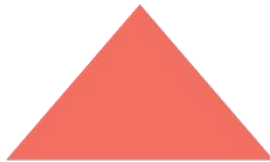


SATTVA

Ummeed CDC - FRC REPORT

2024



Acknowledgements

This study, focusing on identifying support needs of parents and caregivers of children with developmental disabilities and evaluating the contribution of a Family Resource Centre (FRC) in addressing these needs, was undertaken by Sattva Consulting Pvt. Ltd., for Ummeed CDC. This qualitative study was carried out in Mumbai where the FRC programme works with parents and caregivers of children with developmental disabilities.

We would like to extend our sincere thanks to the team at Ummeed CDC including Dr. Vibha Krishnamurthy, Dr. Koyeli Sengupta, Mrs. Vinodhini Umashankar, Dr. Alokanda Rudra and Ms. Adrika Maji for their priceless cooperation and for offering valuable suggestions and inputs during the study. The study team expresses its heartfelt gratitude to all primary and secondary stakeholders who generously offered their experiences, thoughts, suggestions and their valuable time during the execution of the study.

Executive Summary

1 in 8 children (aged 2 to 9 years), in India are estimated to have a developmental disability, and may be at risk of experiencing adverse socioeconomic conditions such as poverty, violence, psychological stresses, inequitable access to education, healthcare, livelihood and social participation.^(1, 21)

Developmental Disabilities (DD) are neurodevelopmental disorders characterised by limitations in function due to disorders developing in the nervous system. These limitations can cause delays in achieving developmental milestones or negatively impact functions in domains such as cognition, motor performance, vision, hearing, speech and behaviour.⁽¹⁷⁾ The severity of their physical, cognitive and socio-emotional challenges, coupled with societal exclusion and negative cultural perspectives, make them some of the most vulnerable and stigmatised children in the world, underscoring the critical need for a holistic support system for children with DD.⁽¹⁷⁾

In the last two decades, there has been a predominant shift in perspective towards the treatment of DD solely from a medical condition, to following a '*biopsychosocial*' approach, which recommends viewing an individual's functioning as a dynamic interaction between biology, psychology, and socio-environmental factors, setting the foundation for family-centred care. To strengthen the implementation of family-centred care, tailored interventions that can enhance parental capacity, address their support needs and create an enabling environment are required. Family Resource Centres (FRCs) - serving as vital community focal points - have the potential to nurture strengths of families and communities by enhancing parenting capabilities and facilitating access to local support services.

About Ummeed CDC:

Ummeed Child Development Center (CDC) is a non-profit organisation with the objective to help children with DD be included in society and reach their full potential, centering its activities around family-centred care. In the year 2021 Ummeed CDC established a Family Resource Center (FRC) - with the support of Credit Suisse - owned by and operated by families, for families. The objectives of the FRC are as follows:

- To give agency to families and caregivers of children with DD and create physical and virtual spaces that are owned and operated by families, for families
- To underscore the importance of collaboration between professionals and caregivers

To cater to the dynamic needs and requirements of parents and caregivers throughout their journey, the three co-founding parents of the Ummeed FRC, designed service offerings to support parent and caregiver empowerment, by building on their knowledge and skills. Over the last 3 years, the FRC has supported over six thousand families through its various activities.

About the study:

Ummeed CDC commissioned Sattva Consulting to conduct a study aimed at bridging the existing research gap in understanding the support needs of parents of children with DD and the systemic barriers they face. The study aimed to explore the potential impact that an intervention such as the FRC can have on enhancing parental capacity, promoting their mental well-being and ability to provide care for their children in the Indian context. Sattva conducted a qualitative research study, adopting the participatory research method. Through the course of the study, Sattva interviewed 43 stakeholders such as parents, caregivers, developmental paediatricians, therapists and the Ummeed CDC team in order to gain a 360° perspective. The interview data was transcribed and analysed using the thematic analysis method to identify primary and cross-cutting themes based on the lived experiences of parents and caregivers. The insights from primary data were corroborated through extensive secondary research.

Key insights:

This study organizes insights into phases of the parental journey in raising a child with developmental disabilities. These phases include receiving a diagnosis, accessing interventions, enabling social participation, navigating family dynamics, and future concerns. Each phase examines parents' needs and identifies necessary support. The support requirements are categorized into four main areas: increasing awareness and knowledge, enhancing family and societal support, providing financial assistance, and improving governmental support.

Theme 1: Awareness and knowledge

Challenges and support needs:



Most parents reported having little to no knowledge about developmental and intellectual disabilities before the diagnosis of their child, which impacted their ability to recognise these differences early on. Similarly, limitations of the healthcare systems and lack of structured and reliable sources of information caused hindrances in parents' journey towards receiving and understanding their child's diagnosis.



Caregivers highlighted that their limited knowledge and information about suitable treatments, expected outcomes and best practices, lack of access to trained healthcare practitioners, and general lack of awareness about developmental disabilities among health practitioners themselves, made it challenging to seek appropriate interventions from the outset.



Parents shared that they had limited awareness of their legal rights for their child, its implications, and the available provisions made under different Government schemes. Moreover, parents often lacked awareness on right to access inclusive education, and found it difficult to find appropriate schools that encouraged non-discriminatory practices, and provided equal opportunities to students with DD.

Aligned activities of the FRC: Information Brochures | Meet the Expert sessions | Know Your Rights sessions | RAISE

Parental Experiences: The informative brochures and access to handpicked books supported parents in understanding their child's disability. A father described how a book he borrowed from the FRC helped him improve his knowledge regarding his son's ASD, and because the book was in Marathi, a language he was most proficient in, he could understand the concepts easily. Similarly, workshops and sessions such as Know Your Rights, RAISE, and Meet the Expert empowered parents and caregivers, fostering mutual learning and informed decision-making. These sessions helped raise awareness about government support, including the UDID card and Niramaya Health Insurance. A mother described that prior to her involvement with the FRC, she had no knowledge of the available government support, and that she was able to seamlessly avail benefits of the UDID card and Niramaya insurance scheme through the information shared from these workshops.

Theme 2: Family and community support

Challenges and support needs:



Through the journey towards receiving their child's diagnosis, some parents, especially mothers, felt isolated, confused, and blamed by societal and cultural attitudes.



Mothers, as primary caregivers, navigated family dynamics to secure interventions for their children, facing strain without adequate family support, leading to emotional exhaustion and emphasizing the need for cooperation from relatives.



Parents also highlighted the need for inclusion of children with DD in accessing communal spaces such as parks, and participate in activities such as dance classes, among others, where children with DD could freely express themselves, and make friends.

Aligned activities of the FRC: Support group | Family Day | मी-time sessions

Parental Experiences: Support groups and मी-time sessions positively impacted parents by helping them understand the importance of prioritising their mental and physical well-being, equitably treating all family members and encouraging participation in leisure activities. Mothers shared that these sessions helped them relax, de-stress, and engage in enjoyable activities, aiding in coping and easing the transition towards accepting their child's developmental disability. Parents noted that connecting with others made them feel less alone in their struggles. Some mothers formed lasting friendships beyond the FRC, finding dependable support among fellow parents, including help with babysitting during emergencies.

Theme 3: Financial support

Challenges and support needs:



Caregivers highlighted the financial strain caused by the frequent and high-cost therapy needs, emphasizing the need for customised financial instruments and enhanced government schemes to cover the expenses for developmental disability intervention more effectively.



Although the Rights of Persons with Disabilities Act, 2016, guarantees essential support such as special educators and shadow teachers for effective education of children with DD in mainstream inclusive schools, parents faced challenges in accessing these services, and shared that the financial burden of having a shadow teacher was to be borne by them.

Theme 4: Additional government support

Challenges and support needs:



Despite the guarantees under the Rights of Persons with Disabilities Act, 2016 - regarding support such as special educators and shadow teachers for children with DD in mainstream inclusive schools - parents often faced challenges in accessing these services, highlighting gaps in the implementation of such provisions.



Public infrastructure often lacks inclusivity, with insufficient ramps and elevators. Public and affordable transportation such as train and bus with separate compartments, or seats for people with disabilities are often crowded or occupied, indicating gaps in implementation of inclusive policies.

The FRC, at present, does not directly address these challenges through streamlined activities. However, the platform created by the FRC getting parents together, provides a space for parents to seek out support from one another who may have undergone similar situations.

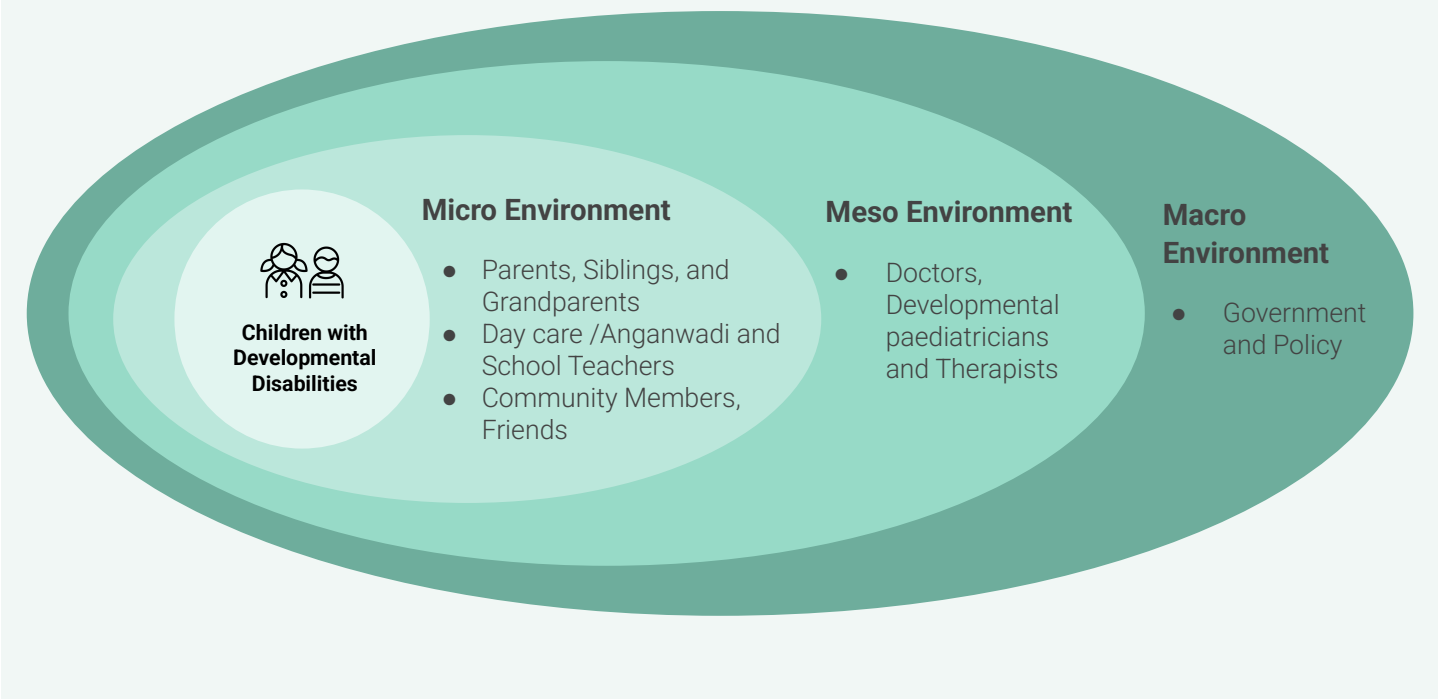
INTRODUCTION

Context and Background

1 in 8 children aged 2 to 9 years in India are estimated to have a developmental disability, according to a large scale pan-India study published in the PLOS medical journal.⁽¹⁾ Developmental Disabilities (DD) are defined as neurodevelopmental disorders that are characterised by limitations in function due to disorders developing in the nervous system. These limitations are evident in infancy or childhood as delays in developmental milestones or lack of function in domains such as cognition, motor performance, vision, hearing, speech and behaviour⁽¹⁷⁾. The International Classification of Diseases-11 classifies neurodevelopmental disorders into disorders of intellectual development (ID), developmental speech or language disorders, autism spectrum disorder (ASD), developmental learning disorder (LD), developmental motor coordination disorder, attention deficit hyperactivity disorder (ADHD), stereotyped movement disorder, Cerebral Palsy (CP), Down Syndrome, and Fragile X Syndrome.⁽¹⁷⁾

