efforts and be willing to learn from each other. M7B: *"[S]ometimes the therapists will understand the kid in one way but the mother can better understand the kid, so they can give suggestions"*.

When professionals made a home visit, the changes were even better, some mothers said. They felt that those professionals were better able to understand the home situation and thus provide a better programme to work with the child. Also, the work would take place in the child's familiar environment and the mother would also be able to see what was happening. A lot of the mother's energy was saved by not having to travel from one centre to another.

M10B: *"...the therapist used to say things to be done the next day... we could see what he was doing...He is the one who first taught us how to bring comprehension"*. Mothers mentioned that they had to coordinate with not just the therapists at the centres but also in the schools once their child reached school-going age. They mentioned how important it was to have common goals everywhere so that the child is not stuck between different goals. M5B: *"...the kid in the middle, the parents, the therapists, the school, every institution involved have to be around and then taking in unison with each other"*.

## 5. DISCUSSION

The findings of this study corroborate the insights of Bronfenbrenner's model by showing not only how the mothers are influenced by the knowledge attitude and practices both of the families and the health professionals, but also shows how this influence can penetrate layers beyond her and also influence her child. The findings also build upon existing literature and



also yield further insights into two main phases of the mother's journey after obtaining an autism diagnosis for her child. The first phase is about how they experience the grief of the diagnosis and the second is about overcoming and coping with this grief and moving forward.

In analysing the first phase, the mothers' struggles while experiencing the grief of their child's diagnosis were described in the literature as feelings of isolation, emotional exhaustion, blame and shifting of priorities (Nicholas et al., 2016). However, this study draws a direct comparison between this phase and that of a mother grieving the loss of a child. Previous studies that analyse the depth of feeling of loss in parents of children with autism explained these in comparison to the unexpected death of a child, categorised by feelings of shock, negation, fear, guilt, anger, and/or sadness (Fernández-Alcántara et al., 2016). The current study goes further and looks at how each stage of the grief process acted as a barrier to early intervention and how the way the diagnosis was given, from a very medical model of working with families, was an added cause of delayed intervention. Previous studies also indicated that, despite being well aware of the significance of early intervention, parents experienced immense stress while deciding about which intervention programmes to follow and what to expect from them. They also showed the need for health professionals to sensitively communicate the need for early intervention. (Edwards et al., 2017). The current study highlights similar struggles but goes on to provide insights into the phase of indecision among the mothers even after being aware of early intervention. The struggle of choosing between intervention programmes, including those of delay in getting appointments with the professionals on time, choosing which professionals, centres, and about being intimidated and feeling vulnerable in front of professionals during the early intervention stages. The findings also point towards the need for effective communication between the parents and the early intervention professionals.

Several studies have highlighted high correlation of clinical depression among mothers of children with autism (Singh et al., 2017). The current study goes on to show how the triggers start from the time the diagnosis is received, and then accumulate due to the lack of support and how this causes delay in starting interventions. The study highlights how mothers still regret not having acted soon after the diagnosis as they were left coping without support with their depressive feelings and thoughts.

Recent studies talk about the significant burn-out experienced by mothers of children with autism and how it affects their overall resilience (Fung et al., 2018). Along the same lines, the current study adds more insight into what causes this burn-out, and what role the family and professionals play in contributing to it, and the significant need for respite.

The paper not only adds to existing knowledge about struggles of mothers soon after a diagnosis of their child's autism but also explains in depth the multitude of struggles and how these are caused and how both professionals and family can either exacerbate the situation or help to mitigate it. The second phase of the findings analyses how the mothers cope with and work towards overcoming their struggles.

The importance of counselling alongside revealing a diagnosis goes a long way in mitigating the parents' anxiety. This has been studied even when a risk of autism is revealed to mothers during pregnancy (Van der Steen et al., 2016). The findings of this study focus on effective counselling approaches when diagnosing autism after the child is already a year or more away so that these mitigate the grieving mother's difficulties. One of the factors, based on the mothers' experiences, was the importance of an individualised child-focused understanding of the diagnosis, rather than a purely medical approach to understanding the diagnosis. This reinforces what has been highlighted in previous studies where parents have highlighted the need for a tailored approach to post-diagnosis support (Rabba et al., 2019). The current study

gives a more detailed understanding of why it is important to offer a tailor-made disclosure of the diagnosis, a process in itself than a one-time event in the life of the parents. This would also help the mothers not grieve over the loss of a child but rather to better understand the child they have and so feel equipped to move forward. Though the effects of early intervention have been prominently highlighted in several studies there are few studies on the perspectives of parents on early interventions. Several studies have explained the need for a family-centred approach that understands the specific needs of the whole family and builds close working relationships are what works best from the perspective of the parents (Galpin et al., 2018). There are also studies that specifically talk about reducing maternal stress, anxiety and depression when parent–child interactions were encouraged in therapy (Agazzi et al., 2017). This study reinforces such insights, and not only mentions the need for a good partnership between parents and professionals, but also a partnership between various professionals working with the same child. A coordinated effort from all the therapists went a long way in helping a mother or parent move forward with interventions. The few studies that explained the need for improved inter-professional collaboration due to the greater understanding of the complexity of autism also talk about professionals taking greater decisions in the programs with limited involvement of families that acts as a barrier (Strunk et al., 2017). The current study adds greater value to this area of knowledge as it speaks specifically from the lived experience of mothers and their perspectives on what act as barriers to early intervention and the role of professionals in facilitating it.

The role of the family in supporting mothers and minimising her struggles during the early intervention phase has also been studied previously, and most studies indicate the positive role that can be played by the grandparents. (Prendeville & Kinsella, 2019). This study also highlighted the moral support provided by the grandparents in helping the mothers cope with some of the struggles and also dealing with the grief. This study further details the nature of

support that the family members can provide the mothers, which are predominantly emotional and moral support, although a few mothers mentioned financial support or help with household chores.

## 6. LIMITATIONS

The study is predominantly focussed on experiences of mothers of autistic children in Kerala, south India. It is also to be noted that not all mothers went through all the stages of grief, the struggles or the overcoming. This study leaves scope for further investigation with larger population. However, since the mothers in this study were highly educated and had a support system considering that they were all married and gainfully employed before the diagnosis it is likely that the struggles experienced by mothers who are lesser educated and with lesser support systems are larger.

## 7. CONCLUSION

This study concludes that biomedical models of diagnosing children with autism tend to lead to significant grief in the mothers akin to that of losing a child. A child- and family-focused individualised methods that start with intervention programmes can be help toward reducing the barriers to early intervention as the mothers are then, better equipped to understand their child and the diagnosis. It is recommended that current practice is makes way to a comprehensive, integrated and family-centred approach that provides adequate support through the stages of grief leading to early intervention. Collaborative efforts by professionals in transferring skills to the mother are more likely to help build stronger bonds within the family that in turn can improve acceptance autism. This can encourage mothers to use their agency and become an advocate for her child. Thus, the mothers could be further

empowered and enabled to accept the child as they are by coping with the grief of an initial diagnosis

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# CHAPTER 7

'BEING MOTHERS OF SUCH CHILDREN, WE ALWAYS HAVE TO BEG'

A QUALITATIVE STUDY ON THE BARRIERS TO AND VIOLATIONS OF INCLUSIVE EDUCATION EXPERIENCED BY MOTHERS OF CHILDREN WITH AUTISM IN INDIA

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## ABSTRACT

This study investigates the non-compliance with the Rights of Persons with Disabilities Act of 2016 – with specific reference to its Chapter 3 on inclusive education – through the perspective of mothers in India who have a child with autism. In order to do this, semi-structured interviews were conducted, and a combination of purposeful and convenient sampling and snowballing techniques were used to recruit participants. In total, n = 15 mothers participated in semi-structured interviews and reported on their experience of their child's schooling. Data collection and analysis followed a theoretical framework deriving from the integration of the KiTeS framework (Melvin et al., 2019) and Harden's nursing education model (1996). The study sheds light on barriers to the rights of mothers and their children with autism when seeking to enrol in school in India. Aiming to understand the child as an individual rather than a diagnosis is a prerequisite for proper engagement at school. Ongoing interaction with and active involvement of the parents is crucial to gain information on the child's interests, capacities, capabilities and strengths. Parents should therefore be equipped to collaborate with professionals in the formulation of an individualised school curriculum for their child.

**KEYWORDS:** inclusive education; autism; India; disability; mothers



## 1. INTRODUCTION

With the aim of ensuring a learning environment that is able to promote personalised academic and professional development of all pupils and students, regardless of whether they have a disability, in 1994 India signed the Salamanca Statement and Framework for Action on Special Needs Education (UNESCO, 1994). Since then, children with disabilities have been prominently included in government documentation on inclusive education in India.

As a result of positive legislation such as the Juvenile Justice Act (2000) and the Right to Education Act (2009), over the past two decades, there has been a significant increase in the number of children with disabilities enrolled in school. For example, from 2003 to 2008 the number of disabled children enrolled in school in India grew from 566,921 to 2.16 million (Singal, 2019).

Nevertheless, there are several barriers to inclusive education in terms of implementation in practice (Sawhney, 2015), such as the lack of teacher training, the lack of alternative functional syllabuses, disparities in enrolment rates, the lack of standardised services and monitoring of their quality, and the lack of effective partnership between relevant stakeholders (Barua et al., 2017; Jairam, 2018; Singal, 2019).

Autism was only recognised as a category of disability in India in the last 20 years, and it was only in 2016 that it was included in India's new rights-based legislation: The Rights of Persons with Disabilities Act (RPwD 2016). Studies conducted before 2016 show that one of the main barriers to the inclusion of children with autism into mainstream schools was complete lack of awareness and training of teachers and the heavy focus of schools on academic achievement rather than overall child development. This left the teachers totally ill-equipped to deal with the unique needs of children with autism (Taneja Johansson, 2014).

Although the RPwD Act brought about legislative advances, there remain gaps between policy and implementation, and the educational services offered to children with autism are still patchy and uneven (Barua et al., 2017). With an estimated 10 million people with autism in India, there is a pressing need to understand the barriers that hinder inclusive education in order to ensure that all children with autism grow up to be productive members of society leading meaningful adult lives (Barua et al., 2017).

Parents of children with autism are the main strategic stakeholders in the process enrolling them in school. It is therefore important to understand what factors hinder the implementation of inclusive education from their perspective (Johansson, 2016). Schooling experiences of mothers of children with autism since the passage of the RPwD Act needs to be understood to greater detail in order to bridge the gap between policy and implementation.

The current study attempts to explore and understand the violations to the RPwD Act of 2016 – with specific reference to its Chapter 3 on inclusive education – through the lens of the mothers' lived experiences, from the time of seeking enrolment to completion of schooling. The questions that this study seeks to answer are: (1) What were the experiences of mothers of children with autism in schools with respect to effective implementation inclusive education as set out in the RPwD Act of 2016? (2) What were their difficulties and how did they cope? (3) What do they see as a way forward for them as they stand today?

Answering these questions will not only contribute to bridging the gap in knowledge of mothers' lived experiences in terms of understanding implementation of the RPwD Act, but will also give deeper insights into how a combined effort of all stakeholders responsible and accountable for enforcing the law can make the intended goal of any law or policy achievable.

## 2. THEORETICAL FRAMEWORK

In-depth exploration of the perspectives of mothers of children with autism with regard to their experiences of the schooling system was enhanced by using an integration of the KiTeS framework (Melvin et al., 2019) – an inclusive bio ecological model – and Harden's nursing education model (1996) (Harden, 1996) (see Figure 1).

The KiTeS framework (Melvin et al., 2019) builds on the conceptual structure of Bronfenbrenner's bio-ecological model and includes micro-, meso-, macro-, exo-, and chrono-systems to organise factors known to influence human development (Bronfenbrenner & Morris, 2006). The KiTeS framework helps in considering various levels of influence in the successful inclusive education of a child with autism (micro-system), while analysing the experiences of their mothers (meso-system) in relation to various stakeholders in the schooling system (exo-system) and how all of this translates into the effective implementation of the RPwD Act (2016) in India (macro-system).

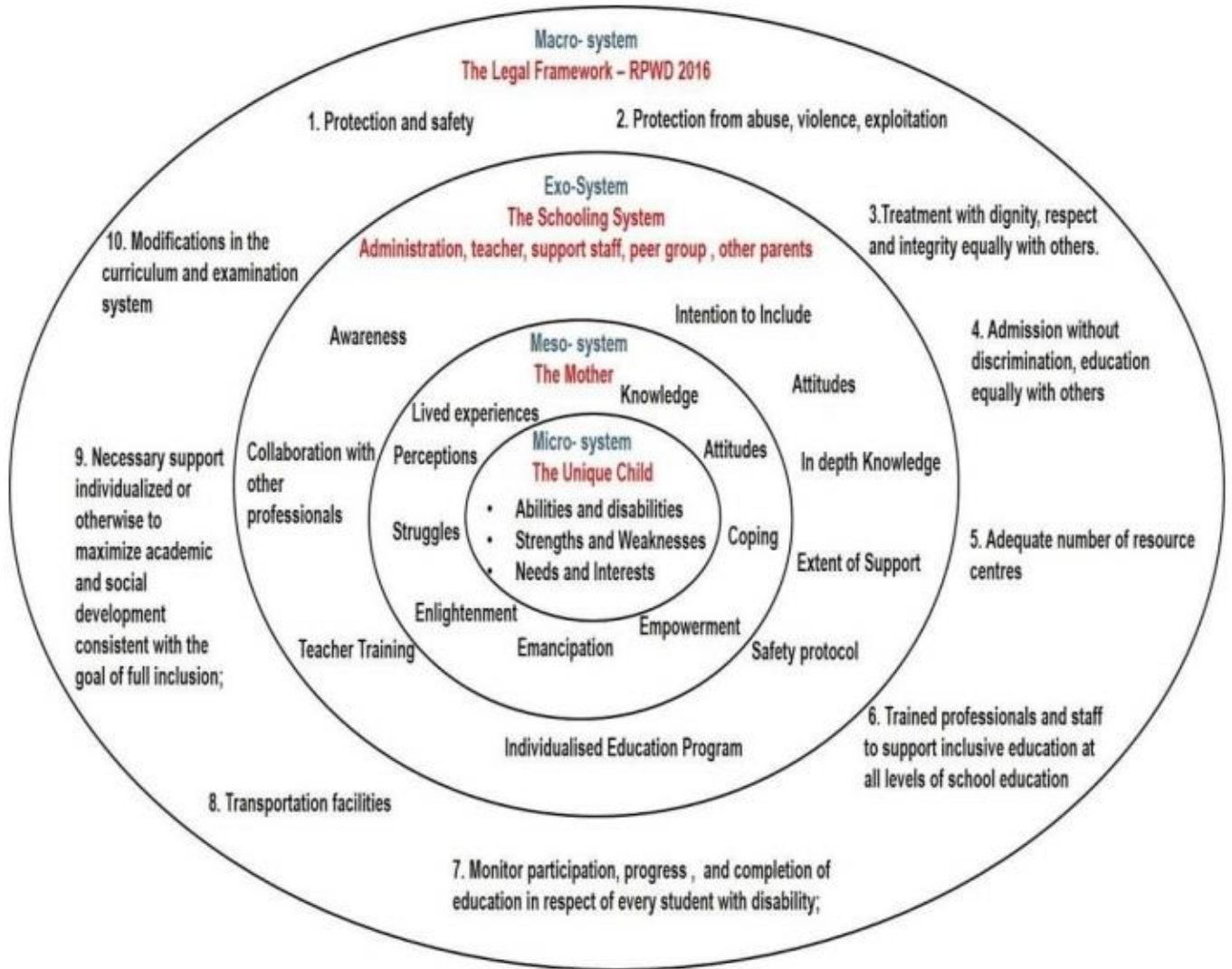
The main points that are of relevance to the schooling of a child with autism formed the RPDW legal framework, through which the macro-system was analysed after grouping them into three principal themes that emerged based on the mothers' lived experiences. A total of nine elements were further grouped into three sections namely

- a. Access to safe and secure learning spaces (*Protection and safety; Protection from abuse, violence; Treatment with dignity, respect and integrity equally with others; Transport facilities*)
- b. Adequate academic growth and development (*Admission without discrimination, education equally with others; Adequate number of resource centres; Trained professionals and staff to support inclusive education at all levels of school education*)
- c. Appropriate support to facilitating inclusion (*Monitor participation, progress and completion of education in respect to every student with disability; Necessary support individualized or otherwise, to maximise academic and social development consistent with the goal of full inclusion*)

Harden's nursing education model (1996) was integrated with the KiTeS framework to account for mothers' processes of 'enlightenment', 'empowerment' and 'emancipation'. In the context of this study, *enlightenment* means the mothers' understanding of their rights and the rights of their child; *empowerment* means the realisation that they are allowed to change their situation for the benefit of their child, by critically questioning themselves and their frame of reference. Finally, the whole process is characterised by *emancipation*, meaning the actions that help them induce a change in the system and proactively claim their rights and the rights of their child. Harden's model is primarily used to understand barriers and facilitators to a mother's agency.