Evidence suggests that individuals with DD are at risk of experiencing adverse socioeconomic conditions such as poverty, violence, psychological stresses, inequitable access to education, healthcare, livelihood, and social participation, and are also often overlooked in mainstream policies.⁽²¹⁾ Children with DD may encounter feeding and nutritional issues and are likely to exhibit behavioural issues, and have lower verbal or non-verbal communication skills. The severity of their physical, cognitive and socio-emotional challenges, coupled with societal exclusion and negative cultural perspectives make them some of the most vulnerable and stigmatised children in the world.⁽¹⁷⁾ Research emphasises that neurodivergent children experience a lower quality of life as compared to their neurotypical counterparts on average, underscoring the critical need for a holistic support system for children with DD, across all their environments.⁽¹⁷⁾ The figure below describes the prominent stakeholders across their micro (immediate surroundings), meso (the interactions of stakeholders from the micro environment with others), and macro environments (societal and cultural contexts) that influence the quality of life experienced by children with DD in varying degrees.

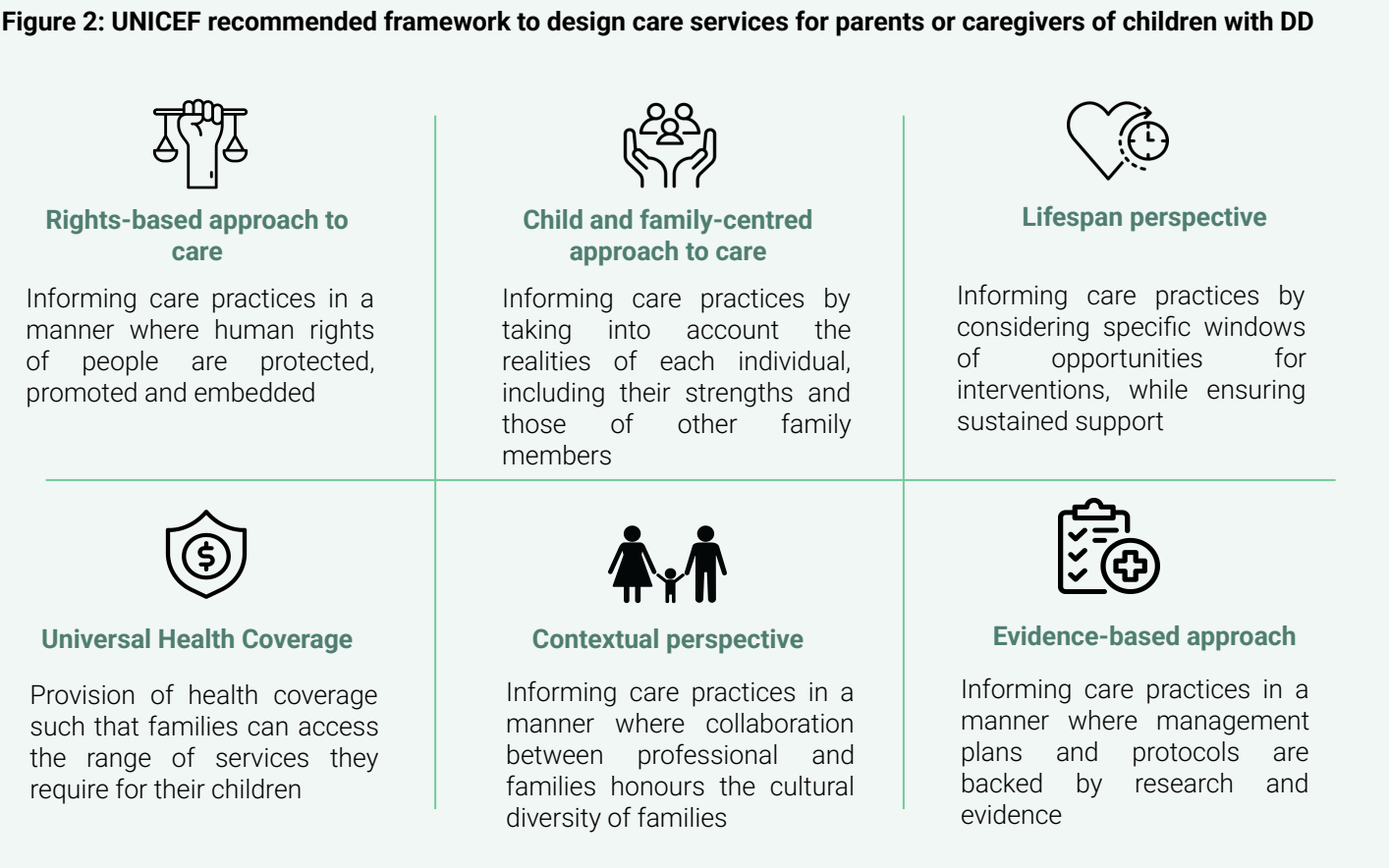
Figure 1: The varying environments and stakeholders for a child with DD



Parenting a neurodivergent child entails greater effort compared to raising a neurotypical child, as parents of neurodivergent children are required to possess a comprehensive understanding of their child's disabilities, be financially capable of providing for their children, and confront the discrimination their child may encounter. Moreover, supporting a child with DD must also be balanced with their own experiences of discrimination and isolation, addressing their biases, adjusting expectations, and making changes to their lifestyle.

Existing evidence indicates a higher prevalence of economic and social hardships experienced by families of children with DD, as the parental role entails multifaceted responsibilities that may negatively affect the parents' mental well-being.⁽²¹⁾ Moreover, disability-related factors tend to increase the financial strain of the household driven by spend on therapy, medication, and special care. This constraint is further accentuated in cases where one parent takes up full time parenting responsibility, siblings feel neglected or have their education interrupted, and families face additional costs related to disability. Elevated stress levels are commonly reported amongst such caregivers in contrast to their counterparts.⁽¹⁸⁾ Although disability can occur in any family, research suggests strong linkages between poverty and the instances of disabilities, leading to them being doubly marginalised.⁽²¹⁾

In the last two decades, there has been a predominant shift in perspective towards the treatment of DD solely from a medical condition, to following a '*biopsychosocial*' approach, which recommends viewing an individual's functioning as a dynamic interaction between biology, psychology, and socio-environmental factors. The UNICEF recommended framework mentioned below underscores the role of parents or primary caregiver's as one of the most critical factors influencing the quality of life experienced by children with DD.⁽¹⁷⁾ The ICF also suggests that improving outcomes for children with DD requires **a holistic approach** by promoting inclusive environments in homes, schools, and communities, setting the foundation for the **philosophy of family-centred care**.



To strengthen the implementation of family-centred care, there is a need for tailored interventions that can enhance parental capacity, address their support needs and create an enabling environment to promote agency and self-advocacy to confront the systemic barriers that families of children with DD face. Family Resource Centres (FRCs) - serving as vital community focal points - have the potential to nurture strengths of families and communities by enhancing parenting capabilities and facilitating access to local support services. Research suggests that FRCs play a pivotal role as key components of holistic, community-centred family support frameworks, focused on the well-being of children and their primary caregivers⁽²⁰⁾.

This study aims to bridge the existing research gap in understanding the support needs of parents of children with DD and the systemic barriers they face. It also aims to explore the potential impact that an intervention such as the FRC can have on enhancing parental capacity, promoting their mental well-being and ability to provide care for their children in the Indian context.

About the Study

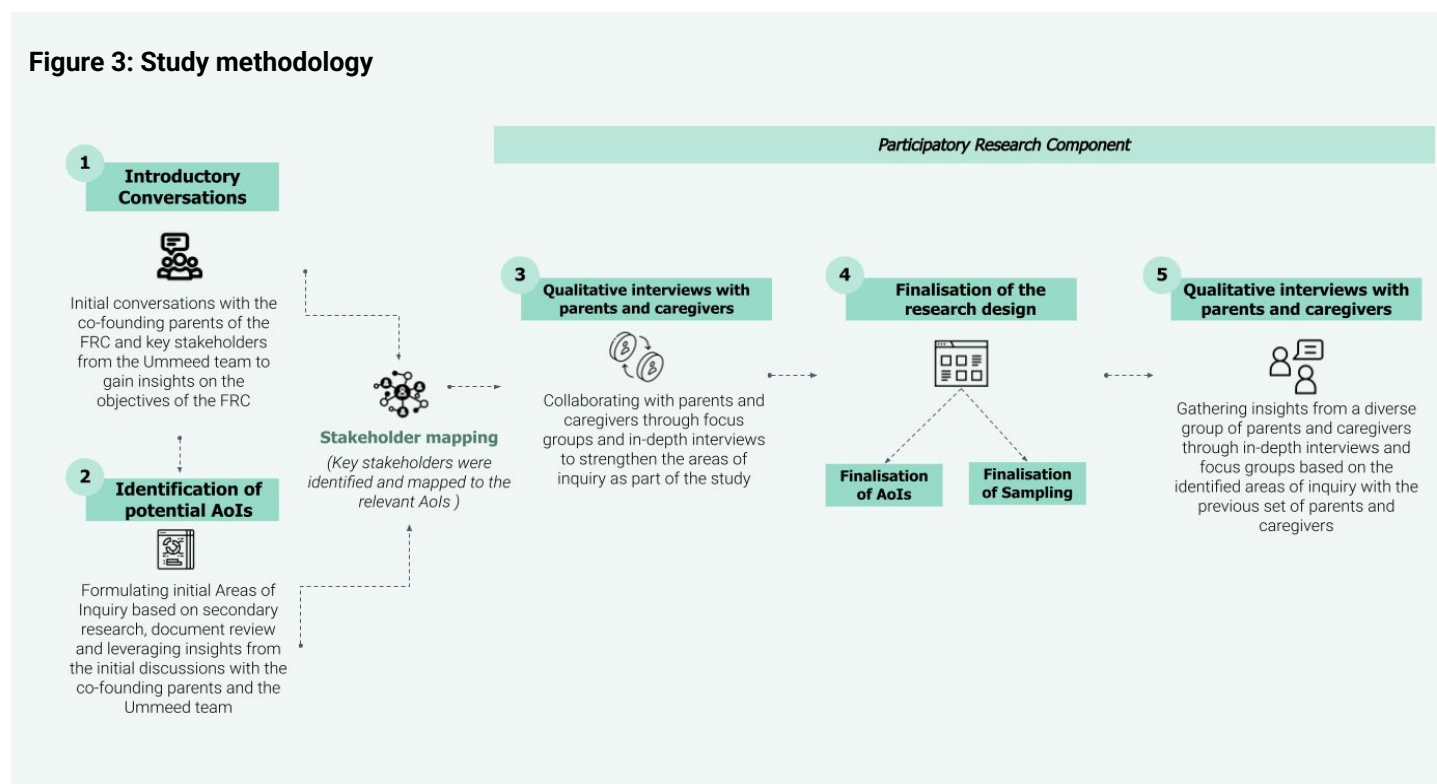
Ummeed CDC is a non-profit organisation with the objective to help children with DD be included in society and reach their full potential. The organisation has consistently centred its activities around family-centred care (FCC), which is founded on principles of information sharing, respectful care, and collaboration between professionals and families. Aligned with these principles, in the year 2021 Ummeed CDC established an FRC - with the support of Credit Suisse - owned by and operated by families, for families.

Ummeed CDC commissioned Sattva Consulting to conduct a study with the objective to understand the needs of the parents, the challenges and barriers they face and the potential of an FRC-model to address these challenges. The secondary objective of the study is to consolidate recommendations from parents and caregivers that could address these highlighted issues. The specific objectives of the study are:

- To understand the needs of parents and caregivers of children with DD, and ascertain the support they require
- To understand the extent to which parents and caregivers leverage or lean on support from other parents, and evaluate the perceived value of this support
- To understand the impact of the FRC on parents' and caregivers' sense of agency, knowledge, informed decision-making ability, coping mechanisms, and empowerment, among others
- To understand the extent to which the FRC has enabled parents and caregivers to prioritise their mental well-being and take time out for leisure and fun activities
- To understand the nature and extent of collaboration between parents and professionals and its impact on the professionals' approach to their practice
- To consolidate recommendations and suggestions from the parents and caregivers to address the identified gaps in the system

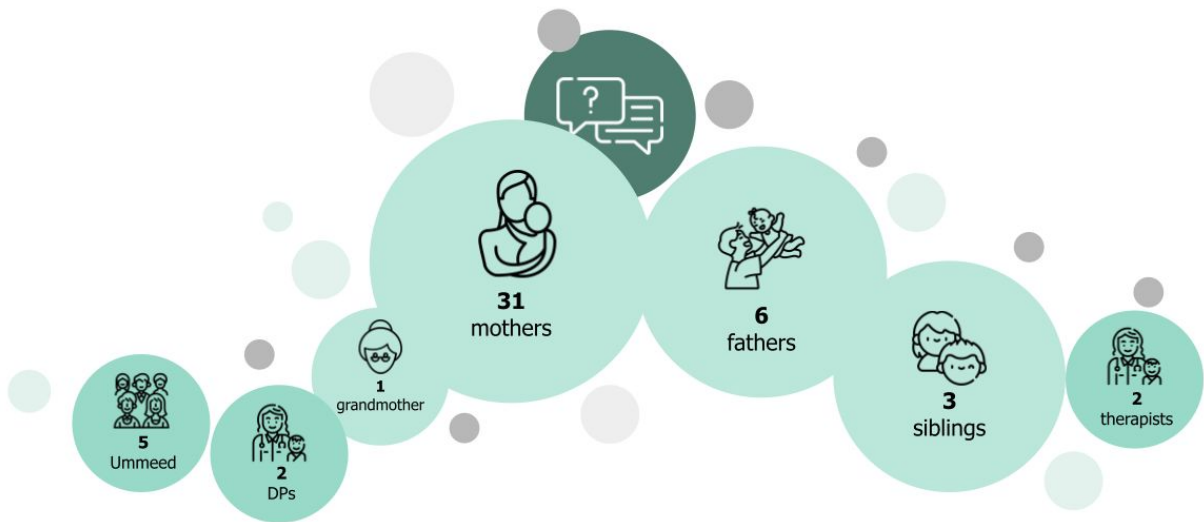
Sattva adopted a participatory research method for the execution of this qualitative study. The following methodology was undertaken to identify and finalise the areas of inquiry in collaboration with key stakeholders such as parents and caregivers of children with DD:

Figure 3: Study methodology



Sattva interviewed a total of 43 stakeholders in order to gain a 360° perspective.

Figure 4: Stakeholder profiles



The interview data was transcribed and analysed using the thematic analysis method to identify primary and cross-cutting themes based on the lived experiences of parents and caregivers. Extensive secondary research was also conducted to corroborate findings from the primary data. The insights gathered through this study have been categorised in two sections and detailed as below:

Figure 3: Report sections

Section 1: Detailing parental experiences to identify their needs and ascertain the support they require

Section 2: About the FRC and its potential to address challenges and support caregivers



Receiving diagnosis of their children



Introducing FRC: A model to support parents and caregivers



Accessing interventions for their children



Impact of the FRC on the caregivers and their extended family



Enabling social participation for their children



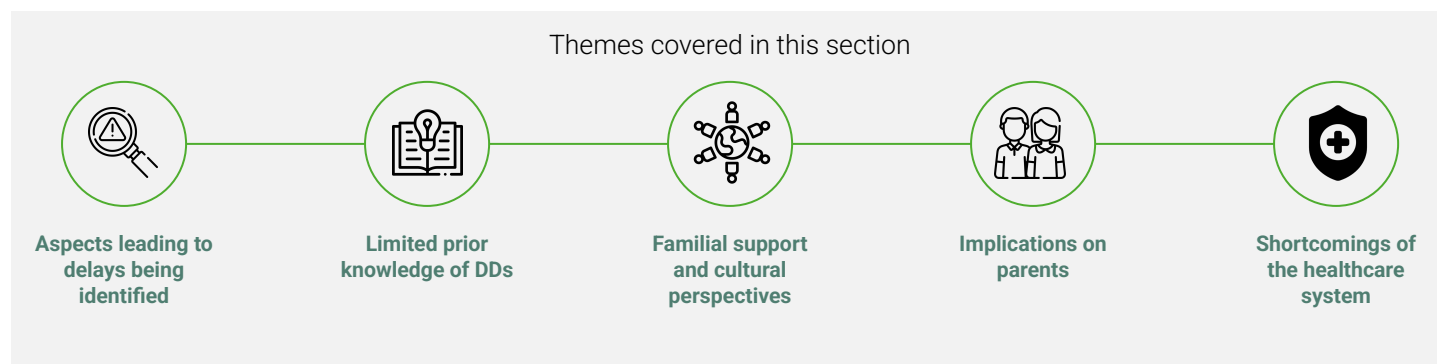
Family dynamics and concerns about the future

The key sub-themes in each section are highlighted at the beginning of each of the sections.

INSIGHTS

Parental experience with receiving the diagnosis of their child

Receiving an accurate and timely diagnosis is the foundation to providing appropriate support for children with DD. However, instances of DD often go undiagnosed because of limited awareness among key stakeholders, shortcomings of the healthcare system, and cultural perspectives. This section of the report describes parental journeys from recognising their child's developmental delays to seeking a formal diagnosis, coupled with their internal turmoil and transition towards acceptance.



Developmental disabilities such as Cerebral Palsy (CP) and Down Syndrome are typically detected pre-birth or at birth, and those such as Autism Spectrum Disorder (ASD), Attention Deficit Hyperactivity Disorder (ADHD) and Learning Disabilities (LD) are recognised and diagnosed generally during the early childhood stage. Paediatricians, medical professionals, parents, teachers and extended family members are some of the key stakeholders that are known to observe and highlight these delays among children.

Parents reported having a diverse experience regarding the stage at which they received their child's diagnosis, even for DDs that are typically diagnosed pre or at-birth. While two mothers of children with Down Syndrome shared receiving the diagnosis from their doctors at birth, another shared receiving it days later from her paediatrician and not from the medical facility as her delivery, possibly highlighting inefficiencies in the healthcare system. However, irrespective of when they received the diagnosis, mothers shared being completely unprepared for the news.

"I wasn't informed that my son has Down Syndrome at the hospital of his delivery or even received any indication of it. So on day five when we took him for a routine checkup to our paediatrician, that's when the news came to us. We were unprepared for it and it was quite traumatic."

- Mother of a child with Down Syndrome

For DDs that are generally diagnosed during early childhood, parents speculated that their child may be different as a result of delays relating to speech, motor functioning, sleep, suckling or behaviour patterns such as aggressiveness, inattentiveness, social awkwardness, and irritation, among others. Similarly, low classroom engagement levels and poor academic performance too contributed to this speculation. A mother shared her observations regarding the subtle disparities she noticed in her daughter's development as compared to her twin brothers, such as her inability to maintain eye contact, and a shy and moody demeanour. She further explained that her knowledge from her Psychology degree led her to act on her speculations that her child may have a developmental disability.

For children with prominent behavioural issues, parents found it difficult to fathom their child's behaviour, and in a few instances, this put a strain on their marriage, as parents differed on their opinions about the child's health and welfare. Mothers were usually unfairly blamed by the family and community members for not being able to handle their child properly. In cases of lack of support from their spouses, it further intensified their emotional burden and plunged them into feelings of guilt and self-doubt with respect to parenting.

"My younger son was very mischievous. He would not sit still, would throw his toys and sometimes hit and pinch his elder brother and me. I could not understand his behaviour, and thought perhaps he has a stomach ache or some physical issue that is troubling him and he is not able to tell me. I wanted to take him to a doctor but his father did not agree and said that I was seeing problems where none exist and that something is be wrong with how I deal with him because he listens to his father and only does not listen to me."

- Mother of a child with ASD

Parents also highlighted the role played by schools and teachers in helping them identify differences and developmental delays among their children. For instance, a father narrated that based on his daughter's academic performance and her engagement levels in school, her teacher speculated some learning-related issues and suggested an IQ test to be conducted which lead to her diagnosis of ADHD and LD. However, the capability to identify these delays was not universal to all educators, as was pointed out by a mother whose child's developmental disability was not identified until grade VI. She speculated that as teachers kept promoting her son to higher grades as per the mandates of the education policy - that states no child should be detained until grade VIII - his academic struggles may have been missed by the teachers, which also led to delayed care for him. This is corroborated by, a study which concluded that this clause in the education policy may lead to late detection of developmental disabilities as schools may not notice these delays until grade IX or X. As a result, these children may lose out on the critical time for remedial measures.⁽¹⁾

Parents found the initial recognition period to be perplexing as they struggled to understand why their children were lagging behind and what the course of action should be. They highlighted that the possibility their child has a developmental disability did not occur to them as they were either unaware or had a superficial understanding of developmental disabilities.

Their immediate reaction included searching on the internet, reaching out to other family members or people in their community for insights and recommendations. Reassurances from family and community members that some children develop later and that there is no cause for concern, often led to further delays in reaching out to a doctor. As they navigated through conflicting views on the child and being blamed for improper parenting by family members, mothers mentioned trusting their gut-feeling or motherly instincts, which gave them the courage to contest against others and get a medical checkup for their child.