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2.1 FIGURE 1. THEORETICAL FRAMEWORK OF THIS STUDY, DERIVING FROM THE INTEGRATION OF THE KITES FRAMEWORK (MELVIN ET AL., 2019) WITH HARDEN'S NURSING EDUCATION MODEL (1996) (HARDEN, 1996).



### 3. METHODOLOGY

This study collected data through semi-structured interviews.

#### 3.1 SAMPLING STRATEGY

Respondents consisted of Indian mothers of a child with autism. There were no exclusion criteria other than being able to speak English, Hindi or Malayalam. Mothers were recruited through the parent support and advocacy group 'Together We Can' based in Kochi and Kerala, as well as from the 'Autism Club' in Kerala. Digital posters were created and shared on the social media sites of these groups. Given the sensitivity of the topic and the main author's affiliation with these organisations, a combination of purposeful and convenience sampling

methods was used. In order to reach more participants, a snowballing technique was added to the sampling method.

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### 3.2 DATA COLLECTION

Data collection began in 2016 with seven mothers known to the researcher who agreed to participate in a pilot study. The mothers were asked to share their experience from when they gave birth to the present, which favoured the choice of using the KiTeS framework to comprehensively map different layers of barriers they encountered.

Drawing on the insights gained from the pilot study, the interview guide was developed, which included open-ended questions where the mothers were encouraged to share: (1) their experiences during their child's school years; (2) their experiences with the teachers and the peer group; (3) the difficulties they faced and their coping strategies; and (4) what they see as a way forward. The demographic details were also collected.

For both the pilot study and the actual study, mothers were given a choice of a face-to-face or a phone interview. For the pilot study, all except one chose a phone interview. For the actual study, all interviews were conducted by phone.

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### 3.3 DATA ANALYSIS

The interviews were transcribed verbatim. The analysis was undertaken by combining inductive and deductive coding, and had several stages. First, open inductive coding was conducted in which several themes emerged. These themes were subsequently interpreted and categorised deductively, by following the legal framework represented by the macro-system presented in Figure 1. Each of the key points of the macro-system was analysed in light of the

theoretical framework as a whole, in order to provide as comprehensive an overview of the mothers' experiences as possible. Overall, the use of the theoretical framework made it possible to understand the extent of rights violations experienced by mothers, as well as how they coped with it and the way forward they envisaged (i.e. enlightenment, empowerment, and emancipation).

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### 3.4 ETHICAL CONSIDERATIONS

Before collecting data, ethical approval was obtained from The Banyan Academy of Learning in Mental health (BALM) Chennai, whose members constitute the Indian Ethical Committee. During the study, explicit informed consent was obtained from each participant in either written or verbal form before any form of data collection. The participants were informed about the aim and procedures of the research, its implications, their rights as participants, and the fact that participation was entirely voluntary and could be stopped at any time.

## 4. RESULTS

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### 4.1 DEMOGRAPHIC DETAILS

In total, 15 semi-structured interviews were conducted with mothers of a child with autism in India. Of the 15 participants, eight mothers had a child who was still of school age and seven had a child who was beyond school age at the time of the interview. Both sets of mothers spoke about their lived experience during their child's school age. A comprehensive overview of respondents' characteristics is presented in Table 1.

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#### 4.1.1 TABLE 1. OVERVIEW OF SAMPLE'S DEMOGRAPHIC DETAILS.

Number of respondents N (%)
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<b>Total</b>		15(100%)
<b>Age</b>		
	30–39	3(20%)
	40–49	8(53.3%)
	50–55	4(26.7%)
<b>Marital status</b>		
	Married	15(100%)
<b>Educational qualification</b>		
	Postgraduate	10(66.7%)
	Graduate	5(33.3%)
<b>Employment status before diagnosis</b>		
	Paid job	12(80%)
	Business	2(13.3%)
	Homemaker	1(6.7%)
<b>Employment status - Current</b>		
	Paid job	1(6.7%)
	Business	2(13.3%)
	Homemaker	5(33.3%)
	Self Employed	4(26.7%)
	Disability-related (Paid)	2(13.3%)
	Disability-related (voluntary)	1(6.7%)
<b>Location</b>		
	Kerala	8(53.3%)
	Karnataka	2(13.3%)
	Maharashtra	2(13.3%)
	Tamil Nadu	1(6.7%)
	New Delhi	1(6.7%)
	Telangana	1(6.7%)
<b>Sex of the child</b>		
	Boy	12(80%)
	Girl	3(20%)
<b>Age of the child (interview time)</b>		
	5–9	1(6.7%)
	10–19	12(80%)
	20–25	2(13.3%)
<b>Age of the child (diagnosis time)</b>		



	<2	2(13.3%)
	2–3	6(40%)
	3–4	5(33.3%)
	>4	2(13.3%)
<b>Ordinal position of the child</b>		
	1st	8(53.3%)
	2nd	7(46.7%)
<b>Type of family</b>		
	Nuclear	14(93.3%)
	Joint	1(6.7%)
<b>Number of children in the family</b>		
	One	5(33.3%)
	Two	10(66.7%)
<b>Number of children with autism in the family</b>		
	One	15(100%)
<b>Type of school</b>		
	Mainstream school	6(40%)
	Special school + mainstream school	4(26.7%)
	Special school + mainstream school + home-school	2(13.3%)
	Special school + home-school	2(13.3%)
	Home-school + resource room in mainstream school	1(6.7%)

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## 4.2 BARRIERS AND VIOLATIONS TO INCLUSIVE EDUCATION

In the following sections, each chosen item of the RPwD Act is analysed separately based on the mothers' experiences compared to what the law mandates.

### 4.2.1 ACCESS TO SAFE AND SECURE LEARNING SPACES

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#### 4.2.1 .1 RIGHT TO PROTECTION AND SAFETY

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One of the fundamental rights of a child is being able to have a safe childhood. Yet, most mothers said that when they approached a school in which to enrol their child, even the child's

basic safety needs were violated. Some mothers spoke about lack of safety in the school infrastructure, with having no compound wall or gate: *'[...] I tried to enrol him in governmental schools, but it did not have any safety aspects, the ground, the compound wall. It was an open ground... the safety aspect was very worrying and so I did not try more'* (M3C). Safety issues also extended to not having enough staff to care for the children and being left on their own, either locked in a room or otherwise. Mothers also said that their children faced bullying and would not know how to defend themselves or ask for help in such situations: *'To this point, my son does not know why that boy hit him. When I ask him: "Why did he hit you?" He tries to create his own sentences, but I don't know... he would not tell me'* (M1C).

Mothers' awareness and enlightenment emerged in relation to protection and safety, as they quickly identified loopholes that would put their child's safety at risk. This awareness, however, did not translate into bringing about change in the school system. Instead, most mothers removed the child from the school for the sake of safety: *'[...] the classroom was locked and there were both boys and girls in the class. There were no teachers or maids around... I got frightened, and within 9 days I stopped her schooling there'* (M4C).

#### 4.2.1.2 RIGHT TO PROTECTION FROM ABUSE, VIOLENCE AND EXPLOITATION

Mothers seemed to very clear and aware of when a violation took place. Some mothers explicitly reported that the entire school system was 'violence', and they spoke mainly in terms of the mental and emotional exhaustion they went through in dealing with various barriers: *'[...] If you think of the whole system, it is violence actually... emotional and mental violence that we are giving the children so drastic. Even we ourselves cannot handle'* (M5C). Abuse was also experienced in the form of being bullied by other pupils, and the mothers would have to deal with their child's resulting emotional turmoil at home: *'She used to come home and complain that they snatched her food'* (M4C). Once again, although present, enlightenment did

not lead to emancipation and mothers spoke of various forms of emotional and financial exploitation they tolerated. For example, some mothers mentioned that they paid exorbitant fees to enrol their child at school, or had to pay for sessions they did not attend to ensure that they did not miss out on the confirmed place: *'[...] They would bill me for therapies unattended, but still we were willing to take that'* (M9C).

Some mothers even reported that their child had been were tied up with ropes or locked up in rooms and that professionals justified this both state and private schools. When abuse was so extreme, however, mothers did feel empowered to move out of the situation: *'I saw that they had tied him up in a rope...or else he might run out to the road...he might take files and destroy it, they had tied him up. I did not send him there after that'* (M14C).

Overall, mothers felt that school administrators were insensitive to the needs of children with autism, and had no training, hence they used terms such as 'mad' to refer to their children: *'[...] He was branded as mad, and people there have openly asked me: "Why don't you chain him at home?"'* (M15C). Such experiences were a gross violation of the fundamental constitutional right of dignity of life and living, which was being denied to both the mothers and their children. Although mothers were aware of such violations, they struggled to use the laws to fight for their rights; thus, they either ended up giving in or moving out of the system.

#### 4.2.1.3 RIGHT TO BE TREATED WITH DIGNITY AND RESPECT FOR THEIR INTEGRITY EQUALLY WITH OTHERS

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Mothers reported how both their own dignity and that of their child was compromised in their attempt to seek quality education. For example, some mothers were shouted at when their children struggled to cope, and even those people who were meant to guide them ended up ridiculing them and their parenting skills.

The significant lack of communication and empathy between the mothers and the school – a clear divide between exo- and meso-systems – was evident when mothers spoke of how unsupported and intimidated they felt in interacting with professionals: *'I went for only 3 months, because they shouted at me for my children's behaviour during my visit. I felt really hurt'* (M10C). These disrespectful reactions were internalised by some mothers and they spoke about this having a paralysing effect on them. Their energies were completely drained by having to deal with such situations: *'the way some people look, the way they talk and the way they ask questions, it is horrible... my brain doesn't work, my hands don't work and my heart doesn't work...I start to hate my kids for making me feel so miserable'* (M11C). Mothers felt so disempowered in front of professionals, that they were willing to compromise their own dignity to safeguard the needs of their child: *'The teachers used to be very rude with me for putting him there...I had to fall at their feet... being mothers of such children we always have to beg. I literally beg them asking them to give education to my child as he needs it'* (M13C). The lack of acceptance and understanding was also experienced in the form of exclusion from simple activities: *'He never gets invited to a party and so we used to have it at home'* (M6C). Other parents said that children with autism would have hindered their own children's education. Some went on to even threaten the school authorities that they would withdraw their children if a child with autism was enrolled: *'They said that if we are sending him, then they would withdraw their children'* (M15C).

#### 4.2.1.4 RIGHT TO BE PROVIDED WITH TRANSPORT FACILITIES

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Another basic right of a child was to be provided with the necessary transport facilities to be able to attend school. Mothers mentioned that disability certificates were required to use transport concessions, but that obtaining a certificate was a tedious process: *'Disability certificate, we have so far not found any use for it.... except for travel'* (M5C), *'[...] the process*

*of getting a disability certificate is very difficult'* (M3C). They mentioned how even public transport was an obstacle, and private taxis or auto rickshaws would also refused to take them, and how they faced immense hurt and humiliation to be able to attend school. This exploitation was not robbing them not only of their money, but also of their dignity: *'In the cab who are not ready to take the child [...] they charge you extra money [...] you feel insulted and timid they would say any odd things to your face, and you are not able to reply'* (M2C). Mothers mentioned that even the schools were not understanding about this situation and would mark their child as being late when they had struggled to reach school against all the odds: *'...they call him latecomer, which is not actually his fault but of the transport that he takes. The auto people don't accept these children to take them to school'* (M13C).

#### 4.2.2 ADEQUATE ACADEMIC GROWTH AND DEVELOPMENT

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##### 4.2.2.1 RIGHT TO BE ADMITTED WITHOUT DISCRIMINATION AND BE PROVIDED WITH EQUAL EDUCATION

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Almost all mothers started the struggle with schooling before even entering a school. Many mothers reported that they moved from one school to another and then to special schools and even there they felt that a lack of acceptance and training among professionals was a huge barrier to being admitted: *'I went to a whole lot of special schools, but they all said: "We are not equipped to handle these sorts of kids"'* (M12C).

Mothers whose child had completed school at the time of the interview felt that the entire experience had been a failure, despite changing and exploring various school options: *'Schooling has been for him almost a failure. By the time he was 14, he had already been to five special schools and one normal preschool. So, he changed six schools'* (M5C).

When some mothers managed to enrol them in school, financial exploitation was apparent. Many mothers could not afford the fees and so looked for other options: *'When the admission was almost done in one school, they told us that therapy should be continued and they said they needed a shadow teacher and we had to pay a good extra amount to the school. I felt that we would not be able to afford all this, also admission was on the waiting list'* (M11C).

Despite knowing the laws, no mother was willing to file a case or fight it out with the system, as they did not seem to have the energy to do so: *'My relatives told me to put her in a regular school, because there is a law "Right to education", but the Principal told that if I give admission to her, then other children will get frightened. I became crippled hearing this. I did not sue her'* (M4C).

#### 4.2.2.2 RIGHT TO BE PROVIDED WITH NECESSARY SUPPORT, INDIVIDUALISED OR OTHERWISE, IN ENVIRONMENTS THAT MAXIMISE ACADEMIC AND SOCIAL DEVELOPMENT

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The majority of mothers reported experiences where schools were functioning as mere day-care centres and there was hardly any trained staff to provide the support that the children deserved. They talked about years of trial and error across the schooling system: *'Everywhere is a trial and error method. So, it continued for almost like six or seven years'* (M7C). Mothers experienced sheer helplessness, despite the school dismissing outright the child's needs: *'I happened to see him and the Janitor in the kitchen of the school. She said he sits there with her every day when he makes trouble'* (M14C).

The lack of trained teachers was cited as one of the main barriers to inclusive education and most children did not receive any support even when they were enrolled: *'they needed to be trained on how to handle her, that did not happen...support from them was quite null'* (M9C). Some mothers felt that this was mainly because each child with autism is different and teachers did not have the necessary training or willingness to adapt: *'the problem is that one autistic*

*child is not similar to another...they cannot have the same kind of interventions. That is what makes it complicated for them'* (M3C).

#### 4.2.2.3 RIGHT TO BE MONITORED IN THEIR PARTICIPATION AND PROGRESS IN TERMS OF ATTAINMENT LEVELS AND COMPLETION OF EDUCATION

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Despite clear laws that mandate the right to participation and schools' responsibility to ensure that every pupil with a disability attains their potential, mothers described negative experiences which led them to change schools frequently; many mothers went so far as to conclude that schooling was not meant for their child: *'We kept changing schools, but none of them clicked. By the time, we had a set mind that school was not the solution'* (M3C).

Most said that schooling had been a waste of time, energy and money for them: *'All said yes, yes, yes... but nothing was done. The two years of schooling was a waste [of time] for her'* (M12C). This was the case not just with private schools but also with state schools, where mothers felt that they ended up sending their children to mainstream schools only for the superficial satisfaction that they are attending a normal school: *'I went to two to three government schools, ready to give admission, but [...] they are just making the child sit there. Other than that, the child does not benefit from there'* (M14C).