Parents had varied experiences with respect to the ease of receiving the diagnosis of their child. While some had a relatively smooth experience, others recounted it to be a convoluted one, highlighting the need for a structured system with improved awareness among doctors regarding developmental disabilities. Many shared anecdotes of having to go through multiple doctors to get a diagnosis or viewed their positive experience as a stroke of luck. A mother emphasised about her struggle of receiving a diagnosis, stating that she had to visit multiple doctors before she got the correct diagnosis for her son. Likewise, some parents and caregivers expressed their frustration stemming from limited knowledge on developmental disabilities along with prevailing misconceptions amongst doctors, leading to delayed recognition of their child's condition.

"My grandson did not suckle breast milk after he was born. Our doctor did not give us proper guidance, he told us that sometimes kids take longer, in 2-3 days everything will be okay. The doctor also said to us he is not suckling breast milk because he is lazy. When we did his tests at the age of 2 we got his diagnosis of William's Syndrome."

- Grandmother of a child with William's Syndrome

A Developmental Paediatrician's (DP) Perspective on Barriers to Early Detection (as shared during an interview)

Severe lack of awareness coupled with poor emphasis given to developmental disabilities by medical professionals and the general population in India, often leads to late or missed detection of developmental disabilities. Paediatricians and general physicians' limited knowledge, adoption of a 'wait and see' approach, inadequate checkup norms and heavily crowded clinics impede their ability to identify symptoms and to seek support from a developmental paediatrician early on. The DP shared that *"In other countries, developmental disorders are often picked up early by medical professionals as the norm is to assess the child whenever they visit a clinic. For instance, when a child comes for an MMR vaccine at 9 months, they should be able to maintain eye contact, smile or react to the doctor's words, these aspects can provide hints on whether or not the child is meeting their developmental milestones. But in India, because of the long waiting lines, it becomes difficult to execute. Additionally, advice such as 'let's wait 4 years' is often provided due to the lack of awareness or importance that has been given to developmental disorders in India."*

Similarly, parents are often not alarmed by their child's developmental delays mainly due to low levels of awareness among them and knowledge regarding how to identify them in a child. She shares, *"It is generally when the child reaches the school-going age and is not able to keep up with other children or when the teacher informs them of their low academic performance or their lack of attention in school that the parents are alarmed."* She further adds that, in her years of experience, she has often come across students even from economically privileged private schools, with LDs that are not diagnosed till 8th and 9th grades, stressing on the universality of the issue. This challenge is further exacerbated by the limited awareness of DPs among parents. She shared, *"Even in such instances, DPs are typically not the first ones approached by parents. The shortage of developmental paediatricians in India further worsens this issue. I think in all of Bombay, you will not find more than six or seven developmental paediatricians, whereas every lane may have five or six general paediatricians. So the density of developmental paediatricians is relatively low."*

Upon receiving the diagnosis for their children, parents found themselves caught in a myriad of emotions. Sadness, and helplessness, accompanied by the poignant feeling of "Why us?". Some mothers spoke of 'going into depression' upon receiving their child's diagnosis. As they struggled to understand and accept why this has happened to them, parents recollected being flooded with questions regarding the nature and extent of their child's condition, and what the future might hold for them. A recurring and constant concern among parents and family members was whether their child would ever be "normal". The parents' internal turmoil and transition towards acknowledging and accepting the diagnosis was deeply personal and challenging and they emphasised on the critical role played by their spouses and immediate family members at this juncture. In certain cases, the lack of support from their spouses and family intensified their challenges, while for others, it's presence facilitated their progression towards acceptance.

A few studies have highlighted that negative attitudes towards disabled persons are prevalent in Indian society⁽¹⁸⁾. Cultural and religious beliefs that disabilities are "caused" by the parents or past sins, often lead to parents of children with disabilities being stigmatised. Research also suggests that as families of children with DD experience heightened stress levels, which may hamper the integrity of their family structure⁽²¹⁾. In certain cases, struggles related to accepting the diagnosis of their children had implications for their marital relationship. A father shared that differing opinions between him and his wife, particularly about the causes of their child's developmental disability and what the future course of action should be, nearly ended their marriage. Likewise, a mother highlighted the negative impact of her husband's and in-law's cultural perspectives and misinformation regarding developmental disabilities, had on her mental well-being and her ability to provide a holistic and supportive environment for her child.

"I had somewhat accepted the diagnosis we got in Mumbai, but my husband and his family were not ready to accept it. I had to make a round trip to my native place because of this. Because I had undergone fertility treatments, there was a lot 'blaming-shaming' from his family that this happened because of the effects of the treatment. My husband has even told me that because I don't practice religious rituals is why we are facing this. Sometimes I would think of leaving this toxic place, but to keep my family intact I didn't."

- Mother of a child with ASD

In a few instances, mothers shared that their husbands had kept them in the dark regarding their children's diagnosis as a way to shield them from the reality of their situation. A few mothers expressed that their husband's denial about their child's condition negatively impacted their contribution to the caregiving responsibilities shared between them. Likewise, mothers also shared feeling ostracised by their family members on account of their children's disabilities. The lack of support from their spouse, coupled with socio-cultural influences that stigmatise developmental disabilities intensified their feelings of loneliness and the belief that they had to fight for their child alone.

Perspective of a Developmental Paediatrician on their role supporting parents (as shared during an interview)

The role of a developmental paediatrician is not just limited to providing the diagnosis of the developmental disability, but extends to supporting parents through this journey, by aiding them in understanding the disability and its implications on their lives. She shared, *"So where I see myself among all the different medical professionals in this space, is in helping families understand the why of the problem. And what is likely to happen or sort of resetting their expectations sometimes. The medical part of it is fairly straightforward and simple. But the role of a developmental paediatrician is to also improve this sense of comfort for the family, to improve their perception of things. To also help in their not feeling alone."*

Reflecting on his journey, a father emphasised the crucial role played by his son's DP in aiding him on his journey towards understanding and accepting his son's disability. He shared that, adhering to traditional gender norms, he initially blamed his wife for their child's condition as caregiving is primarily seen as the mother's responsibility. The DP helped him understand the need of being a supportive husband and ensuring the family's well-being. He further added that the sessions helped him internalise that a father's responsibility is not limited to financial provision, but extends to playing an active role in their child's development. These sessions contributed to not only saving his marriage but also improved health and well-being of both, his son and wife. In instances where both parents acknowledged the diagnosis, they mentioned that they could lean on each other, share caretaking responsibilities and progress towards accepting the diagnosis and its impact on their lives together. A mother narrated how her husband temporarily opted to work-from-home at his job as a way to share parenting duties. In addition to a supportive spouse, parents highlighted the benefits of having an extended support system of family members such as grandparents who not only shared the load, but also provided a holistic and supportive environment for their child with DD to grow up in and experience love and care.

Parental experience with seeking interventions

Evidence suggests that Early Childhood Intervention (ECI), improves the chances of children with DD to reach their full developmental potential and improve their expected quality of life⁽¹⁷⁾. However, there is often a significant delay in accessing these interventions due to limited knowledge among families and professionals about the appropriate next steps, which is further accentuated by the shortcomings of the healthcare system in India.⁽²⁾ This section of the report details the experience and journey of parents towards accessing early intervention for their children, and explores the challenges faced in this stage that shaped their perception of parenting and deepened their acceptance levels.



Research in neuroscience, genetics, developmental psychology, and related fields indicates that the human brain is most adaptable in the earliest stages of life, from conception to adolescence.⁽³⁾ By ensuring that children with DD receive nurturing interactions in the form of early interventions, their development can be positively influenced. They typically require interventions such as speech therapy, behaviour therapy and occupational therapy, among others. However, families often face difficulties in accessing high quality therapies in India due to the shortage of medical professionals, heavy concentration of services in urban areas, limited awareness of DDs among medical professionals, and high therapy costs.

In India, there are approximately 100 trained DPs for the 50 million children under the age of 15 who have or are at risk of having developmental disabilities. This disparity is evident even in urban areas such as Mumbai, where the waiting list for appointments can extend up to three months.⁽⁴⁾ These challenges were corroborated by primary insights, where a mother narrated that her family chose to move to more developed parts of Mumbai to provide quality care for her child. Likewise, a therapist highlighted that families from neighbouring rural areas were compelled to move or commute to the nearby town to access the healthcare facilities for their children, worsening the financial burden borne by them.

Research suggests that barriers to accessing quality healthcare are accentuated by the lack of awareness and knowledge among medical professionals.⁽³⁾ Primary healthcare workers play a crucial role in the early detection of developmental disabilities and the coordination of care. However, a study in the UK reported that less than half the physicians had knowledge of developmental disorders and even fewer were aware about further consequences of the disorders, as healthcare professionals, such as doctors and nurses, receive minimal training in neurology, mental health, and disability inclusion.⁽⁴⁾ A developmental paediatrician highlighted that this is comparable to the situation in India, as the syllabus used in medical colleges does not extensively cover developmental disabilities. This lack of familiarity with the condition among professionals often translates to families receiving misguided information, and being subjected to stigma and discrimination.

A father corroborated this as he described an encounter with a healthcare provider who inadequately explained his son's condition and imparted misguided advice such as stopping television time, avoiding speaking to the child, and interacting only through sign language. While the father perceived this advice to be counterintuitive, he continued to rely on the expertise of the healthcare professional, and it was only after the doctor prescribed medication without proper interaction with him or his child, that alarmed him. Similarly, he noted that many medical professionals continue to follow outdated therapies. He shared that children with ASD often engage in stimming* behaviours, which may be harmless for the child, but many professionals continue to prescribe medication to mask these behaviours based on outdated research. Furthermore, a mother narrated her experience where her doctor advised her against taking therapy for her child.

"I consulted a Homoeopathic doctor who recommended more physical activity and suggested that I do not send my child to school or waste money on Occupational and Speech Therapy."

- *Mother of a child with ASD*

*Stimming – or self-stimulatory behaviour – is repetitive body movements or noises. Stimming might include: hand and finger movements – for example, finger-flicking and hand-flapping. body movements – for example, rocking back and forth while sitting or standing.

With limited access to quality professional support and wanting to provide the best for their child, parents shared that they were open to trying all available options to them. They emphasised that being unfamiliar with best practices and underlying reasons behind widely used interventions, resulted in navigating through “a process of trial and error” before settling in on the best-suited interventions for their children.

Parents also emphasised on the financial burden, caused by frequent and high cost therapy requirements. A father pointed out that therapy costs have steadily increased over the years, exacerbating the financial pressure on the families. Irrespective of the economical background of the parents, they viewed therapy costs as a burden to them, emphasising on the necessity of accessible therapy services. As parents also had to experiment with multiple therapists before settling in on one, it unnecessarily added to their financial burden. A therapist noted that, in India, the absence of insurance policies covering the expenses of developmental disabilities, combined with government schemes such as Niramaya that also fail to provide coverage for therapy, often deters families from initiating therapy.

“Each therapy session costs approximately ₹500, which is half of my husband's daily earnings. If we have to give half of his daily income to therapy costs, how will we be able to survive?”

- *Mother of a child with ASD*

Research indicates that involved parent participation yields advantages both during and beyond therapy sessions, as therapists observed heightened child motivation, enjoyment, and completion of therapy tasks; additionally, attending sessions provides parents with insights that could benefit their emotional regulation and mental well-being, and prepare them to assist their child in managing emotions and maintaining therapeutic progress post-treatment.⁽⁵⁾ However, in this respect too, parents shared having to go through multiple therapists before they could find the right fit. A father highlighted that the therapist they initially sought out conducted closed-door therapy sessions, which limited his knowledge of the proceedings. Similarly, a mother expressed a sense of increased reassurance upon encountering a therapist who actively involved her in the therapy process, unlike her prior experiences, where therapists only shared videos post sessions, which she likened to watching YouTube videos, having limited impact on enhancing her understanding of therapy practices.

A mother of a child with Down Syndrome emphasised that *“therapy is the only solution”* as she reflected on her learnings from the journey, echoing the growing awareness and acceptance among parents about the requirement of continued intervention for their children. In many cases, caregivers, especially mothers, have had to contend with other family members to ensure their children receive the right intervention. One mother shared how she had to mislead her husband and in-laws by claiming to go to the market for vegetables while actually taking her son for therapy. This underlying tension coupled with the anxiety regarding the child's well-being resulted in emotional and mental fatigue, among caregivers, particularly mothers, who unfairly bear the brunt of caregiving responsibilities. Moreover, caregivers admitted that the burnout and physical exhaustion caused due to regular commute of accompanying their children to doctors, therapies, schools, and social events, left little time to engage in any other activity.

“There is a need to empower families to practice therapies at home, as not much can be achieved if the exercises are not practiced. Viewing parents as partners is important, and for parents to take initiative and practice the exercises at home and all the other environments that the child is exposed to, have a more hands-on approach and work with therapist to figure out the execution of the therapy plan.”

- *Mother of a child with ASD*

Caregivers emphasised on their growing realisation of the importance of actively participating in their child's therapy sessions to implement learned strategies across the child's environments. Having a collaborative approach between therapists and caregivers can help them co-create a learning plan that can be implemented across the different environments of the child, such as their home, school, and community, involving all relevant stakeholders. A mother highlighted how her son could practice his OT exercises at school with the help of his teacher as a result of this approach, ensuring consistency across all his environments.

As parents progressed through this journey, they realised the need to re-evaluate and re-adjust their parental milestones, as compared to parents of neurotypical children. Studies show that when a child has a developmental disability, parental milestones can shift and transform significantly, where they may experience developmental milestones, such as their child's first words or steps, in a different or delayed manner than anticipated.⁽⁵⁾

“We don't enjoy our children's milestones the way parents of neurotypical children do. As soon as the child reaches one milestone, we have to start thinking about the next set of challenges to deal with. But looking back on it, I think it's equally important to celebrate these milestones.”

- *Mother of a child with GDD*

Along the journey, quite a few parents encountered milestones related to acceptance, resilience, and empowerment as they adapted to their changed circumstances and advocated for their child's welfare. With increased involvement in the therapy sessions, parents perspective towards parenting skills evolved as well. A mother disclosed that since initiating therapy for her son, she came to realise that scolding or hitting may not always be the most effective approach. Instead, she now distracts her child with toys and games when he becomes agitated. Similarly, another mother emphasised on her learning about giving importance to the child's preferences, and not trying to change their inherent nature. She shared that her child with ASD is averse to social gatherings, and forcing him in these situations may not be what is best for him.

"The journey that we go through as parents with a disabled child is very different from that of other parents in our family and it's important to keep reminding oneself that 'the best' needed for your child will look very different from 'the best' needed for other kids in the family."

- Mother of a child with ASD

In summary, caregivers go through a journey where they learn to accept and internalise their child's differences and that the problems may never "go away" or "get cured" as they had hoped for or had been reassured about by other people. The parents shared that they too evolved alongside their children, learning to accept that each person's journey, problems, and solutions are unique, navigating uncertainties about their child's future, recognising that they were in for the journey with its own ups and downs.

Perspective of a Therapist on the Need for Active Parental Involvement in Therapy Sessions (as shared during an interview)

The therapist highlighted that the limited number of therapists across India and their often restricted understanding of the full range of therapeutic needs create significant barriers to effective intervention for children with developmental disabilities. Consequently, many families have relocated from surrounding villages to cities such as Kanpur to access better healthcare. She also shared that occupational therapy (OT) can extend beyond the confines of a room and benefit from environments such as gardens and other open spaces but the lack of open spaces and adequate physical infrastructure poses additional challenges. Highlighting these challenges, she said *"I would say privatisation or monetisation of the therapy services is causing a lot of gap all over India and a lot of unethical practices happen. Secondly, a lot of centres are coming up who are providing services in a very confined space so it is not possible to keep parents in the session. There is a lack of transparency."*

Therapy sessions, typically only a few hours long, aim to integrate learning into the child's everyday life which is why *"It's very important to empower them because therapy is not just about doing a particular session, it's a guide that helps to understand how in a different occasion and different situation the child needs to be dealt with. Empowering families or giving them right information helps to reduce their stress, and overall improves their own mental health."* Involving parents in these sessions is crucial, as their feedback helps therapists tailor the sessions more effectively, though exceptions can be made based on specific situations. She emphasised ~~on~~ the importance of a community-based support system as she said that the concept of family extends beyond parents to include everyone in the child's proximity, including extended family, teachers, caretakers, peers, and so on. She also emphasised that *"There is no clear understanding among parents of how exactly a particular therapy will benefit the child - what is the role of occupational therapy, or speech therapy, or special education, or behavioral therapy. A lot of the times from my interactions, what I understand is that parents often replace one therapy with the other."*

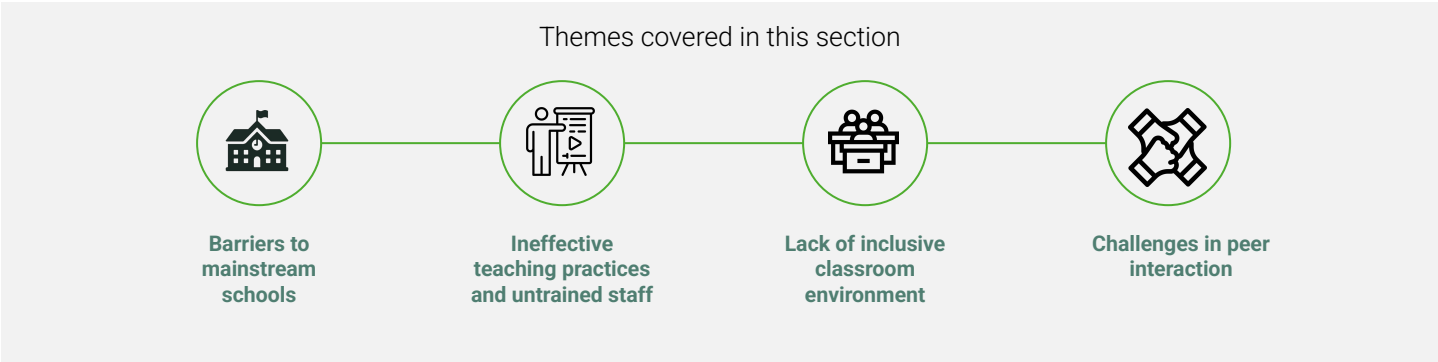
She acknowledged that despite these obstacles, awareness is growing, with around 50% of cases that come to her being self-diagnosed. However, the absence of health insurance for therapy sessions further complicates access to consistent care, making it financially challenging for parents to sustain necessary treatments. This financial burden, coupled with the increasing awareness of developmental disabilities, highlights the urgent need for comprehensive support systems to ensure that these children and their families receive the continuous care they need.

Parental experience in enabling social participation for their child

Social participation is vital as it fosters a sense of belonging, enhances skill development, and promotes emotional well-being. Along with intervention, the next crucial aspect of a child's life is social participation. This includes schooling, community involvement, accessing public infrastructure and services, engaging with peers, and utilising facilities for activities and leisure. This section looks at the caregivers' experience in terms of inclusion of their children in mainstream settings from two main perspectives - schooling and community engagement.

Social participation is frequently viewed as a key intervention goal for children with disabilities, aligning with the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), which enshrines the right to “full and effective participation and inclusion in society” for individuals with disabilities. Social participation for a child with DD includes various facets. Alongside daily interactions, key components involve engagement in school activities, fostering peer relationships, community involvement such as participation in extracurricular pursuits as sports, music, and dance, among others. For children with DD, barriers to participation may arise both from individual and environmental factors. Whether at school, in clubs or playgrounds, at the health centre or the supermarket, the removal of barriers and social structures which impede participation ensures full participation of the individual in all aspects of community life which in turn helps them develop skills, express creativity, experience enjoyment, and build a sense of identity and self-esteem.

Schooling:



A study found that children with disabilities were five and a half times more likely to be out of school compared to their peers.⁽⁷⁾ The 2006 UNCRPD emphasises inclusive education as the key to ensuring the right to education for children with disabilities, promoting empowerment, diversity, and non-discrimination. Recent trends have aimed to integrate education for children with disabilities into mainstream efforts. The Government's Sarva Shiksha Abhiyan (Education for All Movement), launched in 2008, seeks to universalise education for children aged 6 to 14, including those with disabilities, by providing education in an appropriate environment. Evidence also shows that both students with and without disabilities achieve better academic outcomes in inclusive classrooms.⁽⁹⁾ However, despite these efforts, children with disabilities continue to have low enrollment rates and higher dropout rates, and are often placed in special schools.

Though parenting a child with DD brings numerous concerns for caregivers, a study found that lack of support in the schooling system, and biased perceptions of educational professionals become major contributors of stress for the caregivers.⁽⁷⁾ A mother backed this up as she noted that despite the current recommendation for placing children in mainstream schools, there is a lack of awareness among parents about the advantages of inclusive education. A father highlight that schools have been reluctant in giving admission to children with DD, and despite legal protections against discrimination, schools have rejected the child's admission on the account of ***“having too many students with ASD already.”*** Similarly, another mother shared her experience of being rejected from a mainstream school nearly towards the end of the admission process as her son with ASD started demonstrating aggressive behaviours, following which she had to enroll him in a special school.

Studies showed a rapid growth of special schools, especially in urban areas, but as the number of special schools increased, their disadvantages became apparent: they served a limited, mostly urban population, were not cost-effective, and most significantly, segregated children with special needs from the mainstream, fostering a distinct disability culture⁽⁸⁾. On similar lines, caregivers reported that identifying an appropriate school, particularly an inclusive one, for their child proved to be a significant concern for them since the environment would have a huge influence on their child.

“There are hardly any inclusive schools in India, and parents themselves don't understand what inclusive schools really mean. There is a strong myth in society against inclusive schooling. Finding an inclusive school that would accept my child was an uphill task, as there are very few good schools in Mumbai / India that offer inclusive education. Overall, it wasn't a pleasant experience, rather a disheartening one.”

- *Mother of a child with Down Syndrome*

The challenges in mainstream schools in India are characterised by insufficient resources, inadequate facilities, and teachers' inability to adapt their methods, potentially limiting the benefits of inclusive education. Parents highlighted that even in environments where inclusion was a standard practice, equal participation of children and adolescents with DD was not assured across all aspects of the curriculum. A mother recounted an experience where her daughter in grade 3, was compelled to transfer to a special school on account of her poor academic performance, despite her IQ test report indicating that she could continue in her current school. This highlights the lack of awareness about the benefits of inclusive education among educators. Thus the support for special schools among the caregivers appeared to stem not from the merits of that system, but as a reaction to the shortcomings of mainstream education.