Mothers mentioned that most schools and professionals had no idea of how to formulate an individualised education programme and how they would continue to focus on the same teaching methods despite the lack of any results: *'She studied there for three years and all the three years they started from A for Apple. She got bored of it. Also, she showed some tantrums'* (M4C).

#### 4.2.3 APPROPRIATE SUPPORT TOWARDS FACILITATING INCLUSION

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##### 4.2.3.1 RIGHT TO AVAIL OF TRAINED PROFESSIONALS THAT SUPPORT INCLUSIVE EDUCATION AT ALL LEVELS OF SCHOOL EDUCATION

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Almost all mothers expressed their frustration when they worked with school professionals and one even said that all professionals were those who really made her upset and frustrated: *'Professionals have [...] been making me mad these years'* (M2C). She went on to explain that there was so little understanding of the child and that school caretakers rather than trained professionals used to work with children, and how mothers had to explain what works and what doesn't: *'Asking a maid to hold his hand ...asking her to drag him to run that would actually not produce the result. When I questioned, everybody said "Ma'am he was not ready. Ma'am he does not have the skill to run"'* (M2C).

Another mother explained a similar plight where she had to keep explaining her son's needs to the school authorities and staff and how they took no notice despite repeated reminders of his needs: *'He would not sit on that kind of chair at all, and we have to look for things which are more sensory stimulating [...] I have to explain that every day to that school'* (M3C). She added how, when teachers changed school, it would take days before he would adjust to the new school and she would have to explain it all over again to the new teacher: *'He would be at home for a few days, preparing him for it, every time that happens when the teachers change'* (M3C).

A mother recounts how on the very first day of school the authorities decided that they no longer wanted her son to study there and openly admitted not being equipped to take care of him: *'Within 15 min gap after leaving him in school on the first day, they called me from school saying they cannot keep him in school, and he needs special training and they cannot provide that.'* (M14C).

Not only were the school professionals not equipped to teach or train children with autism, but also did not believe the mothers when they said their children were capable of doing certain things: *'The school sometimes says that he is not doing things. I took videos to show them how he does the activities at home. Now they agree that he has skills and is able to do things. But*



*the majority of the effort was from my side'* (M10C). This shows how mothers showed agency and took it upon themselves to not just train their own children, but also prove this to professionals.

Mothers mentioned that schools had no difficulty in saying that they are not equipped, and their inability to handle behavioural issues were termed as being a difficult in child: *'One day I got a call from the school: "Please, come and take him and let him take a long break and medication because he hit a teacher" [...]he did not beat her, but asked her to move and pushed her from her stomach [...]I decided that I will not send him back to that school any more'* (M11C). When faced with such gross violation of the child's rights most mothers went on to get trained on their own and home-school their children in order not to depend on schools.

#### 4.2.3 .2ADEQUATE NUMBER OF RESOURCE CENTRES TO SUPPORT EDUCATIONAL INSTITUTIONS AT ALL LEVELS OF SCHOOL EDUCATION

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Most mothers mentioned that they had to combine school alongside therapies, as schools did not offer therapy services or even those that claimed so did not have adequate professionals. In state schools, the therapist moved from one district to another with one therapist shuttling between more than five schools, meaning that one child had hardly 30 minutes a week of training: *'There is a speech therapist, OT and special trained sports teacher for these special students. But they have shifts in each district. So, they will be available for only one day a week for 30 minutes [...] which is of no use'* (M14C).

Mothers mentioned being forced to move to special schools: *'It was specific that in the long run I knew that he had to have a special school, and there were hardly any... one or two schools in our city which had a special centre'* (M7C). Some mothers mentioned the difficulty of having to travel to the few schools that were ready to admit and train the children and how they had to even move house to be closer to the school and adjust everything else to near where the

school was: *'Then I looked out for a house myself near the school, and rented the house I lived... I struggled a lot, and worked in the school and did a lot for them'* (M10C). Even if they found good schools, most mothers were not able to afford the fees: *'There were schools which are high fee level, gave training in IEP. I could not afford the fees there'* (M4C). Inclusive education was therefore mostly only on paper and right to education was scarcely being enforced.

#### 4.2.3.3 RIGHT TO HAVE SUITABLE MODIFICATIONS IN THE CURRICULUM AND EXAMINATION SYSTEM TO MEET THE NEEDS OF STUDENTS WITH DISABILITIES

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For effective inclusion it is not enough that children are admitted and the teachers are trained, it is equally important that there are modifications in the educational curriculum to suit the needs of the child. The mothers' experiences showed that there were hardly any such modifications and the norm for most schools was to ask children with autism to either leave the school or repeat the year: *'There were lots of complaints in the school. They wanted us to repeat his Lower Kindergarten one more year. So, we did that'* (M8C).

It was, moreover, evident that an individualised educational programme, if not followed through and progress not measured, would not yield any benefit to the child: *'One month they took all the goals and made a program and in two months it just fizzled out. And every year it was happening'* (M7C). Mothers mentioned how, owing to ineffective goal setting, children were made to feel that they were incapable of learning and this affected their self-esteem and, as a result, many decided to home-school them: *'He was a dissenter in the dissenting group, probably their IEP was far-fetched and that was putting him in a sort of emotional turbulence that he is not good enough or something...the reality was that he was not getting any help...that's when I decided that it's time to do home school'* (M5C).

Overall, it was the mothers who ended up modifying the syllabus and teaching the children at home, by understanding their needs: *'How many years we have wasted simply. I am not able to teach him any grammar or any of those things, auditory inputs were not helpful, he always needed visuals and to do so I started doing things on my own. For learning, the general learning method used for other children did not work for him'* (M3C).

Mothers also had to develop their own teaching material as none was provided or used in school and they had to take it upon themselves to prove to the school teachers that their child was able to learn if they were taught differently: *'I got things printed on my own with the things he would like and finally my child actually started responding. [...] Whenever somebody tells me: "Your child is not doing it", I will say I will just do it, I will make videos of it and give it back to him: "See my child is doing it!"'* (M2C).

#### 4.3 PERSONAL STRUGGLES AND COPING

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Mothers mentioned how they coped with the difficulties and found their own ways of coping. For example, they took it upon themselves to gain more knowledge and equip themselves to teach their own children: *'I used to take the written work from the other children and I used to cover the portion at home. I used to wait outside the classroom and listen to how the teacher is teaching and follow the same at home'* (M13C).

Mothers took keen interest in attending workshops or courses to help their children learn. Overall, it ended up being the mothers who 'trained' the school teachers at school, instead of the other way around. However, none of this was easy for mothers and many faced both physical and mental health challenges: *'I also attended lots of workshops. I had to prepare materials, to video record, to send it to the therapist and correct it and take care of the two children. I never got any support from my family too. [...] I was too tired handling all this, got severe back pain'* (M10C).

Many of the mothers spoke about having neglected all other areas of their life during this period and getting exhausted and drained because of the significant lack of support: *'I had to go for counselling, because I had become a jerk. Because sometimes you feel... one month gone. And doing the one single thing and nothing is happening... no result...I started taking care of my health also. It was a slow process of health, like yoga'* (M7C).

Mothers also mentioned, however, that they found ways to cope through meditation, exercise or counselling: *'I try to meditate regularly, I exercise trying to de-stress my body ...there is so much of a lack of awareness...I am trying my meditation, I am trying to calm myself, at the end of the day I am stressful as a parent'* (M1C).

## 5. DISCUSSION

This study aimed to investigate the violations of the RPwD Act (2016) – with specific reference to its Chapter 3 on inclusive education – through the perspective of Indian mothers of children with autism. Through the use of a combined framework and a legal perspective on the RPwD Act, this study shed light on various violations of the rights of mothers and their children when seeking to enrol in school.

There are studies that specifically discuss the ineffective implementation of the RPwD 2016 and cite the lack of trained professional and infrastructural requirements. (Ahuja, n.d.) The current study goes into depth in each of the key mandates mentioned in the inclusive education chapter and brings out the ineffective implementation by following lived experiences of mothers of children with autism.

The aim of the study was not only to identify the specific violations but also to explore how the mothers coped with these difficulties and understand the key components that empowered

them and led them to agency. The components that emerged are presented as recommendations on how to facilitate the inclusion in school of children with autism. Overall, having the *intention* to deeply understand the child as an individual rather than a diagnosis is the prerequisite for the appropriate experience of the child at school. An ongoing *interaction* with and *involvement* of key stakeholders, including parents, is crucial in order to gain insights and information on the child's interests, capacities, capabilities and strengths.

It appears that mothers go through a process of enlightenment, empowerment and emancipation when trying to get their children admitted to (Harden, 1996). *Enlightenment* happens when mothers realise that the schooling system and professionals are not respecting their child's rights. *Empowerment* occurs when mothers proactively take decisions regarding their child's school attendance, and choice of one type of school over another. *Emancipation* happens when mothers become change agents and show teachers how to handle their child in the best way possible. It is noteworthy that this process happened spontaneously; even though mothers appeared frustrated and lacked trust in the school system, many were in the end able to proactively participate in their child's education.

Previous studies highlight how teachers' attitudes and intent towards the inclusion of pupils with autism depend on their level of training and years of specific experience with working with students with autism (Roberts & Simpson, 2016). Garrad et al. (2019), for example, report that training the teachers and encouraging them to reflect on their attitudes may facilitate the inclusion of children with autism in school (Garrad et al., 2019). In addition to highlighting the need for proper teacher training, this study also urges the empowerment of parents, as they often have intent and experience and so the potential to be the change agents for assisting school teachers.

In tune with the current study, earlier studies also find that parents experienced an unending battle to support their children's participation in mainstream schools. Though parents tried to

enhance their participation, most observed that they had little or no control over their participation in mainstream schools. Thus, policies should be implemented to boost the accountability of mainstream schools in relation to accommodating pupils with autism and facilitating the meaningful contribution of parents and students in educational design (Harrington, 2014). In line with these findings, the current study recommends that parents are educated and empowered to reach emancipation and to facilitate the implementation of existing laws. In fact, the problem is not in the lack of policies or laws (macro-system), but in the lack of agency in those for whom the law is made, in order for them to act as change agents. What is needed is a mechanism for the quick redressal of issues, as well as parental agency to speak up about the issues with the appropriate authorities.

Overall, the need emerged to ensure individualised and learner-focused pedagogies to support children with autism. A study exploring parents' experiences in school and literacy learning revealed that parents had in-depth knowledge of their child's strengths and interests, but the child's skills that emerged at home were not further developed in formal school contexts (Johansson, 2016). This demonstrates that parents have the potential to be the best allies in their children's education. While the current study endorses and supports Johansson's stance (2016), it stresses that the role and importance of parents should be considered equal – rather than superior – to the role of professional teachers. This parent–professional partnership in education should be centrally recognised in policy and practice. Despite existing policies mandating individualised support and adaptation of the curriculum, none of this happens in practice because parents' views are rarely taken into account – which is why they often end up home-schooling their children.

Some strengths and limitations of this study are highlighted as follows. Among the strengths are the in-depth qualitative analysis of the mothers' lived experiences, the use of an integrated theoretical framework and a legal lens to explore inclusive education in India, and having

piloted the interview guide before data collection. The main limitations are that it is impossible to generalise results and the fact that the sample of mothers was predominantly highly educated.

## 6. CONCLUSION

Parents of children with autism should be equipped to collaborate with professionals in the formulation of an individualised curriculum for their child in formal schooling.

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# CHAPTER 8

A REALIST EVALUATION OF TOGETHER WE CAN (TWC) – AN ADVOCACY GROUP IN KERALA:  
“FROM BREAKING OF A BONE TO A BREAKTHROUGH IN POLICY CHANGE”

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## ABSTRACT

In 2015, in Kerala, an autistic child broke their arm during therapy. This incident was the beginning of the Together We Can (TWC) movement, leading both to policy change and to greater awareness of the problem of the implementation of the rights of people living with a disability. This study aims to explore the journey of TWC.

Realist evaluation methodology used to test the middle-range theory identifies five change mechanisms: double-loop learning, community of practice, change agent, structure of feelings and resource mobilisation. These are tested on primary and secondary causes TWC has embraced.

The study results could help future movements that advocate for rights of marginalised and vulnerable groups.

**KEYWORDS:** Advocacy, Mechanism, Realist Evaluation, Disability, Social Policy, Community of Practice

## 1. INTRODUCTION

Complex or wicked problems are social problems to which there are no straightforward and simple solutions, because they are multifaceted and are seen differently by different actors (Forrester et al., 2018). There are often contrasting and opposing views among groups of stakeholder – or even within the same group – and often no single perspective is more relevant than another. Such different views typically lead to stagnation in the search for solutions since it is impossible to agree on a single line of action. Wicked problems arise when complex social issues such as, livelihoods or mental or physical health, are at stake, as there are diverse contributions towards solutions from those facing the problem and those considered to be experts in the field. We see these wicked problems as complex problems that can be described as “systemic”, because they are often linked to multiple complex adaptive systems, such as the health or the economic system.

Systemic problems involve diverse and interdependent stakeholders, who should be able to self-organise through iterative learning processes, and should possess sufficient flexibility to adapt to unpredictability (Keestra & Menken, 2016). Studies that have methodologically explored what it means to address complex problems have consistently highlighted the importance of learning, unlearning, and re-learning among all groups, as well as understanding and including all perspectives to find sustainable solutions (Elia & Margherita, 2018). Many debates have claimed that a purely scientific approach might not be entirely suited to comprehending complex social issues; scholars have agreed on the need to study wicked problems, especially those concerning public policies, require creative thinking, and complex and comprehensive iterative approaches. This calls for a different scientific approach (Head, 2019).

In India, where there are diverse languages, cultures, religions, political ideologies, and access to basic resources, bringing about social change and solving complex problems might appear difficult, if not impossible. After more than 60 years since the establishment of the

Indian Republic – constitutionally declared to be socialist – social protection remains unavailable to the vast majority. Bringing about policy change in this context implies confronting challenges in defining a movement oriented to change, as well as in setting goals and milestones. This calls for a creative and “outside the box” collective solution to working for broader social change.

One complex public health problem in India, which can be seen as wicked, is the lack of an effective mechanism to ensure the rights of children with disabilities and enables their social inclusion (Arora et al., 2018). The issue of disability in children is complex in that there are multiple adaptive systems at stake: the family, health, education, social security and legal systems. Hence, working with children with disabilities is by its very nature interdisciplinary (Keestra & Menken, 2016), which leads to the need to include diverse perspectives from multi-stakeholder groups. This complexity is reflected not only in policy-making, but also in academic research. In light of the growing body of scholarship advocating greater recognition of the rights of children with disabilities, there is a clear need for an integrated approach to arrive at or provide solutions, coordinated by relevant stakeholders.

What appears crucial is the need to empower parents, who have the most significant experiential knowledge, as key stakeholders. Indeed, it is the parents (i.e. the family system) who are constantly interacting with all other systems to support their child who has a disability. In turn, all the other systems adapt and learn from the family system to develop appropriate support mechanisms. The importance of including families’ knowledge is also crucial in advocacy (Goldman et al., 2020). This calls for strengthening the family system and for considering parents’ perspective in formulating solutions. It is remarkable that in practice there are few or no policies or regulations to ensure that parents’ empowerment and training are given priority in relation to permanent disabilities such as autism, intellectual disabilities or other genetic disorders (Math et al., 2019). Although India is a signatory to the

United Nations Convention on the Rights of Person with Disabilities (UNCRPD), subsequently ratified on 1 October 2007, there has been a lack of effort to make training and parents' empowerment mandatory in working with children with disabilities. While child rights laws are aimed at ensuring child safety and protection, there is little or no systematic regulation on how this can be made possible by empowering the parents. The most recent laws on disability, Rights for Persons with Disabilities Act 2016 (RPWD), enforce several mandates on schools and workplaces, but they do not focus exhaustively on the process towards their implementation in ways that protect the rights of the families who a child with disabilities. Such a disconnect between the intention of the policy and its practical implementation adds to the complexity of the issue, which thus qualifies as a wicked problem.

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#### 1.1 GENESIS OF THE CURRENT STUDY

A year before the RPWD 2016 was implemented in India, an incident in the State of Kerala triggered debates on the rights of parents of children with disabilities. In March 2015, a six-year-old, who was non-verbal and diagnosed with autism, broke his arm while receiving therapy at a private centre. The quest to understand what happened at the centre revealed a lack of parental participation and inclusion in early intervention programmes. The indifference of the professionals in charge and the dependence and helplessness of families with regard to therapies were glaring.

The principal researcher in the current study, who has been working in the field of disability, education and mental health since 1998, acted as a boundary spanner (between being a mother and a professional) and connected with the mother of the autistic child who broke his arm. A shared vision of speaking up about the injustice that both of us have long perceived emerged. Soon, another mother of an autistic child, whom we both knew, joined. A well-connected disability rights activist, with extensive background knowledge of working

towards advocacy and policy change for the disabled in India, was roped in to give proper direction to the group and act as a legal partner. An informal WhatsApp group to discuss the problem and an action plan, called *Together We Can (TWC)* was begun. TWC soon started a Facebook page to broaden its reach, build visibility and create momentum in public discourse and engagement. More mothers joined, and one with an adult autistic son stayed on with the core team. A media partner, who shared the same vision, connected with TWC. The movement was based in Kochi, Kerala, but not all of its core members were. Within a year, the need for a scientific and knowledge partner was realised, and the first author began a process of discovery into understanding and including diverse perspectives to navigate the complex problem. The scientific guide then became an indirect key player in the TWC journey.

TWC has continually transformed along the way with the entry and exit of multiple stakeholders – parents, professionals, media partners, lawyers, researchers, disability rights activists, students, policy-makers and the general public. TWC started out as a movement calling for the regulation of therapy centres in Kerala. This movement spanned five years, from filing the first petition in 2015 to guidelines being formed and published in the Kerala gazette in 2020.

While the regulation of therapy centres was the main objective of TWC, along the way it took up several related causes as and when different individuals or groups came forward asking for support and seeking intervention. Many of these causes were synergistic with the primary cause, when they involved different kinds of injustices to children within the therapy or schooling system. But TWC also supported many other causes, like networking to find safe spaces for victims of domestic violence, highlighting wheelchair accessibility issues, coordinating access to financial aid for needy families and petitions to education boards on inclusion. This happened because of the trust and credibility the movement gained while

working towards its main cause. These broader activities were not originally envisaged, but the subsidiary goals were interlinked with the core goal of addressing broad inequities arising from the same legacy and tone.

In the interest of progressive social change, the group kept abreast of the problems of individuals and groups who were vulnerable or marginalised, and evolved with this recognition and knowledge. The main focus was not on finding a simple solution, but on moving the structures that caused the problems.

This study presents a deeper understanding of TWC's journey from its inception to date, using a realist evaluation approach (Pawson & Tilley, 1997). This approach was chosen in view of the complexity of the issue at hand, which is further complicated by an intricate interplay between various social actors: policy-makers, practitioners, scientists, non-government organisations (NGOs), and family members. Realist evaluation allowed us to explore the detailed change mechanisms and outcomes that play a role in the field. The study aims to clarify the *initial programme theory* of a social change in the field of childhood disability and its translation into the middle-range theory of change. The initial programme theory includes questions about how the core members of the movement enhanced learning, unlearning and re-learning; how they garnered support; their key driving force and turning points.

With the aim of understanding TWC's trajectory from its inception to the present, the study first identifies and analyses the core mechanism for change in the journey in the primary cause of TWC, which starts with the *context*: a child breaking his arm enabled a small group of individuals, mainly mothers, to achieve such a significant *outcome*: policy change. Second, to test these mechanisms for their role and relevance in the other secondary causes that the TWC movement supported.

## 2. METHODS

This study used realist evaluation (Pawson & Tilley, 1997) to develop an initial programme theory, and then refine it to a middle-range theory (MRT) that could be tested by conducting realist analysis on important events and turning points occurring during TWC's journey.

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### 2.1 REALIST EVALUATION

Realist evaluation is a theory-driven strategy that enhances the understanding of complex processes and methods of continuous reconstruction and interaction that any movement striving for sustainable change must go through. It is an emerging paradigm in social work practice, designed to understand complex processes of social change. It has the potential to not only understand outcomes, but also track and systematically evaluate the mechanisms that lead to these outcomes, as well as the context that generates these mechanisms (Kazi, 2003).

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#### 2.1.1 INITIAL PROGRAMME THEORY

As outlined by Pawson and Ray (Pawson, 2010) realist evaluation starts with the identification of certain assumptions and perceptions of the actors involved. For this purpose, narratives from the core members were collected, on the basis of the following the questions. *Summaries of the TWC journey; Barriers and facilitators in the journey; Methods used to overcome the barriers; Turning points in the journey; Key lessons from the journey.* The authors had several discussions about these narratives and arrived at five core assumptions:

1. *Openness to learn* among all core members
2. Conscious attempts to *creating turning points* in the journey
3. *Garnering support* from other stakeholders
4. *Channelling emotions* to move forward

## 5. *A cohesive teamwork* despite setbacks

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### 2.1.2 MIDDLE-RANGE THEORY

The middle-range theory (MRT) was formulated through a realist interview between TWC's scientific and knowledge partner, and the core TWC member (first author). The two engaged in a teacher–learner cycle as described in realist interviews whereby the interviewer places each component of the initial programme theory and the interviewee either confirms, falsifies or adapts it until the theory is refined and consolidated (Manzano, 2016). In the beginning of the study, the knowledge partner was the interviewer and TWC member the interviewee. During the study the interview was more in the form of dialogues, discussions and conversations.

Every component of the initial programme theory was developed with scientific embedding to frame the MRT. Consequently, elements of the MRT went back to the TWC journey to learn more about the core mechanism of change. The five core theories or mechanisms of change that worked across TWC's trajectory were identified and are presented below.

#### 2.1.2.1 DOUBLE LOOP LEARNING THEORY

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*Openness to learn* among all core members of TWC can be aligned with the theory of double-loop learning in which the basic assumptions of theories of change are challenged and adapted. Double-loop learning in social movements increases their ability to help themselves and others to become more effective leaders, learners, and facilitators of double-loop change (Argyris, 2002).

#### 2.1.2.2 THEORY OF CHANGE AGENT

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A conscious attempt by a member to *create turning points* in the journey was embedded in the Theory of Change Agent whereby, in most social movements, like the TWC, an event or a person acts as a change agent that drives the movement forward and is the connecting link with all the other actors (Lunenburg, 2010).

#### 2.1.2.3 RESOURCE MOBILISATION THEORY

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The process of *garnering support* from other stakeholders links closely to *resource mobilisation theory* in social movements that emphasises the variety and sources of resources; the relationship of the movement to the media, policy-makers, the court authorities, and other parties; and the interaction among movement organisations (McCarthy & Zald, 1977). Resource mobilisation with respect to the TWC movement mainly used social media. It can also be associated with theories that explain the potential to build “virtual [social movement] communities” of sympathisers of movement organisations who act professionally on behalf of the causes that resonate loudly with public opinion (Diani, 2000).

#### 2.1.2.4 THEORY OF STRUCTURE OF FEELINGS

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Propelling the journey by *channelling emotions* links to the *theory of structure of feelings* that explains how emotions are an integral part of social movements. It shows how the emotions are framed, how they can become an opportunity for change in different cultural contexts and how they contribute actively to social movements (Ruiz-Junco, 2013).

#### 2.1.2.5 THEORY OF COMMUNITY OF PRACTICE

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*Cohesive teamwork* among all the members, despite setbacks, can be linked to the theory of Community of Practice (COP). The COP theory is used to understand the coming together of the four key members of the TWC movement, who are mothers of children with autism, and

one of whom has closely worked with and experienced similar struggles in parenting. Within this group of mothers there is uncertainty but at the same time trust and not the traditional top-down approach of working. Each member is seen to contribute and add strength to the movement in her own unique way. COP theory is used to understand the dynamics between these four members and also the inter-dynamics of each of these members as they interacted and how they influenced other actors along the journey (Mortier, 2020).

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### 2.1.3 THEORY TESTING

The five core mechanisms of change that are hypothesised in the MRT were first tested and exemplified within the context and outcome of the primary cause supported by TWC, which led to policy change and lasted for five years. Then the role of these mechanisms was explored within the contexts and outcomes of many other secondary causes that TWC supported from its initiation to date. Four other secondary causes were randomly chosen based on their diversity and outcomes from the primary cause. Two of these had a favourable outcome and two had unintended and even undesirable outcomes.

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## 2.2 PARTICIPANTS AND CHARACTERISTICS

A total of eight members can be seen as key players who actively influenced the course of the movement either directly or indirectly (Table 1).

*Table 2.2.1: Actors and description of characteristics*

ACTOR	CHARACTERISTICS
TWC MEMBER 1 [KEY INFORMANT 1 – KI2]	Mother of the child who broke his arm

TWC MEMBER 2 [KEY INFORMANT 3- KI3]	Active social media user; friend of TWC member 1
TWC MEMBER 3 [KEY INFORMANT 4- KI4]	Mother of an adult son with autism; great social connections in the community
TWC MEMBER 4 [KEY INFORMANT 1- KI1]	Professional (Psychologist and Special Educator); principal researcher
KEY PLAYER 1	National-level disability rights activist; mentor all along TWC's journey
KEY PLAYER 2	Media partner responsible for news dissemination and visibility of TWC
KEY PLAYER 3	Legal partner; represented the public interest litigation filed by the core members at the Kerala High Court
KEY PLAYER 4	Knowledge partner on policy change and research (co-author) who guided the principal researcher

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### 2.3 RESEARCH DESIGN

A qualitative methodology was used to explore TWC's journey. The principal researcher (first author) engaged closely with each step from 2015 to the present. Primary (i.e. interviews) and secondary (i.e. social media posts, court cases, petitions and minutes of

meetings) data were analysed using realist evaluation as a guiding framework. The efforts that worked and those that did not, and how the relationship between the context and the mechanisms – i.e. movements towards change – evolved and transitioned in each step, were identified.

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## 2.4 DATA SOURCES

A wide variety of sources were considered for the analysis:

- Interviews were conducted with three core members in November 2020, when TWC had completed five years;
- Formal documentation and communications between TWC core members and key players and other stakeholders were scanned for key turning points, main facilitators and barriers encountered;
- Research notes and documentation of interactions between core members and key players;
- All minutes of meetings and petitions sent to policy-makers and other authorities were scanned to understand context, mechanisms and outcomes of each turning point;
- Detailed examinations of public interest litigation filed by TWC core members in Kerala High Court from 2017 to the final verdict in June 2020;
- Other case studies similar to TWC were analysed for the role of the same mechanism as emerged from the primary case study – the broken arm case.
- Media reports and responses on social media were analysed to gain insight into the public dimensions of the TWC journey.

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## 2.5 ETHICAL CONSIDERATIONS

This study was based on secondary data (i.e. media reports, public social media posts and minutes of meetings which TWC members attended). All the data have been anonymised. Before gathering data from the core team, ethical approval was obtained from The BALM (The Banyan Academy of Leadership in Mental Health) in Chennai, which has an independent ethical committee. During the study, explicit informed consent was obtained from each participant in either a written or verbal form before any form of data collection. The participants were informed about the aim and procedures of the research, its implications, their rights as participants, and the fact that participation was entirely voluntary and could be stopped at any time.

### 3. RESULTS

The five core patterns observed during the TWC journey were interpreted through a context-mechanisms-outcome configuration and allowed for confirmation and refinement of the MRT. The five mechanisms are referred to by the patterns that emerged in the initial programme theory for the purpose of retaining its significance to the core members of TWC: *openness to learning; creating turning points; garnering support, channelling emotions, cohesive teamwork*. These theories were tested in two parts.

Section 1 highlights each of the five patterns (i.e. mechanisms) being tested as having occurred between the initial context of the autistic child breaking his arm to the outcome of policy change.

Section 2 exemplifies how these mechanisms related to specific contexts and produced desired or unexpected outcomes in many secondary causes TWC took up along the way.

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#### 3.1 TESTING THEORY WITHIN THE PRIMARY CAUSE OF TWC

Five key change mechanisms were identified by focusing on instances of change and uncertainty and on specific catalytic moments that often resulted in significant shifts in TWC's journey. These mechanisms did not occur in isolation and were constantly and interchangeably interacting along the way.

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### 3.1.1 MECHANISM 1: OPENNESS TO LEARNING – THEORY OF DOUBLE LOOP LEARNING

*Openness to learning* was a central and constant process, manifested most explicitly when something had to change quite rapidly or when the outcomes of certain actions were not favourable.

At the outset, the name of the movement, “Together We Can”, came about as an outcome of *openness to learning*. When the WhatsApp group was created, it was called PIL (Public Interest Litigation) in keeping with the group's initial objective to file a court case, citing the injustices prevalent in the system. Observing that other mothers were reluctant to join in anything related to a court case, the group's name was changed from PIL to TWC (Together We Can). Thus, *openness to learning* facilitated the journey: “*Everyone felt that they did not want to be dragged into any case, we surely needed more parents and hence...change the name from PIL to something neutral...*” (KI1). Another instance of *openness to learning* happened when the initial lawyers were not effective and the group unanimously decided to find a new one. Each member played a role in ensuring that this transition happened smoothly: “*Social media post-TWC: 'Due to unavoidable personal circumstances within #TogetherWeCan we are having to go in for a change of advocate'*”. The TWC members decided to team up with professionals from other states who supported the cause and the movement: *Social media post of TWC page “#NATIONAL\_LEVEL\_SUPPORT [mentions credentials of the professional supporting and links it to their own court case] #MORE\_POWER\_To\_PIL!* The outcome of this mechanism was that the group learned to adapt quickly and be flexible while remaining firm about its goals.

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### 3.1.2 MECHANISM 2: CREATING TURNING POINTS – THEORY OF CHANGE AGENT

A *creation of the turning point* was by an individual or a catalytic event that coalesces and directs critical moments towards change. Both aspects of this mechanism were evident in the TWC movement: in one case the *creation of the turning point* was by a single person taking a lead and giving direction to the others, in the other the *creation of the turning point* was an event that was instrumental in causing the change.

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#### 3.1.2.1 CREATION OF TURNING POINTS BY A PERSON (OR PERSONS)

Although TWC was a solidarity-based group endeavour, every so often one person succeeded in facilitating a significant change. While no single individual could have taken the whole movement forward, the role of individuals in taking the lead and bringing the collaborative effort together was evident throughout. Even where the *creation of turning points* was achieved by a single individual, it was only in the dynamic and collaborative group efforts that the individual could become a *creator of the turning point*. In this context, the ability of the rest of the team to follow the lead and take the efforts in one direction and have a common shared vision becomes a mechanism for change: “...we should have a wider coverage, that is possible only through social media like Facebook...we started taking our own videos and posting .it reached a lot of people... it was her brain behind...suggesting these ideas at the right time...took us forward” (KI2).