Although the Rights of Persons with Disabilities Act, 2016, guarantees essential support such as special educators and shadow teachers for effective education of children with DD in mainstream inclusive schools, parents have voiced challenges in actually accessing these services. A study pointed out a severe lack of remedial teachers, even in a large city such as Mumbai, with most schools lacking an on-site remediation centre.⁽⁸⁾ In some cases, parents were unable to afford the services of special educators employed in private schools. A father noted that schools often faced challenges in fully implementing government policies due to practical limitations such as high student-teacher ratios and a low number of students needing shadow teachers or special educators, resulting in a limited availability of such resources.

“It is difficult to continue sessions with a special educator as the costs are not only high but also have long-term implications. About 5 years back, the rates were 700-900 per session, and one would need to take 2 sessions per week along with OT sessions.”

- *Father of a child with LD and ADHD*

In order to compensate for the acute shortage of additional support, regular school teachers are encouraged to take up the additional responsibility of becoming remedial teachers. The RTE Act mandates that school teachers possess the necessary professional qualifications to ensure quality education, providing funds for teachers to undergo training and acquire essential skills. However, according to available reports, there is currently no pre-service training for regular teachers that familiarises them with the education of children with special needs. They are expected to learn on the job. Such pre-service training has the potential to reduce misconceptions among teachers, as an improved understanding of DDs can help them identify learning challenges rather than attributing these difficulties to the children's personal traits.⁽⁸⁾

Caregivers also complained about mistreatment of their children in the hands of the educators and other school staff. A mother highlighted that along with school teachers, it is important for the other staff who the child will be potentially interacting with, to be trained in this regard. As was highlighted in the interviews, teachers sometimes discourage and exclude children with developmental disabilities from group activities and events such as exhibitions and annual day performances, assuming they cannot cope or perform. This exclusion hinders the child's ability to participate fully in society.

“The special school my son went to would tie him up to his seat for 5 hours to prevent him from running around and did not even inform us of it. I later found out from another parent.”

- *Mother of a child with Down Syndrome*

A mother observed that children always have a desire to learn, but the key lies in how the information is presented and the language used by the educators to convey it. She emphasised that teachers need to be mindful and communicate information in a more simplified manner. Additionally, she suggested that teachers should be considerate and proactive by informing children with developmental disabilities about upcoming homework or projects in advance, providing them with the necessary extra time and support to complete these tasks effectively. Organisations in the education ecosystem could also enable these children to build skills and potentially a career, as parents constant worry is about their child's future. A recurring question and reason for anxiety amongst most parents was *“what after us?”* Though DPs typically recommend that caregivers should concentrate on achieving short-term goals rather than worrying about the distant future, identifying career prospects, means of livelihood, and the ability to sustain themselves remain significant ongoing concerns for parents.

Community Engagement:

Themes covered in this section



Lack of inclusive public infrastructure



Poor implementation of government policies



Challenges in accessing facilities for extra-curricular activities

Research indicates that community participation of children with disabilities is influenced by features of the physical, social, and attitudinal environment, which can be affected by their micro (e.g., built environment, transportation, programmes and services, social supports, actions, and attitudes of others) and macro environments. (e.g., institutional policies and procedures).⁽¹⁹⁾

A study shows that a lack of organisational infrastructure, such as public transportation or assistance with community activities, creates significant barriers to successful community participation.⁽¹¹⁾ Caregivers shared the numerous challenges they faced in commuting and accessing public infrastructure. Despite India signing and ratifying the UNCRPD in 2007 and updating the act to accommodate people with disabilities, significant gaps remain in infrastructure accessibility. For instance, most train stations in cities such as Mumbai lack ramps and elevators, and accessibility has been overlooked even in some newly built metro stations.

According to the Rights of Persons with Disabilities Act, 2016, fare concessions are provided to PwDs; however, this alone is insufficient to ensure physical accessibility. There is a need for a radical shift in people's mindsets and additional provisions to ensure that the benefits of the Act can be implemented effectively. A mother voiced her difficulties in commuting in the train with her son who has Down Syndrome, highlighting that while there is a separate train compartment for individuals with disabilities, the general public often does not respect these provisions, as a result of which these compartments get crowded and cannot be accessed by people with disabilities. Furthermore, children with DD are prone to being overstimulated by loud noises and bright lights while utilising public transportation in India. Parents shared that their children struggle to cope with these sensory stimuli, often resulting in them acting out or throwing tantrums, which further limits their movement in public spaces.

"The buses are very crowded and you do not always get a seat for yourself. My son does not like if somebody is standing very close, or their skin is touching, but how do you avoid that in a bus? He becomes aggressive and starts screaming and cursing."

- Mother of a child with ASD

Public play spaces hold significant value for children with disabilities and their families, providing opportunities for play, fun, exploration, social participation, interaction with animals, access to nature, and learning. However, for children to fully engage with confidence and autonomy, they must feel safe and be protected from physical and emotional harm. While in conversation with us, caregivers also complained about the lack of accessibility in public spaces such as parks and gardens because of discriminatory behaviour by neurotypical kids, or the park equipments being unsuitable for neurodivergent kids which might result in the children getting injured. In a lot of cases their children were not granted access to other facilities such as swimming pools, music classes, dance classes and so on. A mother shared that her son, who is fond of dancing, was rejected from a dance class on account of potentially making the other children there uncomfortable. Another mother recounted her proactive efforts to establish activities for kids in her home to provide her son with extracurricular activities. However, her attempts to involve other children from the building were met with disinterest, as their parents were reluctant. Despite feeling dejected by this response, she highlighted the necessity for parents to advocate for their children and to persist in creating inclusive opportunities, rather than withdrawing in the face of such challenges.

"He loves swimming. I have taken him to many swimming classes, and nobody has taken him in - when he sees the water, he gets excited and starts screaming. I have been upfront with people that he has a problem, but people are apprehensive that something might happen to my child or he might do something."

- Mother of a child with ASD

Parental experience of differentiated caregiving for siblings

Parents often need to manoeuvre complex family dynamics carefully, with a recurring concern about providing long-term support for their children. This section details out how parents navigate providing for their children and the impact it has on siblings of neurodivergent children. Additionally, it describes the concerns shared by parents about the future of their children.

Themes covered in this section



**Limited information
or awareness of the
condition of their
sibling**



**Disparity in caregiving
between the siblings**



**Caregiving role
taken up by the
neurotypical child**

Reflecting on her experience, a mother revealed that following the diagnosis of her younger child, she redirected almost all her attention and time towards the child, inadvertently neglecting her elder son. She expressed remorse over depriving her elder child of an ideal childhood and experiences that they could have had if things were 'normal'. Another mother observed that even in every day decisions, which could be as simple as choosing a restaurant for dinner, the preferences and conveniences of the neurodivergent child would be prioritised over those of the neurotypical child. This often led to the sibling feeling deprived, unloved, and dejected. She mentioned that there is a need for caregivers to be more mindful while adapting and navigating through these family dynamics and also taking the siblings along in this journey.

On the other hand, a few neurotypical siblings shared that they spent most of their childhood being uninformed of the developmental disability of their sibling as their parents never mentioned it or talked to them about it. This formed a perception that they and their needs are not as important and they are not cared for as much. A sibling recounted that her parents frequently asked her to provide additional care for her brother, to ensure that he was not bullied at school or left behind, without adequately explaining his differences. Likewise, another sibling shared feeling that her parents gave more attention to her neurodivergent younger brother, assisting him with his academics, while she was left to manage on her own. Such experiences, at an early age, led to the siblings feeling isolated, confused, and often anxious as they felt they had done something wrong. Caregivers shared that in an attempt to prevent comparisons between the siblings, they often enrolled them in different schools. The mother of twins, one neurodivergent and the other neurotypical, described the effort she makes to prevent family members from making comparisons or discriminating between her children to not let the other one feel insignificant. This can be achieved when caregivers are mindful about the needs of the neurotypical child to ensure their mental and emotional well-being and equal involvement in the family.

In a few situations where either the gap between the two children was much more or the families were more vocal about the condition of their neurodivergent child, parents recounted scenarios where the neurotypical child would often take on a caregiving role for their sibling. A mother disclosed that her older daughter provided support and care for her brother with Down Syndrome who was 8-9 years younger than her, resulting in a strong bond between them. A neurotypical sister who is also a therapist noted that the sibling without special needs plays a significant and influential role in the life of the other one. Giving them time to play together or participate in activities together results in forming a deeper relationship. In certain cases, this has also led to the neurodivergent child not being solely dependent on the parent. In cases where there is a high degree of interaction, they often emulate their sibling and seek similar experiences or harbour aspirations.

"They do need to connect with people- it's just a human thing. I think when it starts from home it becomes much easier for them to connect with others and especially if you have someone of similar age or, both being kids, it helps them to connect more with you or talk about things which they might not be able to talk with their parents easily."

- Sister of brother with ASD




"I hope she is not dependent on me forever-I want her to earn for herself someday and support herself. I do not know exactly what kind of jobs are available for them but I hope we can find something"

- Mother of a child with ASD




Summary of parental support requirements

This section of the report summarises the key support requirements of parents and caregivers across different aspects of their journey (*as denoted by the icons used*):


Awareness and knowledge:

-  Most parents reported having little to no knowledge about developmental and intellectual disabilities before their children's diagnosis. Accessing reliable information for understanding the diagnosis was also challenging, highlighting the need to raise awareness among parents and the society at large by providing systematic and easily accessible information sources.
-  Caregivers highlighted that their limited knowledge and information about suitable treatments, expected outcomes, and best practices, and the lack of awareness about developmental disabilities among health practitioners, made it challenging to seek appropriate interventions from the outset
-  Parents often lacked awareness of the benefits of inclusive education, or had little information on mainstream schools, as a result of which they struggled to find an appropriate school which encouraged non-discriminatory practices, and were willing to admit children with developmental disabilities



Family and societal support:

-  Some parents, especially mothers, felt isolated and blamed due to societal and cultural attitudes, particularly when lacking spousal and family support, emphasising the importance of social support networks.
-  Caregivers, particularly mothers, have had to navigate familial dynamics to secure appropriate interventions for their children. This strain, compounded by inadequate family support and concerns for the child's welfare, led to emotional and mental exhaustion among caregivers, disproportionately impacting mothers, thus highlighting the need for cooperation and understanding from other family members
-  Teachers sometimes exclude children with developmental disabilities from activities, assuming they can't fully participate, limiting their societal engagement. Caregivers noted their children's limited participation due to public space inaccessibility and discriminatory behaviour, restricting access to facilities like swimming pools, music, and dance classes, emphasising the need for greater social cooperation and acceptance.

Financial:

-  Caregivers highlighted the financial strain caused by the frequent and high-cost therapy needs, emphasizing the need for customised financial instruments and enhanced government schemes to cover the expenses for developmental disability intervention more effectively.

Governmental support:

-  Despite the guarantees under the Rights of Persons with Disabilities Act, 2016 - regarding support such as special educators and shadow teachers for children with DD in mainstream inclusive schools - parents often faced challenges in accessing these services, highlighting gaps in the implementation of such provisions.
-  Public infrastructure often lacks inclusivity, with insufficient ramps and elevators. Public and affordable transportation such train and bus with separate compartments, or seats for people with disabilities are often crowded or occupied, indicating gaps in implementation of inclusive policies.