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#### 3.1.2.2 CREATION OF TURNING POINTS BY AN EVENT

Change was sometimes triggered by a specific event. For example, when the child broke his arm, his mother mentioned that it was very clear to her that she had to do something, but needed someone to show her the way. This decision came about only when the child broke his arm: “I knew that this is not the right way...what I was doing till now was not at all

*working. So, when she said..., if you stand with me, then we will take it forward...I was looking for that support from the people around” (KI2).*

Another example was the social media campaign gaining nationwide momentum and wider stakeholder support due to a case of trolling on a social media page: *“The trolling on Facebook was a turning point event for us. Though it was targeted to bring us down it had the reverse effect: more parents and professionals started to voice their support without us having to ask them. The biggest setback turned out to be a huge comeback with wider support across the county”.*

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### 3.1.3 MECHANISM 3: COHESIVE TEAMWORK – THEORY OF COMMUNITY OF PRACTICE

A shared vision, a shared understanding of the problem and the way forward, and a shared commitment to work together in a *cohesive teamwork*, were present throughout TWC's journey. Overall, despite several differences of opinion within the core group, each one stood firm in their commitment and moved forward and supported each other: *“We gave each other a sense of strength and courage that together we can do it... believing in each other's strengths, voicing for our children. If we don't speak, nobody will ...not to be bogged down by negativity...” (KI4).*

It is important to note, however, that this shared vision alone was not enough and the group members had prior trust and faith in each other. The TWC core members knew each other before developing the movement; thus, when the child of one of them broke his arm, the event very much affected each of them, strengthening the bond within the group: *“She is a friend from before...it was very shocking for all of us, because it was an avoidable error ... it refocused our thoughts about why our children need to be alone when they are going through such important steps in their development in their life and why they have to be alone”.*



It is noteworthy that none of the key members was directly dependent on the schooling system when they joined the movement: Key Informant 2 mentioned that she has decided to stop visits to any therapy centre after her son broke his arm; Key Informant 3 was home-schooling her child; and Key Informant 4's son was an adult and was not dependent on any centre. *"I stopped going to Therapy Centres.... [KI4], whose son was more than 23 years old, she didn't have to be directly in touch with Therapy.... [KI3] "...none of us had any direct connection with any therapy centres. Parents used to come for the training... [KI1] was hearing all horrible stories, more than what happened to me"* (KI2).

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#### 3.1.4 MECHANISM 4: GARNERING SUPPORT –THEORY OF RESOURCE MOBILISATION

From the beginning, one of the shared objectives was to get more people to support TWC's cause and to voice their support. The process began through personal contacts of key members and the creation of the WhatsApp group. Cohesive teamwork was established. Key Informant 2 talks about how she was already part of several parent groups in which untoward incidents in therapy centres were discussed and she was confident in being able to obtain the support of all those mothers to join the *cohesive teamwork*. *"...there was a group called Supermoms and we would share even the minute things that happened...I was confident that they all will support me in this cause..."* (KI2).

To build momentum, several discussions were initiated deliberately in the group so that parents would write their stories and these would automatically be documented and recorded. Adding more people became the objective. Key Informant 2 explains how discussions in the group helped the *cohesive teamwork* become stronger: *"we started very informal...WhatsApp group all my friends... got added to that group... there was a lot of discussion happening...."* (KI2).

However, it was soon realised that professionals had to join in as they could facilitate change. Once they had enough confidence many parents were willing to speak up, and visits to therapy centres were initiated by the key members. Key Informant 3 explains how, despite starting with a large group initially, a four-member *cohesive team* was eventually arrived at through group discussions and by making the objective of TWC clear: “...*Visits to different therapy centres and speaking to parents gave us a not so good review...parents were afraid to speak up as they felt they would be denied therapy*”. *Openness to learning* too was evident within the methods used to *garner support*. When the need for support from a larger community was evident, the *cohesive team* adopted other methods like social media to *garner support*. “*We started writing our stories ... first time I wrote about the incident. I gave a write up about it in the page itself... it reached a lot of people ... again we started getting media coverage...*” (KI2). Each additional resource person became a change agent by bringing their own resources and support for TWC. When one mother posted her experiences in a video format, it created a snowball effect. It motivated parents to come out with stories and record their own videos, and the turnaround from being fearful and silent to posting self-videos began. “[*O*ur own experiences in the therapy centres we started posting videos on Facebook...it reached a lot of people. We started getting videos from people who saw our videos” (KI2).

The professionals opposing the movement were then seen as opposing the parent movement. The *cohesive team* chose this moment to contact professionals to join the video campaign and it happened easily. “*A few occupational therapists who also supported videos on social media and spoke in favour of our case and the need for regulation...*” Resource mobilisation started with personal contacts leading to other contacts, thus setting in motion a snowball effect that helped in mobilising enough support across the country and to raise the issue to be regarded as being of public interest.

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### 3.1.5 MECHANISM 5: CHANNELLING EMOTIONS – THEORY OF STRUCTURE OF FEELINGS

Emotions as a mechanism have been present throughout TWC's journey, fuelling and driving the group forward. They both facilitated, gave rise to and drove change, while also changing and evolving in the process. Emotions were applicable to many contexts and also helped in triggering particular outcomes. Often, they were more than just a driving force but helped the organisation stay together and navigate complexities, keeping the members motivated throughout.

In her account about how and why she joined the TWC movement, Key Informant 2 explains her prior experiences as a parent with the system. She spoke of emotions of anger, sadness, helplessness and frustration too: *"I was like running behind all these Therapy centres...that was the most painful days in my life, when...I knew that what I was doing ...was not at all working...I was seeing my child suffering... I was very upset and...but I was not in a position to take that decision to stop the therapy"* (KI2). Key Informant 3 also spoke about her frustration in navigating a system that was not supportive of her child, and was shocked because professionals were insensitive and non-inclusive during therapy: *"It was a shock for me ... to be told ... I as a parent am a hindrance and that the therapist cannot function well with the parent in the room and that the child will not function well...it was not something that sat well with me"* (KI3).

These underlying emotions connected all the members and made the *cohesive team* stronger, urging members to action. However, not all emotions were of anger, sadness and irritation. Emotions of excitement, thrill and deep gratitude were also immediately shown, and every little positive comment or news and action from policy-makers celebrated. Deep emotional connections were constantly being built by sending thank-you letters, acknowledging via Facebook posts and more. It can be observed how the structures of feeling changed and

evolved as the movement became stronger and started seeing more outcomes. A main emotional shift came about within a year into the journey when the core TWC member partnered with the scientific guide. This changed perceptions of projecting the movement from being based on activism to one of empowering parents. With this change within the mechanism the outcomes also became more desirable, with professionals and policy-makers taking the movement more seriously.

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### 3.2 TESTING THEORY WITHIN SECONDARY CAUSES OF TWC

While the different structures can be identified and analytically separated, they all worked together, forming a continuous feedback loop. The journey started with *an openness to learning* among all key members that things need to change; the change began with an event acting as a *creator of a turning point*. This event created anger and frustration and this *emotion was channelled into garnering support* from diverse groups (all stakeholders) including the formation of the *cohesive team* with key players. For example, KI3 mentions how a particular journalist's reporting led to public awareness and policy-makers took notice of the group's voice. These media reports made the group stronger and emotions changed from anger and frustration to a sense of finally being heard and understood: "*The media especially [names the journalist and media house] kept writing about us and we were heard by [mentions key policy-makers] and this gave us credibility and more support. We were so relieved and soon more parents and even professionals were willing to support*" (KI3).

It can be observed that no mechanism was disjointed from the others. However, for the purpose of clarity this section is depicted in a tabular form, highlighting the key elements of context, mechanisms and outcomes. Table 2 indicates many events happening during the TWC journey.

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#### 3.2.1 CASE 1: [TABLE 2]

Context	Mechanism	Outcome
<p>Senior students in a mainstream school are being hit on the head as a form of discipline, and the mother of one of the students seeks TWC's support to stop the practice (May 2019).</p>	<p>A TWC member <i>creates a turning point</i> by <i>garnering support</i> of other key players who are in charge of regulating such practices in schools.</p> <p>The mother's <i>emotion is channelled</i> into action by encouraging her to speak to the right authorities. There is <i>openness to learning</i> from previous experience; the higher authorities are contacted first for quicker action.</p>	<p>The Kerala State Commission for Protection of Child Rights (KeSCPCR) intervenes, issues a warning to the school and the practice is stopped.</p>
<p><b>Quotes</b></p> <p><i>"Don't take a soft stand okay....coz they will be try to persuade you to say it was not a big deal"</i> (KI1, in the attempt to channel the mother's emotions to action – research notes of interactions).</p> <p><i>"Admissions with a clause. Private schools are becoming money-making enterprises. Unfortunately, parents are ready to accept to whatever said by these institutions"</i> (KI2, garnering public support by sharing the petition on social media – social media post).</p> <p><i>Openness to learn</i> is at play when the petition is directed to the child rights commission office rather than the education board as one person in the office is part of this case's <i>cohesive team</i>: <i>"We at TogetherWeCan strongly believe that KeSCPCR will take action in</i></p>		

such a manner that no child or parent feels threatened to report in future too” (excerpt from the petition).

3.2.1 CASE 2 [TABLE 3]

Context	Mechanism	Outcome
<p>A journalist alerts TWC about a PhD student with a disability having no access to the toilet during her examinations and facing the embarrassment of wetting herself.</p>	<p>The student acts as the <i>creator of a turning point</i> by writing on her Facebook page asking for support. <i>Openness to learning</i> is visible when the petition is not sent by TWC but by the student, who is capable of <i>garnering support</i> and is able to <i>channel her emotions</i> of embarrassment into action. The <i>cohesive teamwork</i> is now between the student, a key player and a core member of TWC.</p>	<p>The Department of Social Justice – Ministry of Kerala serves notice to the learning centre and orders accessible toilets for all students henceforth.</p>
<p>The <i>creation of the turning point</i> is –the student’s public Facebook post: “<i>I have Spina Bifida...makes it difficult for me to walk long stretches... inhibits my bladder control and</i></p>		

*makes squatting difficult... I cannot use Indian toilets...western toilets were not available ... ended up wetting myself and had to write the entire exam in wet pants and clothes...”.*

*Cohesive team member this time the key player garners support by writing publicly on social media by channelling her emotion to a call for action “... why are we letting [the learning centre] get away with an offhand non-apology of a response?”*

Headlines of media reports each of which acted as *turning points* and *garnered more support* by using *emotions as a driving force*. Several media houses were contacted by TWC, and a few are quoted below:

*“Locked, unused, unclean: The struggle to access disabled friendly toilets in Kerala”.*

*“Ph.D. student undergoes an embarrassing ordeal due to lack of toilet ...”*

*“After differently-abled student protests lack of toilets..., the Social Justice Dept. seek report on accessibility”.*

*“Social justice Dept. reports slams ... for keeping toilets locked, leaving disabled student in distress”.*

### 3.2.3 CASE 3 [TABLE 4]

Context	Mechanism	Outcome
A journalist asks for comments and reactions from TWC core team member on the controversy	TWC <i>garners support</i> when one member attempts to <i>create a turning point</i> via <i>channelling everyone’s emotions</i> with a post	Does not initiate communication with Yale University, but instead highlights the need for

<p>surrounding the Yale University research on anxiety in young children with autism; this research has met with criticism and the university posted a rejoinder on its website.</p>	<p>on social media about the research. But no <i>cohesive teamwork</i> emerged. There is <i>openness to learning</i> when the core member connects with key players on how to take it forward, but this does not lead to further action.</p>	<p>ethical practice in research and creates a discussion on social media from several stakeholders.</p>
<p>Though TWC successfully evoked strong emotional sentiments, no cohesive teamwork ensued and hence there was no further action other than emotional reactions from various stakeholder groups. This was probably because the case did not relate to India and TWC did not liaise with anyone directly affected by this case.</p> <p>The journalist and key player share the controversy about research to another core member and urges action “<i>Gross. They should be taken to international court for violating human rights, child rights and medical ethics</i>”.</p> <p>TWC key member’s social media post: “#UNETHICAL! I have the full paper...Toddlers exposed to emotional and social threats deliberately with consent of parents...Can parents give consent to just about anything? Earlier it was in the name of “therapy” now “research”.</p> <p>Some of the stakeholders’ reactions (parents, professionals, and researchers, public) to the public post were filled with anger and shock, expressed in strong language. While some questioned the ethical committee behind the research, a few wanted to read the full article.</p>		



Some volunteered to be part of the cohesive team, but soon backed out for different personal reasons. There was no conscious creation of a turning point to follow on this.

3.2.4 CASE 4 [TABLE 5]

Context	Mechanism	Outcome
<p>Referred by the District Child Welfare Committee Chairperson, a father seeking justice for the death of his 11-year-old autistic daughter in a special school approaches TWC. The school authorities cite no reason for the death and the hospital authorities do not conduct a post-mortem. The father is still unclear how his daughter died.</p>	<p>The <i>cohesive teamwork</i> is between a TWC member and the child's father and the advocate who files the case. TWC members <i>create a turning point</i> by contacting a television journalist, an earlier supporter of TWC's primary cause. <i>Openness to learning</i> is visible when the TWC member insists that the father too be open about the issue, as in previous cases when the affected party is unwilling to speak to the media there is less possible <i>channelling of emotions</i>.</p>	<p>Backlash from a few professionals based on an interview that highlighted the lack of training among professionals. The court case is still pending a verdict and no significant action taken on the school or its authorities.</p>
<p>Excerpts from the father's narrative on public television [translated into English from Malayalam] "<i>My child is dead. She will not come back...there are many such children and</i></p>		

*many such parents...a permanent solution must come from the government...No father or mother should have to go through this...”.*

There was backlash following this interview in which a core TWC member highlighted the lack of trained professionals and that even those who are trained do not include parents in therapy. The TWC page and the core member is then targeted in the public page of Kerala Branch of All India Occupational Therapy Association (KBAIOTA) using an edited video of the actual footage.

However, openness to learning is seen here as well when negative emotions against TWC are channelled to garner more support. TWC's issue gains greater visibility when the media reports the backlash from professionals.

*Media report: “For questioning malpractices associated with Occupational Therapy, Kerala researcher targeted”.* This prompts KBAIOTA to remove the edited footage and TWC manages to *garner support* from occupational therapists beyond the state and country.

While this exploration theory testing gives insights into how each mechanism was crucial in bringing about change, it also shows great contextual variation. The cohesive team was not the same throughout, the actors triggering turning points were varied and the nature of the support garnered differed. Emotions were channelled to gain support, and sometimes they triggered a backlash. Nevertheless, the five identified mechanisms played a role along the entire TWC journey, not just in its primary cause but also in other secondary causes, irrespective of their outcome.

#### 4 DISCUSSION

This study reviewed the mechanisms of the social change through the example of the actions of a small group of mothers of children with a disability. One of the key findings highlights the power of a small group (mainly mothers), who would otherwise not be taken so seriously by law- and policy-makers, successfully sustaining a movement for five years from the initial context to the outcome of a first of its kind in policy-making in Kerala. Hence this movement shows that any social change starts from the bottom and not from top. The complexity itself was one of the movement's driving forces. It was necessary to use complexity theory to understand the relationship between the parts and the whole movement to illuminate the difference between the complicated and complex nature of non-linear outcomes; the effect of various processes and actors that enhance or diminish the effectiveness of the journey, and how double-loop learning helped the actors move forward despite the complexity and use it to achieve the desired results. (Pycroft & Wolf-Branigin, 2016).

The results confirmed the MRT and each of the five mechanisms of change had a significant role in the entire journey of TWC to date. As with all social change, these specific mechanisms helped the group achieve more than it set out to. While *double-loop learning*, *change agent*, *community of practice*, *resource mobilisation* and *structures of feelings* were identified as the key mechanisms, all of these were deeply interconnected. When one mechanism failed the others took over and sometimes multiple mechanisms were used at once. Not all of the mechanisms resulted in the desired outcome and not all desirable outcomes were intended by using any one mechanism. However, when all the five mechanisms acted together, a desired outcome was most likely. Despite the non-linear nature of such complex movements, the results indicate the emergence of a new theory of change – the *Together We Can theory of change* – where all five mechanisms act together, each one complementing the others.

Though each mechanism is linked to an existing theory of change, the findings show further characteristics within the mechanism that are more likely to bring about the intended change. Within the COP, there is both uncertainty and trust. Each member is seen to contribute and add strength to the movement in her own unique way. COP is used to understand the *intra* dynamics between these four members and the *inter* dynamics of each of these four members as they interacted and how they influenced other actors along the journey (Mortier, 2020). What improved the COP's cohesive was their prior connection and knowledge and mutual trust. It was important that when the COP had ample lived experience of the system they were attempting to change but were not dependent on the system, the shared vision became stronger. The existing friendship among key members of the COP helped it to work cohesively despite setbacks. All of the members were successful in their respective field of work and a credible image of each of the members added strength to the COP. The support of key players in the background, if not within the COP, contributed to its wider influence. The scientific and knowledge partnership helped the COP to change the direction from "*finding problems*" to "*aiming for solutions*".

As in other studies that focus on victim advocacy and the influence it can have on policy change, this study also shows that when the COP includes at least one victim/affected party, the movement gains a stronger and more credible voice. The structures of feelings are strongly embedded when the members of the COP have been directly affected by the lack of change. It was important to have at least one member in the COP who has a strong emotional drive and was also indirectly or directly seeking justice for a personal tragedy (Taylor-Dunn, 2016).

In the TWC movement, similar to most social movements, there is a change agent who is the link connecting all the actors (Lunenburg, 2010). However, it can be argued that the change

agent was not always one person, it could also be an event, or different stakeholders taking on the role of change agents that act as a facilitator to remove barriers along the way.

The ability of the COP to quickly perceive the roadblocks, upgrade their skills and knowledge that helps its members to become better leaders are all products of the change mechanism with TWC too – the double-loop learning (Argyris, 2002). Double-loop learning was possible as the conviction on the vision was clear to all the members at all times. Being focused on the goals but flexible regarding the methods was a strong feature of double-loop learning in the TWC journey.

A strong mechanism is the manner in which ever more stakeholders become involved into the process of change, causing it to move forward or change direction. This study also uses the theory of resource mobilisation and emphasises the variety and sources of resources: the relationship of the movement to the media, to parent groups, professional groups, policy-makers, the court authorities, and the general public (McCarthy & Zald, 1977). Resource mobilisation with respect to the TWC movement was predominantly in the virtual rather than the real space. The potential to build “virtual [social movement] communities” of sympathisers of movement organisations who act professionally on behalf of causes that have huge public resonance is explained. The COP in the case of TWC was predominantly a virtual community that was effective in communicating and facilitating a collective identity and solidarity, as (Diani, 2000) explains.

One of the important additions to common mechanisms seen in other social movements is the theory of structure of feelings. The study highlights the importance of emotions, and especially to combinations and interactions among emotions, challenges, and cause and effect

that dominated the TWC movement, is described in various other studies. There was a constant stream of emotions in every flow of action, and anger turns out to be at the core of many of the causal mechanisms (Jasper, 2011). Other studies focus on emotion-inspired advocacy strategies, such as blaming and shaming, fear-mongering and boosting, but the present study specifically dwells on how feelings and emotions are consciously used to mobilise resources and influence public opinion and attract more stakeholders who feel the need to speak out for change (Salgado, 2018).

The realist approach used for this study draws parallels with other studies that used such an approach to understand large-scale changes in health care. Despite TWC being change driven by a very small group of mothers, the mechanisms and how it emerged can be compared to those found in studies dealing with larger organisations. The similarities can be seen when an ambitious change programme shifts from its original goals and meets unforeseen challenges (Greenhalgh et al., 2009). The use of this lens allowed us to examine the intricate mechanisms at play to understand how social change can be achieved and what conditions and mechanisms can contribute to more successful outcomes.

This study shows the scope for the replicability of certain mechanisms of change regardless of how big or small the organisation or movement or advocacy. It also seemed to cross all the cultural barriers in bringing about change. A key strength of this study is that while such evaluations have mostly focused on large organisations and multi-layered systems, it focuses on a small one, which was a lot easier to analyse, thanks to the relatively high visibility of the actors and the mechanisms. Owing to its smaller scale, the study allowed frequent and in-depth consultation with the participants, which further increased the ecological validity of the findings. Future studies could draw insights from this that, when conceptualising and addressing a complex social problem, the size of the acting group does not matter.

## 5. CONCLUSION

The main goal of the study was to identify the key mechanisms of change in the TWC journey to help give direction to its core members in understanding their own patterns of work and use these to their advantage in broadening the future scope of work. The study shows that mechanisms of change can work in the same way in small or large movements, and when there is scientific backing even a small group can lead a movement to policy change. The movement was successful in reducing several challenges such as breaking fear and silence by being the voice of the vulnerable, creating a strong network of stakeholders working together for a common cause, and policy-level changes that include beneficiaries' inputs.

However, there remain some great challenges facing TWC's future work, namely the implementation of the policy change achieved, the maintenance of the drive and energy to mobilise resources and finding relevant communities of practice, depending on the

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# CHAPTER 9.

## 9. DISCUSSION AND CONCLUSION

The objective of this research was to attempt to reduce the gap between policy-making in the field of rehabilitation of autistic children in India and experiential knowledge of the mothers of such children by gaining a deeper understanding of barriers and facilitators of inclusion of maternal knowledge for improving the well-being of children with autism.

The main research question was formulated as follows:

How can the lived experiences of mothers with an autistic child be understood and supported so as to enable sustainable long-term solutions?

In order to guide the investigation, the following research sub-questions have been formulated:

How can we understand the lived experiences of the mothers, their challenges and coping strategies from the time of child birth to noticing differences in their child?

How can we understand the lived experiences of the mothers and the gaps in support from the time of noticing differences to reaching an early diagnosis of autism in their child?

How can we understand the lived experiences of the mothers during the diagnostic process and early intervention stages – the facilitators and barriers in her agency?

How can we understand the lived experiences of the mothers from a right's perspective during the schooling years of their child?

How can we understand the agency in a few mothers and the mechanisms they used to lead to policy change? ‘

In this chapter, we will first address each of the sub-questions separately and place them within the broader scientific context. Regarding the first sub-question, we will discuss how lack of support for the mothers can lead to unintended consequences regarding the use of technology. We will discuss the recent changes regarding technology use post 2020, when the global pandemic shifted the accents regarding the utilisation of gadgets in child upbringing. And we will finish off with the possible suggested directions for combatting the vulnerability. For the sub-question two, we would start with the role of mothers' intuition in the process of seeking diagnosis. Then we will discuss the role of the professionals in the process and we will finish off by showing some of the barriers to seeking care and their implications. When talking about the early intervention stages, we will discuss the emotional impact of the definitive diagnosis on the mothers upon moving to the measures that can be utilised to make the process less impactful. Furthermore, when talking about the impact on mother and child, it is important to discuss the school year period, which was investigated through the lens of human rights and more specifically what is the role of inclusion in ensuring the rights of the child. Finally, we will discuss how some mothers' agency can lead to policy change and how this can be further enhanced. The final part of the discussion will touch upon the issues of validity and suggestions for further research before reaching the general conclusion of this thesis.

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#### 9.1 HOW CAN WE UNDERSTAND THE MOTHERS' LIVED EXPERIENCES, THEIR CHALLENGES AND COPING STRATEGIES, FROM CHILDBIRTH TO NOTICING DIFFERENCES IN THEIR CHILD?

As shown in Chapter 4, mothers' lived experiences after childbirth were characterized by vulnerability arising from a burden of responsibility and a lack of support or knowledge in caring for their child. This commonly resulted in the use of technology as a means of coping, with mixed results. Mothers frequently found that technology had the effect of calming and occupying their child in a way that made their differences easier to manage, in that it helped them to fit within the boundaries and expectations of conventional motherhood. Ultimately the

potentially negative effects of media use led mothers to conclude in hindsight that they would not recommend using technological solutions as a means of coping, showing that a lack of knowledge can place them in difficult situations. However, as shown in the article and further supported in this discussion, new developments have found that the use of technology is not uniformly negative, and if it is used effectively, with knowledge and support, it could provide precisely the help and resolution mothers sought. These findings regarding mothers' lived experiences are integrated into the further literature under key themes, presented below.

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#### 9.1.1. LACK OF SUPPORT

Mothers framed their turn to technology as a means to cope with the lack of external support in dealing with the initial differences and problems. The findings of this thesis corroborate other research on complex family dynamics arising from autism and parenting (Brezis et al., 2015). Among other things, mothers often sacrificed their careers in order to care for their child and household, but when the fathers came home, they rarely engaged with their child, preferring to rest and watch television in a way that made clear the response of turning to technology (Farooq & Ahmed, 2020; Krishnan et al., 2017; Brezis et al., 2015). The questions of the child's extended family in relation to its development or education were consistently directed only at the mother in a way that made abundantly clear her responsibility, and the potential to be criticized in the event of any problems. This lack of direct support in the domestic sphere is corroborated in the findings of Brezis et al. (2015) in which fathers included in courses for parents of autistic children referred only to their wife and not to their own personal relationship with their child. Indeed, though this experience was shared by Indian women who migrated to Australia, they also noted that local health services compensated to some degree through the consistent support of midwives, which included psychosocial support

and education, and could present an alternative path for future research and action (Rao et al., 2020).

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#### 9.1.2. COPING THROUGH TECHNOLOGY

The universally complex burden of the transition to motherhood, compounded with differences in the child's development and a lack of external support, placed mothers in a difficult position, in which they quickly found that having recourse to technology seemed to be the best response. The child could be calmed and occupied by the television or a smartphone, thus allowing the mother to focus on household tasks or be calm in her family functions. Mothers also experienced technology as positive; such as watching cartoons together with siblings, providing a space for social connection or for learning opportunities that helped bridge the developmental issue. This was further supported by literature establishing the benefits of co-viewing as a form of social interaction. These findings are aligned with further research on multiple levels. The affinity of children with autism with technology is well documented, and many researchers cover the use of technology either as an alternative "babysitter" in some cases, or as a form of stress-free family bonding (Stiller & Mößle, 2018). Surveys of parents of children with autism have also found the frequent use of technology as an educational tool (e.g. learning vocabulary and spelling by searching on YouTube), and a means of strengthening or building friendship (Laurie et al., 2018). There is also further evidence of the use of technology as a means of compensation, reward or distraction from behaviour that parents want to discourage (Ceranoglu, 2016). Nonetheless, scholars generally agree that there has been too little research on this association, especially pertaining to early childhood, where children with Autism are often exposed to technology at an earlier age than their peers (Laurie et al., 2018; Slobodin et al., 2019; Stiller & Mößle, 2018).

Mothers expressed concerns about this even when they first began relying on it, but felt they had no other option in trying to meet new and unfamiliar challenges. Their uncertainty is not easily resolved when looking at the literature, as in contrast to the positives described above, much research points to potentially damaging effects. In addition to general concerns about developmental issues noted in the literature review, further research concerns the impact of technology in exacerbating social deficits from non-social use, the neglect of other leisure activities and less sleep resulting from use (Ceranoglu, 2016; Mazurek et al., 2016; Stiller & Mößle, 2018). Indeed, Stiller and Mößle noted something similar to the “addiction” mothers noticed in the form of oppositional behaviour when the technology was removed from the child (2018). Given the conflicting arguments in the literature, and the further gap between this and the information to which mothers have access, it is unsurprising that they were uncertain about their reliance on technological solutions. This uncertainty, the risk of being blamed for failing to care properly for their child because of a lack of concrete knowledge which makes them vulnerable in this instance. While actively seeking solutions with their child, as shown by this reliance, shows a certain degree of agency, it is ultimately wasted energy because it lacks direction. It may further have the side effect of masking the child’s problems for longer, thus preventing parents from seeking help and treatment at an earlier stage.

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### 9.1.3. TECHNOLOGY POST-2020

Given the uncertainty about the impacts of frequent use of technology by children with autism, some of the literature ultimately advises limiting or avoiding it altogether, especially among younger children (Slobodin et al., 2019). However, as society is increasingly saturated with various kinds of media, this makes imposing abstinence even more complicated to enforce. This is especially true during the lockdown measures related to the COVID-19 pandemic and the move to online education and work. Parents were encouraged to set up supervised peer

video chats and even some pre-schools moved online (Mental Health and Coping during COVID-19 | CDC, n.d.). Indeed, it has since been demonstrated that technology can help children learn and comprehend stories even at pre-school age (Gaudreau et al., 2020). Furthermore, Cristia et al. (2017) note how the use of technology, rather than being an influence in and of itself, is an integrated system of influence involving parents, content developers, educators, community culture, incentive structures and events. This coupling of research and recent events indicates a need for a paradigm shift in how researchers approach the question of technology use by children with autism, away from a linear positive/negative outcome and towards a dynamic understanding of how to navigate and achieve positive effects. The question becomes less about whether we should use technology and more one of how we can go about using it safely and productively. Future research should therefore address the issue of empowering parents, whatever their background, to use technology in an informed manner.

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#### 9.1.1.4. COMBATting VULNERABILITY: SKILLS AND SUPPORT

Going beyond the question of the positive or negative impact of the reliance on technology, the point remains that it arose in all situations because of a lack of support or alternatives in supporting the child. Indeed, the effort to make the child conform to expectations and needs, which technology was used to achieve, demonstrates a lack of knowledge about child development and how to deal with differences or deviations from expected norms. To that end, it is worth considering approaches identified in the literature that might otherwise have provided the support or skills that the mothers needed to use their energy more effectively in supporting their child. The provision of extra support or parenting guidance in the first year of a child's life is common practice in many countries, yet its exact nature varies greatly across settings. In Sweden, for instance, antenatal classes that might otherwise focus only on birth

also address parenting practices, though studies show that parents would like the focus to be more on the latter and allow more space for questions and discussion (Barimani et al., 2018). Furthermore, it is unclear whether a topic like development milestones and deviation from them are included in the classes, though it would be fairly simple to integrate. In Australia, rather than classes, research mentions the ongoing support of medical services as integral both in providing some respite or support in household tasks and in building a relationship with a specific midwife whose knowledge and resources are made available to mothers (Rao et al., 2020). In particular, the attention to emotional support was also noted, which is most helpful given the stress that mothers experience (ibid). As these examples show, there are numerous ways to potentially increase support and knowledge for new mothers, although the literature offers almost exclusively western examples. Examples from elsewhere are generally focused on a specific problem or dynamic, as in the case of parenting courses in Iran that specifically cover child development as a way to manage expectations, and prevent irritation in order to tackle maltreatment (ED et al., 2014). One example was found of a parenting skills programme in India, specifically aimed at parents of children with autism, which proved effective in reducing parents' stress, but was unsurprisingly contingent on diagnosis and thus irrelevant to mothers' initial stress and ways to cope, without considering possibilities for early intervention (Brezis et al., 2015).

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## 9.2. HOW CAN WE UNDERSTAND MOTHERS' LIVED EXPERIENCES, THE GAPS IN SUPPORT, FROM NOTICING DIFFERENCES TO THEIR CHILD'S EARLY DIAGNOSIS OF AUTISM?

Mothers' experiences as they begin to seek help, outlined in detail in Chapter 5, are characterized by their intuition being dismissed by various levels of the systems in which they function. Despite the lack of knowledge about social and emotional developmental milestones, mothers began to notice something 'amiss' in their child. In line with the Family Adjustment Adaptations and Response (FAAR) model, their taking action on this was informed by

consulting with their direct family, where they were either reassured or blamed, both of which stalled their decision to seek help. In the professional sphere, mothers noted that paediatricians were unfamiliar with the child's social development, and thus initial concerns were again dismissed. This discussion therefore considers three key points of their experience in further depth: the lack of screening or early recognition by professionals, intuition and its lack of recognition as legitimate knowledge and barriers to seeking help.

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#### 9.2.1. INTUITION

The mothers' intuition that something was wrong arose as early as three months, and as a result of the family delays, they often expressed distress that they allowed themselves to be reassured and thus took longer to obtain the care their child needed. Those who did not trust their intuition lost confidence and regretted their choices, whereas the few who acted on it felt empowered. Maternal intuition has been researched to some extent, with a focus on decision-making and emotion (Tomljenovic et al., 2019; Kirchner et al., 2020). Yet, its significance is often underestimated, as in professional contexts, it is dismissed unless it has been confirmed that there is some reason for concern (Warland et al., 2018). The importance of intuition is well documented in nursing and midwifery, which is formed by expertise and rapid, unconscious clinical observation (Erisman et al., 2020). While it must be considered reflexively, Floyd and Davis also note that it might be considered a form of 'authoritative knowledge' that places value on connection and context in emergency situations (Floyd & Davis, 1996). There are therefore major arguments for valuing maternal intuition, and though it may not need to be acted on without further consideration, to dismiss it immediately is unfortunate and unnecessary.