Introducing FRC: A model to support parents and caregivers of children with DD

Addressing the need to support parents and caregivers has been highlighted in the previous sections of this report. The requirement includes providing access to relevant and reliable information and forming a community that fosters a sense of belonging across the various stages of a child's development. It is crucial for caregivers to feel empowered to take care of themselves and their children. Furthermore, ensuring the effective implementation of government policies and being able to advocate for the needs of the child is essential for addressing the dynamic challenges faced by these families. Parents need holistic support to effectively navigate these challenges and ensure the well-being of their children.

Evidence suggests that FRCs are an invaluable source of support for families and caregivers, serving as a community hub to strengthen child and family relationships, and build parenting skills.⁽²⁰⁾ FRCs provide access to vital information, resources, and support services tailored to the unique needs of each family. Caregivers can benefit from educational workshops, support groups, and counseling services that enhance their understanding and management of their child's condition. FRCs foster a sense of community and belonging, enabling caregivers to connect with others facing similar challenges, which can alleviate feelings of isolation. Additionally, FRCs often assist in navigating complex healthcare and educational systems, ensuring that caregivers can secure the best possible care and opportunities for their children.

About Ummeed's FRC:

Ummeed has consistently centred its activities around family-centred care (FCC), which is founded on principles of information sharing, respectful care, and collaboration between professionals and families. Inspired by the PACER centre founded by Paula Goldberg in Minneapolis, Dr. Vibha Krishnamurthy, the co-founder of Ummeed CDC hoped to create a Family Resource Center at Ummeed, with the objective of creating physical and virtual spaces that are owned and operated by families for families, with the eventual outcome of influencing service delivery at Ummeed. The FRC at Ummeed was conceptualised and set up in the year 2021 by three co-founding parents, Smita Pathak, Revathi Iyer and Rashmi Jha, with the support of Credit Suisse.

"At Ummeed, our belief is that disability is not just a medical condition and having a 'biopsychosocial' approach is important where we engage families of children with DD, and all other individuals who engage with them as stakeholders. I visited the PACER centre in Minneapolis, founded by Paula Goldberg, which is a centre for parents, and I was inspired by that. Through her research what she found was that parents were so busy fighting the grind that they had no idea what their rights were and nobody was implementing them either. I was really moved by what the centre had managed to do, and I felt that Ummeed too was ready to have that located at the front and centre of the organisation: a Family Resource Centre that was run by families for families, with the eventual hope that it influences service delivery at Ummeed itself."

- Dr. Vibha Krishnamurthy, Co-founder of Ummeed CDC

"As parents, we used to come to Ummeed ourselves for our children and we always felt the difference that family centred care and a strengths-based approach made. When this opportunity to be a part of a family run team at Ummeed came up, we were happy to put our hand up for it. Families form the immediate ecosystem around the child, yet their needs often remain unmet. Moreover, being a caregiver of a child with disabilities can be a lonely journey. Our objective is to make FRC a safe space for families where they can express themselves freely, share experiences & support each other, learn about rights and prioritise their own well-being while caring for their children."

- Smita Pathak, Co-founding parent, FRC at Ummeed CDC

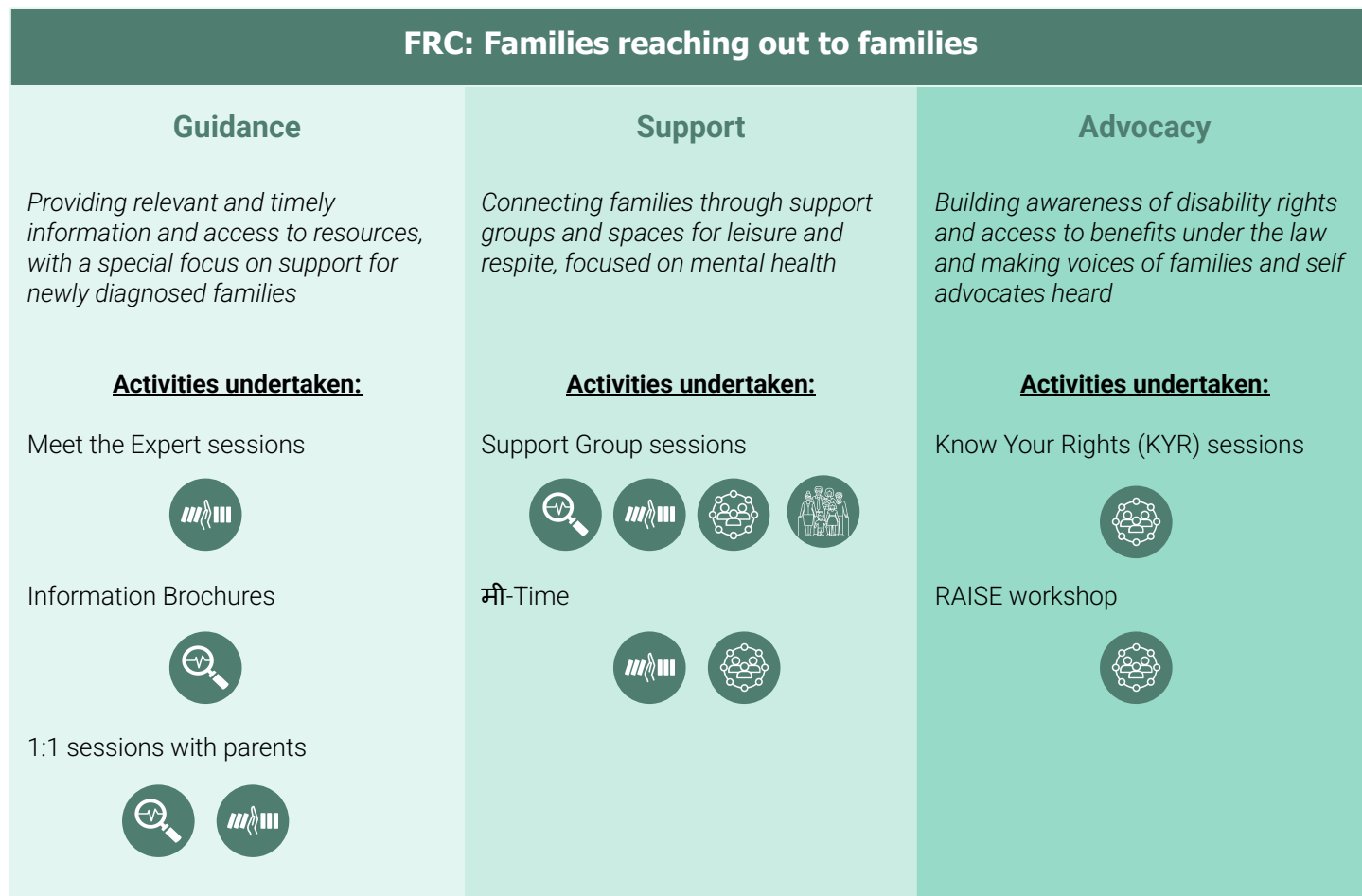
The objectives of the FRC are as follows:

- To give agency to families and caregivers of children with DD and create physical and virtual spaces that are owned and operated by families, for families
- To underscore the importance of collaboration between professionals and caregivers

To cater to the dynamic needs and requirements of parents and caregivers throughout their journey, the co-founding parents designed the service offerings of the FRC to support parent and caregiver empowerment, by building on their knowledge and skills.

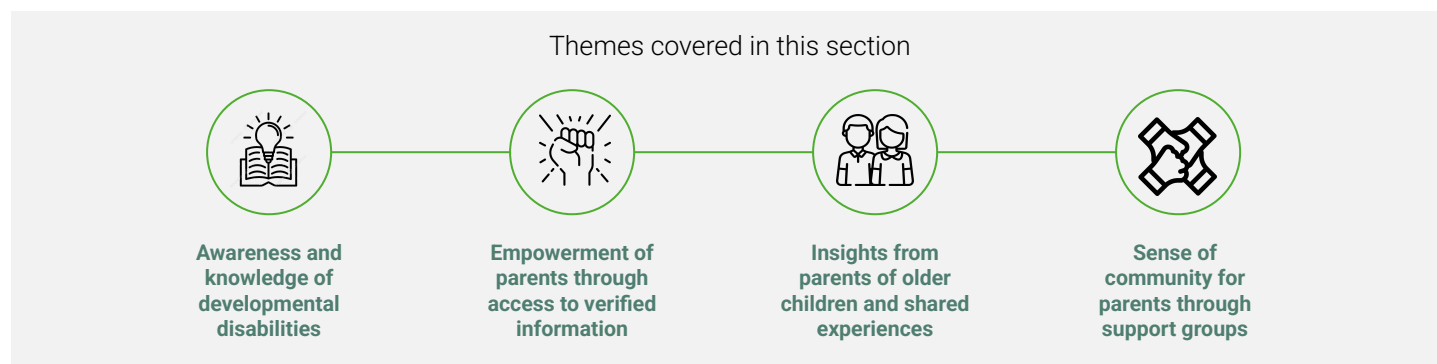
Over the last 3 years, the FRC at Ummeed has catered to the needs of **6094 families**.

The service offerings under the FRC are categorised into 3 pillars - Guidance, Advocacy and Support. The following figure mentions the key activities undertaken by the FRC, and maps it to the support needs of parents and caregivers throughout the different stages of their parental journey (as denoted by the icons used), as described in the previous section of this report.



Impact of the FRC:

The following section captures the influence of the FRC on the lives of parents and caregivers of children with DD. The anecdotes highlight aspects of the FRC that the parents or caregivers acknowledge, learn from, and deeply value.



The primary consideration by parents while joining the FRC was to gain information to be better equipped to support their children, where their areas of concern typically surrounded topics related to their child's development and welfare, such as information about therapists, schooling, parenting tips, among others. However, they reflected that along this journey and through the support services offered by the FRC, they found valuable insights and unintended benefits for themselves too.



To support in parent's understanding of their children's disability and set expectations about their parental journey, the FRC team developed informative brochures and provided access to handpicked books. The brochures were authored by parents as a way to bridge the gap in relatable and easily comprehensible information for parents. A father described how a book he borrowed from the FRC helped him improve his knowledge regarding his son's ASD. He added that because the book was in Marathi, a language that he was the most proficient in, it he understood the concepts easily.

In addition to information, workshops and sessions such as Know Your Rights, RAISE, and Meet the Expert, empowered parents and caregivers, helped them learn from each other and make informed decisions. The sessions also provided awareness on governmental support such as the UDID card and the Niramaya Health Insurance scheme. Feedback from parents suggests that they found these sessions to be immensely useful, providing sufficient information for them to be able to access the support provided by the government. They also shared the usefulness of WhatsApp groups created by the FRC team in reaching out to others for recommendations regarding schools, and therapists for their children.

The informal interactions provided parents a platform to gain parenting tips from others on how to deal with certain behaviours of their children, which they found immensely valuable. A father shared that connecting with a parent who had an older son with ASD, was beneficial as he could provide relevant parenting tips. He believes that there is merit in facilitating 1:1 connections between parents based on such similarities. Likewise, a mother noted that other parents found her strategies for managing her son on public transport useful, and is now collaborating with the FRC team to create and disseminate a YouTube video to share these practices with other parents. Subsequently, a mother emphasised on the need for moderation and validation of data shared through such platforms as a way to minimise the spread of misinformation. As parents advanced in their journey towards advocating for their children and themselves, some recognised the potential value of a parental perspective in informing the delivery of services such as seeking diagnosis and interventions for their children. A speech therapist and mother emphasised on the importance of a two-way communication model between parents and medical professionals, noting that therapists, particularly early practitioners could benefit from spending a day with the family to understand their realities and have better informed therapy practices.