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#### 9.2.2. SCREENING AND KNOWLEDGE OF HEALTH PROFESSIONALS



Health professionals' lack of knowledge was identified in two recent studies in India, which note a lack of training and awareness, resulting in false reassurance and delays of 18 months in diagnosis (Bhavnani et al., 2021; Shorey et al., 2019). These studies emphasized a need to leverage existing human resources and non-professional experts to foster awareness, conduct training of first-contact health professionals, and apply screening tools to monitor child development (ibid). Screening tools can have a huge potential, as discussed in further research, given that they are also useful for predicting children's future behaviour before pre-school, and thus enable more immediate and effective coping (Kalstabakken et al., 2021), such as creating richer environments to promote skills and abilities (ibid). In this sense, mothers' concerns that earlier intervention might have significantly benefited their child have been shown to be valid. Other research, however, has identified the role of communication with health professionals in treatment and wellbeing (Bhavnani et al., 2021). Furthermore, it has been established that children's timely referral might result in the more effective use of the scarce resource of child development specialists in India (Divan et al., 2021). There is, therefore, substantial evidence both for the existence of what Divan et al. (2021) call a detection and care gap, and for the benefits of remedying the situation. In relation to mothers' specific experiences in this research, the lack of awareness, dismissal through reassuring narratives or blame, and the ongoing advice to wait and see resulted in disempowerment and vulnerability where there might have been a bolstering support for mothers' agency by individuals trusting or responding to their intuition.

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### 9.2.3. BARRIERS TO SEEKING HELP

This thesis contributes to the body of research on barriers to seeking care and early diagnosis of autism. These barriers exist at the personal, social and professional levels, each of which is well documented in the literature. At the personal level, findings show that misperceptions about autism and denial on the part of the immediate family prevent early diagnosis, and indeed

Chapter 5 demonstrates that mothers' perceptions of autism, if they had ever heard the word before, did not do justice to what they were experiencing (Bhavani et al., 2021). At a social level, Shorey et al. (2019) note the way in which collective child-rearing practices (initially seeking support from the family, as our research shows) and cultural narratives regarding child development (as with the use of gender as an explanation for differences) can influence how families seek care. Finally, at a professional level, multiple studies outline the need to shorten paths to seeking help, improve outreach and increase the knowledge of first-contact health practitioners (Bhavani et al., 2021; Farooq & Ahmed, 2020). Despite mothers' agency and intuition, the barriers to care they experienced prevented them from taking action for their child, such that multiple levels of lack of knowledge and skills created vulnerability. As a last note it may be worth considering the ways in which support is contingent on diagnostic pathways, while ongoing research by leading experts in global mental health indicate a need to shift beyond this to trans diagnostic approaches aimed at low-threshold, ongoing and easily available mental health support (Michelson et al., 2020).

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### 9.3. HOW CAN WE UNDERSTAND MOTHERS' LIVED EXPERIENCES DURING THE DIAGNOSTIC PROCESS AND EARLY INTERVENTION STAGES – THE FACILITATORS AND BARRIERS TO THEIR AGENCY?

The diagnostic process experienced by mothers, as described in Chapter 6, was characterized by the dynamics of grief and analysed as such. In line with research on the potentially negative impact of diagnostic disclosure, our research identified the ways in which the medical approach was often a barrier to mothers seeking early intervention. As they worked their way through the various phases of their grief, many mothers were unable to follow through on treatment, or when they attempted to do so were met with a confusing wall of information, they felt unable to manage. Thus, the socio-emotional dynamics of blame and grief in the family, coupled with

the recurring theme of lack of knowledge and deregulated services, exacerbated mothers' vulnerability.

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### 9.3.1. EMOTIONAL IMPACT

The recognition of the affective toll that the moment diagnosis takes, depending on the nature of disclosure, is well established in the literature (Reed & Osborne, 2018). Tait et al. note that diagnosis is either “a therapeutic turning point or a brief confusing and emotionally devastating lecture” (2016). Indeed, it has been argued that the experience of receiving a diagnosis varies across cultures in relation to different (mis)conceptions about autism and differences between cultures that emphasize the collective or the individual relating to perceived shame (Papadopoulos et al., 2018). The moment of diagnosis is therefore of great significance, and the problems mothers experience are very much in line with patients' concerns relating to the disclosure of a diagnosis in many different fields relating to lack of support in understanding the condition and its implications (Besson et al., 2013; McMullan et al., 2019). With knowledge thus being a key barrier, it is worth considering the way that emotionally charged disclosures, such as those for cancer, are often supported by explicit guidelines for health professionals (Besson et al., 2013). This negative state is further compounded by the emotional experience of having a child with autism, involving a burden on emotional and financial resources, a lack of visible improvement and lack of emotional reciprocity (Krishnan et al., 2017). A proportion of this initial distress is also attributed to the loss or lack of appropriate support networks, although these do improve over time (Papadopoulos et al., 2019).

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### 9.3.2. MEASURES FOR IMPROVEMENT

Given the issues pertaining to diagnosis, knowledge, isolation and lack of support, it is worth considering possible means to improve the experience of diagnosis. Firstly, any existing

guidelines for disclosure might help to alleviate the initial shock. Furthermore, assistance in navigating initial treatment options by actively involving parents in treatment processes could help to remove some of the knowledge barriers mothers' experience, as well as the isolation and lack of support. Indeed, including parents in their child's treatment has been found to reduce their distress and improve the child's treatment outcomes (Burrell & Borrego, 2012).

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#### 9.4. HOW CAN WE UNDERSTAND MOTHERS' LIVED EXPERIENCES FROM A RIGHT'S PERSPECTIVE DURING THEIR CHILD'S SCHOOL YEARS?

A recurring term in Chapter 7, which addresses the school years, was the incomplete application of the term "inclusion" across the exo- and macro-system levels relating to the child and the mother. Inclusion appears to be contingent on a diagnosis, rely on educators with little knowledge about the needs of children with autism, and involve a failure to implement laws and policies for its application. Rather than understanding the child's inclusion in education as a right, systems related to the mother seem to consider it more as an act of charity. Where a right means the duty bearer has an obligation to engage fully in meeting an individual's needs, charity assumes that the mother and child should be happy with any accommodation made. Indeed, the emphasis was seen to be placed on adapting the child to fit within the system to enable "inclusion", rather than looking for ways the system might accommodate the child.

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##### 9.4.1. INCLUSION AND EDUCATION

This research demonstrated the ways in which inclusive education was not being put into practice as stipulated by law, leaving the pressure and work to the mothers to help their children fit into the system. Teachers requested support from mothers, rather than the reverse, and children were often excluded through use of "special rooms" and "special teachers". In this way, the mothers aligned with the roles described by Pillay et al., where mothers were a primary force in resisting a "deficit" understanding of autism (2020). Moreover, such approaches in

education are fairly common according to the literature, with Singal (2019) for instance, noting that most research focuses on their assimilation rather than the quality of learning experienced by disabled children. This ties into the point expressed by mothers that they were pushed to make their child fit with the educational system, irrespective of any potentially negative impact. This “take it or leave it” approach places the children at risk and creates yet another source of stress for the mothers. The one-sided approach to inclusion of making the child fit the system rather than vice versa ignores the benefits inherent in inclusive education at the educational, social and economic levels (Ainscow et al., 2019). Teaching across individual differences could only improve education for all children, inclusion could contribute to the creation of a non-discriminatory society, and by keeping all children within one educational system, and all additional costs might be saved (ibid). Yet, in some cases, even parents felt that inclusion was not mutually beneficial, because they also internalized the “charity” understanding, rather than a rights-based one (Mathur & Koradia, 2018). This one-sided definition of inclusion also lacked the more theoretical development of the meaning of the term “inclusion”, such as privileging the voices and experiences of those more often assigned to the periphery in various ways, or the potential decolonizing function of inclusion in education (Slee, 2011; Walton, 2018). Walton (2019) argues that educational systems by default exclude and marginalize some people because of their colonial heritage. The knowledge hierarchies that produce these privileges for certain voices is also observed by Slee (2011). It can therefore be concluded that when educational institutions make only one-sided accommodations this will not produce true inclusion, but wastes mothers’ potential energy and agency by creating burdens and stress, preventing them from being able to contribute to the co-creation of improved knowledge and practices.

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#### 9.4.2. INCLUSION AND MOTHERS

The role of the mothers in the area of inclusion is multi-layered, as the inclusion of parents in educational processes generally and those involving children with autism in particular are also topics of much academic debate. At one level, mothers are striving for their child to be better included, but hit barriers of what knowledge is considered valuable that in turn exclude them and their contributions. Mothers are thus precisely some of the voices on the periphery that Slee argues true inclusion would prioritize (2011). The value of parents' participation in education seems well established in research discussing the ways in which their involvement can be increased (İlik & Er, 2019). Yet the nature of the debate, where teachers indicated challenges in including parents in individual education programmes, again creates a false hierarchy of consultation or educating parents that does not allow for real co-creation (ibid). At the same time, circumstances seem to have addressed these issues better than any previous work had done, in that the impacts of the COVID-19 pandemic and associated lockdowns leading to home-schooling have forced parents and teachers into a different kind of dialogue (Nayir & Sari, 2021). Indeed, the assumption that parents could apply the same knowledge of curricula and teaching at home as in school proved to be completely insensitive to the lack of involvement before the pandemic (ibid). Since the start of the lockdown, there has been an increase in parents' participation, where teachers increasingly educate, monitor and respond to parents in new ways such that, for instance, life skills become further integrated into education (Krishna & Rajaraman, n.d.). For the mothers in our sample, educating their own children is nothing new, nor is educating teachers, peer groups and other parents. Yet with this reformulation it is demonstrated not only is true participation possible, but that there is indeed an added value in including parents in education.

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#### 9.5. HOW CAN WE UNDERSTAND SOME MOTHERS' AGENCY AND THE MECHANISMS THEY USED TO LEAD TO POLICY CHANGE?

The final article presented in Chapter 8 charts the course of the Together We Can movement in its campaign for policy change to protect the rights and safety of children with autism. The violation of children's rights to safety and dignity during therapies from which mothers were excluded, despite the communication difficulties shown by some children with autism. The successful movement to generate policy change is used as an example of the factors that contribute to successful collective action, where five mechanisms are identified and discussed: double-loop learning, theory of change agent, community of practice, resource mobilization and structure of feeling. This discussion places this model of understanding in the context of research on human rights-based approaches to mental health as well as other theories of collective action.

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#### 9.5.1. HUMAN RIGHTS APPROACH

The TWC movement began in a collective response to a human rights violation that was channelled by social media, contacting and working with a diverse group of stakeholders. In calls for broader action regarding Global Mental Health, researchers have noted that mental disorders and patterns of abuse need to be made more visible through public action (Patel et al., 2018). In this sense TWC can be situated within larger global movements that understand the need for collective action and awareness. Other works on similar approaches emphasize the ways in which those with mental health problems bear a disproportionate burden of human rights abuses, and that particularly vulnerable groups such as children have been neglected, notwithstanding the potential of immediate action to reduce the burden of mental disorders in adulthood (Patel et al., 2011). As for how this response might be approached, researchers emphasize the need to share tasks with non-specialized workers to address shortages, for which the buy-in of professional bodies is essential (Patel et al., 2011). Such arguments, while not

expressly focused on the resources provided by those with experiential knowledge as caregivers, offers a further argument for integrating specialist and alternative perspectives and knowledge for the successful co-creation of movements that present opportunities to improve the circumstances of those with mental disorders. What most rights-based approaches, even those addressing vulnerable groups, have not acknowledged – and was dominant in this research – was the role of mothers as caregivers to safeguard the rights of their child, who cannot do so alone. The contribution of these findings to the wider debate then relates to a broadening of the scope of potential stakeholders and forms of knowledge included to consider the network of individuals and experiences related to the person whose knowledge, emotions, agency and resources can be either a barrier or a part of the solution. Furthermore, the successful collective action demonstrated in Chapter 8 also highlights the significance of the approach that “injustice anywhere is a threat to justice everywhere” in calls for collective social responsibility.

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#### 9.5.2. SUCCESSFUL COLLECTIVE ACTION

The question of what makes a successful social movement is well documented, and offers diverse solutions. Numerous models have been developed to understand this question, such as the Social Identity Model, focusing on the idea of what the collective “we” will and will not tolerate (Zomeran et al., 2018). However, researchers also emphasize the limitations of such initial models, in that they require more critical reflection on what sorts of information might be excluded in their underlying assumptions (ibid). For instance, in this research, collective identity was based on parents knowing what they would not tolerate (exclusion and rights violations) but was primarily successful because of its ability to shift focus to a positive perspective of what it did stand for. Yet the question of what creates the “we” that stands for



something might still need further critical reflection. One potential answer is presented by Ahmed (2004) in work on the ways in which emotion plays a dominant role in the shaping of a collective body, through the emotional attachment to an object of symbolic value. Indeed, the focus on anger or outrage about the case (which becomes a symbol) of the abused child was a significant aspect in the formation of the collective. Ahmed's description covers the unifying effects of hate and fear in governments as well as movements, emphasizing the creation of symbolic threats which, once imagined, may persist (ibid.). Yet, in the development of the work of Ahmed and others since the building of pervasive social networks around the world suggests that the nature of that imagining may be changing drastically. For instance, Zeynep Tufekci (2021) considers the ways in which social media may both facilitate and weaken contemporary social movements by being able to improve immediate connection without the necessary capacity building required by older movements. Yet, in our own example, both in the early days of the movement and the more recent work during lockdown, social media served mainly as a cohesive platform for core activism, which made it possible to establish real-world connection with stakeholders and collective action. The ultimate contribution of this research to the ongoing debate on the success of collective action is to draw attention to the complexity at its core, given how it relates to intertwined social systems and interaction. While the Chapter 8 identifies five clear mechanisms, and notes how they compensated for each other or acted synchronously, their non-linear action indicates a need for detailed reflection. The success of this movement and the question of sustainable action in the future relies on leveraging numerous dynamics relating to the human rights approach that is inherent in the way we value knowledge in society, how issues are framed at the public level and how change agents can facilitate the leveraging of resources and capacities. The alignment of numerous factors in this particular case, and the ways in which barriers and vulnerabilities were traversed to empower mothers, shows a promising starting point for future work relating to all the different places in

mothers' lived experiences where their resources might be better applied for their child's protection and flourishing. Realizing this promise depends on grappling with connection and complexity for which current theoretical developments provide only the barest framework, whose comprehension will require continued critical and reflective work.

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#### 9.6. METHODOLOGICAL APPROACH AND VALIDITY OF RESEARCH

This study investigated the real-life stories and lived experiences of mothers of autistic children through explorative qualitative research methods. A number of potential limitations and measures to address them can be identified. The research was based on a relatively small sample size, which is not uncommon in qualitative research studies. This was a matter of prioritizing the in-depth exploration of individual narratives, rather than emphasizing generalizability. In addition, consultation with numerous stakeholders, the piloting of the study and the document analysis of the realist evaluation were used to orient these findings within broader contexts, and iteratively restructure the research approach where needed. Findings were further integrated into wider contexts, where, for instance, the mechanisms identified in Chapter 8 are corroborated by other research and in other settings. Second, the researcher's positionality in relation to the mothers as a professional with whom they were previously acquainted may introduce bias. This was addressed through active collaboration within the research team for coding and analysis in each article. Given the researcher's own context, reflexivity was also a key area of attention. Indeed, it was advantageous that the researcher experienced no cultural or language barriers, but also required active awareness of potential bias and interpretation and thus being actively attentive to these issues throughout the process. It is also of importance to note that the sample used for this study was relatively homogenous in both geographical position (South of India, predominantly province of Kerala) and in socio-

demographic characteristics (mothers being on average highly educated and having nuclear family units). This should be taken into consideration when interpreting the findings of the study.

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## 9.7. IMPLICATIONS FOR POLICY AND PRACTICE

The main aim of this thesis is to understand the journeys of mothers who have a child with autism and to determine effective ways to provide support for them. This resulted in an understanding of how vulnerability is constructed by contextual factors, and the role of collective action and stakeholder buy-in in remedying that process. Furthermore, this research highlights the limitation of knowledge hierarchies that privilege certain ways of knowing, in that they leave valuable resources untapped. A mother's agency and empowerment, and thus her child's wellbeing, was found to be strongly tied to norms and values related to mothering, disability and diagnosis and require reconfiguring understandings of mental health in order to safeguard human rights. Concrete suggestions for future action are grouped into three categories: knowledge and parenting, strength-based interventions and co-creation.

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### 9.7.1. REFLEXIVE KNOWLEDGE AND KNOWLEDGE EXCHANGE

As demonstrated in the above discussion, knowledge gaps were significant in the mothers' experiences of vulnerability. In particular, there was a lack of awareness of social and emotional milestones in early child development, the implications of relying on technology from a young age and basic information about autism. This knowledge gap had implications for delayed intervention and family wellbeing. To address this gap, steps need to be taken at each level of the ecological systems discussed in this thesis, involving multiple stakeholders. Knowledge generation and knowledge sharing among stakeholders need to be addressed on a

large scale, beginning with active education for those who are relevant to caring for and supporting autistic children, with the understanding that evidence-based knowledge is dynamic and therefore requires a regular updating of practices. This includes stakeholders such as pre-school teachers, school management, frontline health professionals and therapists. Second, the nature of knowledge exchange needs to be adjusted so that each stakeholder is placed in a dynamic conversation with others on an equal standing of respect. For instance, collaboration with and inclusion of parents in processes of education, treatment, or other matters concerning their child, would be beneficial for all parties involved, but require a baseline recognition of the value of their experiential knowledge and input.

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#### 9.7.2. STRENGTH-BASED INTERVENTION OVER DEFICIT-BASED DIAGNOSIS

The central place of diagnosis, as both a goal and a barrier for mothers in the narratives analysed, demonstrates a mismatch between individual needs and systematic classification. Where mothers are initially seeking help and being dismissed, they later express confusion and grief on receiving a diagnosis. Although a diagnosis is a prerequisite for care, the way it was approached in the mothers' experience and local understandings focused largely on irreconcilable deficits and their management. In contrast to this approach there are two core suggestions: investigation of the potential of strength-based interventions and a reconfiguring of deficit and inclusion. Some research has already been done on the impact of strength-based interventions for autism in relation to positive parental adaptation, stigma and education and employability (Pesonen et al., 2021; Steiner & Gengoux, 2018). Research on this approach in relation to the experiences of mothers in India would be a good starting point but needs to be directly linked to a movement to seek changes in medical approaches to diagnosis and treatment. Second, the emphasis on autism deficits results in one-sided, limited understandings

of inclusion and how to facilitate it. As such, dialogue leading to policy changes and action plans should be facilitated with schools and health professionals to create practical and feasible approaches to more holistic inclusion.

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### 9.7.3. CO-CREATION OF KNOWLEDGE AND COLLECTIVE ACTION

Established issues related to knowledge hierarchies in research and medicine find clear parallels in rehabilitation systems in relation to the mothers' lived experiences. In its campaign for the recognition of their knowledge and their role in safeguarding the basic rights of their child, TWC presents clear evidence of the strength of co-creation and collective action in addressing this gap. The efforts of all institutions and individuals involved in future work to support the rights and needs of children with autism should be structured through a recognition of the input of all stakeholders. The role of TWC in providing a platform for such interaction is one example of how to facilitate such conversations.

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### 9.8. FUTURE RESEARCH

This research further identified numerous topics that would benefit from further research. First, the confusion and distress surrounding young children's use of technology, especially in the context of pandemic-related lockdowns, suggests the need for further work on this topic. A broader survey of experiences could be a starting point to confirm and build on our findings at a regional or national level. This should be followed by clear and coherent overviews of the impact of specific kinds of the early use of technology on child development. Furthermore, the findings presented in this thesis suggest that it would be beneficial to build an approach to the topic based on recognizing the ubiquity of technology, particularly among young people, and

that focuses on effective and safe use rather than simply advising limiting use where possible. Second, it is worth noting that this research focused primarily on the mothers' journeys, and did not address fathers' parenting journeys. Future research to understand fathers' perspectives and the role that they can play in supporting and protecting the child would help to build a more complete picture. Indeed, some work has already begun to understand the parenting of a child with autism in India, and the findings related to knowledge suggest that this should continue with an eye on workshops for young parents, with modules to better equip them on what to expect and how and when to intervene (Brezis et al., 2015). Another key area for future research would relate to deficit-based diagnostic models and the delay this creates for early intervention. First steps are being taken towards trans-diagnostic interventions and approaches to mental health and support, and these findings further contribute with the added dimension of the significance of considering the role of home environments in such research (Michelson et al., 2020). Further research would also be greatly beneficial in establishing the possibility of early screening as a workaround for diagnosis. Finally, given where this research stands within literature on inclusion and diversity in school contexts, more specific research on this topic in the context of India's school systems presents further opportunities.

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#### 9.10. GENERAL CONCLUSION

The experiential knowledge of mothers of autistic children, notwithstanding its value and importance, is often excluded from the rehabilitation process in the context of Southern India. Ultimately, we can see how the mothers' experiences studied in this research are characterized by specific forms of vulnerability on multiple levels of building an identity. Their experiences of vulnerability, agency, and expertise are a unique area of study that could bring further contributions to meeting research gaps at each of the levels identified. In order to best represent

their specific lived experiences this research approaches their narratives with the following research questions:

How can the lived experiences of mothers with autistic children be understood and supported so as to enable sustainable long-term solutions?

Based on the findings presented in this thesis, it can be said that vulnerability is a construct that is central to the stories of the Indian mothers of autistic children, starting with the lack of knowledge, lack of collective support, the push to fit into the construct of disability in relation to an assumed norm, human right violations and segregation from policies that aim to improve their quality of life. The patterns of experiences can be seen in all four investigated phases of the mothers' journey: from birth to noticing first differences, during the diagnostic process, early intervention, and further during the whole schooling phase. The research also showed the importance of including maternal knowledge in the diagnostic and intervention process and elicited the added value of empowerment. In the last chapter we have shown that this vulnerability does not have to be a status quo: when a mother's agency is not blocked by such barriers, she is empowered to make informed choices about her life with her autistic child. Moreover, it was shown that there is a strong potential for the advocacy and self-organisation of the mothers, which can lead to significant policy and practice changes through varied replicable mechanisms of change. Such movements have potential for reducing several challenges such as breaking the fear and silence by being the voice of the vulnerable, and creating a strong network of stakeholders working together for a common cause.

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*"...Alone we can do so little; together we can do so much..." Helen Keller*

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## SUMMARY

Lived experiences have become increasingly significant within research in mental health, particularly for working on service reforms from a human rights perspective. (Bellingham et al., 2021). For both physical and mental disabilities, efforts have always been focused on

early identification and on family support and empowerment, beginning as soon as a child is born, or is suspected of having a disability. (Mittler, 2019) This necessitates the need to focus the families towards playing the role of caregivers for children with disabilities.

Paucity of evidence and, and the lack of research on burden and risk factors contributing to neurological disabilities in children in India, impedes policy and action programmes that support the families of children with disabilities. (Arora et al., 2018). A study in 2018 showed the highest prevalence of children with developmental disabilities in in South Asia.(Olusanya et al., 2018) . Despite the growing emphasis on supporting the families towards early intervention, with specific reference to autism, there is usually a one and half year delay between parents reporting concerns to them getting a diagnosis and starting intervention. (Bhavnani et al., 2021). The need for culturally relevant conceptual frameworks to understand the screening, diagnostic process in autism had been highlighted even in recent studies and its implication in practice and policy explained significantly. Culturally specific understanding lived experiences is important as the affordability, availability, accessibility, and acceptability of services varies depending on context and the extent of mental health stigma and mental health literacy within the specific communities. (de Leeuw et al., 2020)

This thesis emphasizes the need for making the lived experiences of mothers of autistic children in India matter so that insight can be drawn from the same to help support them in their journey as caregivers.

The objective of this thesis was to understand, from the lens of the mothers of autistic children, what they perceived as barriers and facilitators along their journey.

Main Research Question: How can the lived experiences of mothers with an autistic child be understood and supported so as to enable sustainable long-term solutions?



The answers to these questions are provided in five parts. First four parts are based on the four phases of the journey of the mothers, and the last part showcases how their voices can be made to matter in policy change. Part 1 dwells into the phase from childbirth to noticing differences in the child; Part 2 draws insights from the phase of noticing differences, to seeking help; Part 3 is about an in-depth understanding into the phase from getting a diagnosis, to seeking early intervention and Part 4 is the schooling phase.

The main question was thus approached with the following sub-questions:

*Sub-question 1:* How can we understand the mothers' lived experiences, their challenges and coping strategies, from childbirth to noticing differences in their child?

*Sub – question 2:* How can we understand the mothers' lived experiences, the gaps in support, from noticing differences to their child's early diagnosis of autism?

*Sub-question 3:* How can we understand the mothers' lived experiences during the diagnostic process and early intervention stages – the facilitators and barriers to their agency?

*Sub – question 4:* How can we understand the mothers' lived experiences from a right's perspective during their child's school years?

*Sub – question 5:* How can we understand some mothers' agency and the mechanisms they used to lead to policy change?

This thesis used a combination of exploratory and qualitative methodology to find answers to these sub questions. While the Bronfenbrenner's ecological model was used to understand the various phases in the life of the mother and the influence of various actors, the KAP model was used to analyse the nature of these influences. Detailed document analysis was ongoing prior to the research and during its course as well, to gain perspectives from various stakeholders about the problem. Since the aim of the study was to improve insights into long-term solutions, the Harden's model of enlightenment, empowerment and emancipation was

used to understand what factors contributed to their agency. For insight into the various mechanisms of change in the journey of the mother, the realist evaluation framework is also used.

The thesis navigates through the lived experiences of 24 mothers, through semi structured interviews conceptualised based on a pilot study with 8 mothers from which the underlying themes were generated for different phases of the study.

Chapter 4 provides answers to sub question 1 - how can we understand the mothers' lived experiences, their challenges and coping strategies, from childbirth to noticing differences in their child? The chapter shows how mothers experienced vulnerability predominantly due to the lack of adequate knowledge and support as they begin their journey with a child. This chapter first highlights the significant lack of support for a young mother while coping with her new-born infant, from being conflicted on whether to give up careers or not, to the subsequent increase in household responsibilities, lack of energy and time to devote to other members in the family, and hence turning to technology and screen media for support. As she tries to do that, she is faced with criticism and correction for not being able to handle her new role effectively. In addition to this, a scoping literature review of influence of screen media on the language development in infants is analysed in this section which shows how there is conflicting, non-conclusive and inadequate knowledge not just around her but also in scientific literature showing influence of screen medium and technology on infants. This highlights the need for urgent and more research in these areas, as post the pandemic, screen medium is not something one can think of avoiding entirely anymore, when even education has shifted to the online mode. This again increases the responsibilities of the mother. The chapter concludes by highlighting how the mothers tend to become vulnerable because of this lack of knowledge compounded by lack of support and lack of skills to navigate through the initial years of motherhood.

Chapter 5 provides answers to sub question 2 – How can we understand the mothers' lived experiences, the gaps in support, from noticing differences, to their child's early diagnosis of autism? The chapter first shows how there is a tendency to dismiss the mother's intuition as a relevant knowledge, not only in the family members, but also by health professionals. The level of knowledge of both family members and health professionals, their ability to pass it on to the young mothers by particularly giving them individualized feedback, is where a substantial gap is noticed. The chapter goes on to narrate how lack of knowledge about developmental disabilities, and autism in particular, acts as a barrier to help seeking behaviours in the mothers. It is shown how this knowledge was lacking among the family members as well, with them ending up denying the mother's need to seek professional help. It shows how the professionals too followed a diagnostic approach to first dismiss the fears of an autism diagnosis in the mothers, and leaving them without any further insights or follow up action plan.

Chapter 6 answers the sub question – “How can we understand the mothers' lived experiences during the diagnostic process and early intervention stages – the facilitators and barriers to their agency? This chapter describes the dynamics of grief, post a diagnosis of autism, and how the medical model of diagnosis delivery most often acts as a barrier rather than a facilitator of early intervention. In addition to exploring the various phases of grief, the chapter also analyses the phases of overcoming the same. The chapter concludes that a more individualized and family centred approach to diagnosis delivery, alongside educating parents on intervention programs, would go a long way in reducing the emotional impact that the diagnosis has on the mothers. In addition to this, including the mother's experiential knowledge while formulating the intervention plans, and considering her as a valuable part in

co-creating her child's support program, can help her feel more empowered to take on the journey with confidence.

Chapter 7 answers the sub-question "How can we understand the mothers' lived experiences from a right's perspective during the child's school years? In this chapter the incomplete application of the term "inclusion" across various systems that the mothers interact with, is highlighted. The chapter particularly dwells on the provision in the schooling section of RPD Act, 2016 and analyses the nature and extent of violation experienced and perceived by the mothers, as they navigate the schooling years of their child. It shows how the mothers struggled to fit their children into a schooling system that was lacking both knowledge and understanding, on how to accommodate and support the children and their diverse learning needs. This chapter concludes that when one-sided accommodations are made by educational institutions it rarely produces true inclusion, and wastes the potential energy and agency of the mothers, and adds further stress by preventing them from contributing towards the co-creation of knowledge and practices. Thus, it would be imperative to include the mother's experiential knowledge while formulating inclusive education programs and policy, as it adds much value towards understanding ground realities.

Chapter 8 answers the sub question – "How can we understand some mother's agency and the mechanisms they used to lead to a policy change? This chapter navigates the journey of Together We Can (TWC), an advocacy movement in Kerala, that was initiated to protect the rights and safety of children with autism. This chapter highlights the need for collective social responsibility while addressing issues related to global mental health, and the need to include diverse stakeholder perspectives wherein the voices of those we propose to support does not go missing. The mothers who lead this movement showcase how there is effective support and knowledge sharing when they are able to make their voices heard. and also create a collective platform to raise a voice for the safety of their children, and eventually bring

about policy change. The chapter concludes that the mechanism that came to play within the TWC movement can be a promising start to using the same while aiming to include other groups that are now considered vulnerable and marginalised and thereby empower them to voice for themselves.

This thesis summaries the complex challenges and opportunities in the lives of mothers of autistic children. Reflexive knowledge and knowledge exchange among stakeholders needs to be addressed on a large scale, beginning with active education for those who intend to care for and support autistic children. Keeping the parent's knowledge and experience outside the facet of working with children is not only a waste of their energy and agency, but also gives a skewed understanding of the complexities in rehabilitation while formulating sustainable solutions. A strength-based intervention approach over a deficit-based diagnostic approach can act as a facilitator to the mothers' agency from the time of childbirth onwards, throughout their journey. Collective action, social responsibility, and breaking the knowledge hierarchies in research and medicine, can go a long way in safeguarding the rights of children with autism, as showcased by the TWC movement.

The vulnerability that is central to the stories of the Indian mothers of autistic children, starts with a lack of knowledge and support. It is further compounded by the construct of disability within a diagnostic medical model, and followed by human rights violations and segregation from policies that aim to improve their quality of lives. These vulnerabilities can be mitigated by including the mother's knowledge in the diagnostic and intervention process, thereby empowering her to make informed choices about her life with her autistic child. The Mothers' agency when not blocked has a strong potential for advocacy and self-organisation, and that can reduce several challenges such as breaking the fear and silence, by being the voice of the vulnerable, and by creating a strong network of diverse stakeholders working together for common good.

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