The most talked about aspects were the support groups and **मी**-time sessions which positively influenced their learnings on prioritising their mental and physical well-being, treating all members of the family equitably, and taking out time for leisure and fun activities, among others. Mothers shared that the **मी**-time sessions helped them relax, de-stress, and engage in activities they enjoy which they normally would not be able to take out time for. They found that these activities helped them cope and enabled an easier transition towards acceptance of their child's DD. Parents also added that connecting with others helped them feel less lonely during their struggle. A few mothers expressed being able to forge connections that extended beyond the FRC, finding dependable friends among other parents who supported in activities such as babysitting for each other in cases of emergencies. Similarly, another mother emphasised the value of forming a small group of friends through the FRC who meet up to unwind by watching a movie or going shopping to a nearby market together while their children are in school. This bond, as they call it, would not have been possible had it not been for the FRC acknowledging that they need downtime too and providing them the space or platform to do so.



Family Day

The Ummeed Family Day to mark International Day for Persons with Disabilities (3 December 2023) was held on 10th December 2023. This was the first time that such an inclusive event was held in Mumbai which advocated the right of children with disabilities to participate freely in fun activities in community spaces, without barriers. It also underscores Ummeed's belief in the importance of fun and leisure in the overall development of children and in the well-being of their families.

It was attended by around 180 families and had a footfall of approximately 550 people which included families, friends and well-wishers of children with disabilities. The event included product stalls by persons with disabilities, their families and by organisations working with persons with disabilities; games and activities, greatly enjoyed by children and caregivers alike; a quiet/sensory zone for those who needed some downtime to self-regulate; and entertaining performances.



Case Study 1: A support system such as the FRC, particularly focused on younger parents

(A mother's perspective - as shared during an interview)

Aparna* is a working mother living in Bangalore with her husband and a 13 year old son, who was diagnosed with ASD at the age of 2 years. She emphasised on the need for building parental capacity as one of the key levers to be able to provide adequate support for children with ASD. She shared participating in Ummeed's Parenting Program for Autism (UPPA) in order to acquire new parenting skills to be able to care and advocate for her son. At the FRC, Aparna attends the 'Tea & Talk' support group and has participated in the Family Day event as one of the stall owners. Through an in-depth interview, Aparna emphasised on the need to and potential benefits from accessing a support system such as the Ummeed FRC, particularly focused on parents who are at the start of their journey. She believes that accessing support groups such as the 'Tea & Talk' can positively influence parents with younger children in the following ways:

Being reassured about their parenting efforts and gathering insights from more experienced parents: Aparna shared that parents of children with ASD, especially younger children, are prone to feeling lost and burnt out as they navigate through various therapies, with a constant overwhelming feeling that their efforts are not sufficient. She emphasised on the supportive role that more experienced parents can play at this time, stating that *"Reassurance that what you are doing is good and enough can be immensely beneficial to parents, especially with younger children."* She noted that parents at this stage, put themselves on a lower priority, neglecting their physical and mental health as well as their needs and wants. She emphasises that through spaces similar to the FRC, experienced parents can provide useful insights, such as the importance of self care both for their own sake and also from the lens of being able to care for their child in the long run. One of the most significant contributions of a space such as the FRC is in helping parents realise the importance of prioritising and taking care of themselves.

She further shared that the journey towards acceptance is long, and as parents go further along in their journey, their acceptance levels deepen. Thus, parents who are further along in their journey can help others, especially those who are at the start of their journey towards deepening their acceptance levels by learning from one another in a nuanced setting.

Relatable and understanding community: Aparna also highlighted the benefits of being part of a community of like-minded individuals who share similar experiences. She emphasised that the neurotypical world often cannot comprehend the depth of the challenges faced by parents of neurodivergent children as well as those who have lived through similar experiences. She stated, *"Through support groups at the FRC, parents can share their heart out without the fear of any judgement. There are many challenges, for example, sleep issues, that the neurotypical world does not understand, but the community does."*

A space to de-stress and learn new skills: It is important for parents to have spaces where they can de-stress. As the FRC organises workshops aimed at fun and leisure, parents have the opportunity to relax and participate in activities they may not have been able to otherwise. She highlights the importance of learning new skills and its positive impact of the mental well-being of parents and a sense of accomplishment.

Being able to visualise the future possibilities: Parents, especially with younger children have a tough time in being able to visualise what life would look like for their children, whether the issues their children face will continue for life. She believes that seeing other children, and their growth and journey gives hope to these parents. She shares, *"I am not saying that sensory issues for children will autism will go away with time, but just knowing that there is a possibility these issues can be managed gives parents hope."*

Case Study 2: Influence of the FRC in enabling a sense of belonging and empowerment

(a mother's perspective on mental well-being as shared during an interview)

Niharika* is a homemaker from Mumbai who lives with her two children, husband and in-laws. She shared that since her marriage, she has devoted her time in fulfilling her roles as a mother, wife and daughter-in-law, with little time left for herself. Her elder son is diagnosed with multi-disabilities which impact his vision and memory, along with an ASD diagnosis and her younger son, aged 5 is neurotypical. Upon receiving the diagnosis of her child, Niharika shared "going into depression", feeling irritable and lost, and perceived that she had limited support from her family.

Niharika heard of the FRC through Ummeed and has attended support groups, and *श्री*-Time sessions, online workshops, and events such as Family Day and attended at an IPL[™] match at the stadium. Through an in-depth interview, Niharika highlighted the FRC's impact on her life in the following ways:

Exposure to information about government support: Niharika described that prior to her involvement with the FRC, she had no knowledge of the available government support for individuals with DD and their caregivers. She learned of the UDID card and the Niramaya insurance scheme through the online workshops, and based on the information shared, she was able to create a UDID card for her son and enrolled for the Niramaya Health Insurance scheme.

Internalise the importance of prioritising oneself and accessing an enabling environment for it through the FRC: Niharika highlighted that through interaction with other parents at the FRC, she understood the importance of taking care of herself and internalising that not everything rests on her shoulders. She recollected that, *"It was only at the FRC that I understood the importance of taking care of myself. One of my learnings was that I don't have to take up every responsibility, and that I should take support from my family too. I also learned how to manage my time so that I can take out some for myself."* She participated in workshops such as dance, zumba, *mehendi* and wall painting sessions. She further shared that, *"because we have money issues, we don't participate in such activities but since everything is made available to us for free, I can fully relax and enjoy myself."* Niharika also emphasised that during these sessions there are volunteers to take care of their children so she can focus on herself.

Develop a sense of community and belongingness and its impact on her mental well-being: Niharika found her community with the parents she met through the FRC. She shared that *"Everybody at the FRC is very friendly. It does not matter if the parent is a man or a woman. Because our sadness is the same, we understand it and can share it with one another. Relatives and neighbours don't accept our situation very well or are not able to understand the depth of our problems. But through this community, I feel like there is somebody for me too"*, highlighting how connection with other parents with similar lived experiences can lessen the feeling of isolation and alienation. She further added that connecting with parents who are further along in their journey gave her hope that her life situation can get better, and that families such as hers can and should find happiness and joy too. *"Listening to the journey of a boy with blindness and of his mother gave me strength, and I could learn from their experience."* Over time, with inputs from other parents and improvements in her child's condition, she observed positive changes to her mood and perspective towards life, and found herself *"coming out of depression"* and feeling less irritable.

Access an inclusive environment for her family: Niharika attended the Family Day event and an IPL match screening with both her children and recollected that she had never seen them enjoy themselves so much. Attending any social event with a neurodivergent child requires preparation from the parents to ensure that the environment is conducive for their child, often necessitating adjustments such as leaving events early. Concerns such as *"Will I have to leave the event halfway"* did not occur to her because of how well-planned and thought out these events were. She highlighted that since these events were organised by parents of children with DD, they were inclusive by default. She spoke of how the event had a sensory room, which her neurodivergent child could access whenever he felt hyperactive or overwhelmed with the hustle and bustle of the event. She further emphasised that there are limited spaces that children similar to hers can access and entirely be themselves.

Case Study 3: Strengths of the FRC and the value it adds to a parent

(A mother’s perspective as shared during an interview)

Harpreet’s* son is diagnosed with ASD, and has been utilising the services at Ummeed since the COVID-19 pandemic. During this time, she has participated in 6-7 workshops (both online and offline), *ਸ਼੍ਰੀ*-time and Fun Club sessions and was a participant at the Family Day event organised by the FRC. She highlights the transformative role that Ummeed has played in her life, providing a holistic and nurturing environment for children with DD and their family members. Through an in-depth interview, she highlighted the strengths and value-add of a space such as the FRC.

Understanding of parent’s realities: The FRC offers flexibility in the mode and frequency of its sessions to accommodate the needs of the parents as they are frequently tied up with multiple caretaking responsibilities. She mentioned that as the support groups are conducted both online and offline, parents can choose according to their convenience. She personally found the online option more convenient, as it allowed her to join sessions and connect with others from home, eliminating concerns about leaving her child unattended. Harpreet explained, *"A lot of times, there is nobody at home to take care of my son, so I cannot leave the house. On such occasions, I have the easy option of joining these sessions online."* However, she acknowledged that attending in person sessions allowed for better connections with other parents. Moreover, for the in-person sessions, the FRC team had made provisions to take care of her son in the meantime so she could bring him along easily, where he could play safely while she attended the sessions. She emphasised the FRC’s benefit of accommodating caregivers by offering sessions in the mode that best suited their needs.

An inclusive environment for everyone: She spoke of how Ummeed has been a safe space offering acceptance to both her children - neurodivergent and neurotypical. She shared that her son with ASD dislikes activities requiring him to sit still for prolonged periods of time, and Ummeed offers a space where he can run around and play, preventing agitation. There are many toys and games available to the children at all times which keep them distracted and busy. She also frequently brings her younger neurotypical child to the FRC, and he receives the same level of attention. *"When you have a neurotypical child, they often get less attention, but at Ummeed, they receive the same attention,"* she acknowledged. Overall, she feels that Ummeed provides a positive and nurturing environment for her children, which is highly beneficial for their development.

Build and sustain connections beyond the FRC: Harpreet expressed that participating in in-person support group sessions has afforded her the opportunity to establish new relationships, some of which have evolved into meaningful friendships beyond the FRC. She has met many other parents with similar experiences, from whom she has learned a great deal. She shared that she looks forward to attending events such as the dance workshops, and the IPL match day, as they provide occasions for her to reunite with friends. Talking to these parents makes her feel like part of a community with shared lives and experiences, alleviating feelings of isolation. Harpreet emphasised that she deeply values the connections fostered by the FRC, which provide her with support, a sense of belonging, and enduring friendships.

Strengths of the FRC:



Usage of inclusivity as a guiding principle for all activities designed for parents or children



Prioritisation of mental well-being by offering a space to destress, interact freely, and learn new skills



Formation of a community to create a safe space and support each other through shared experiences

ANNEXURE

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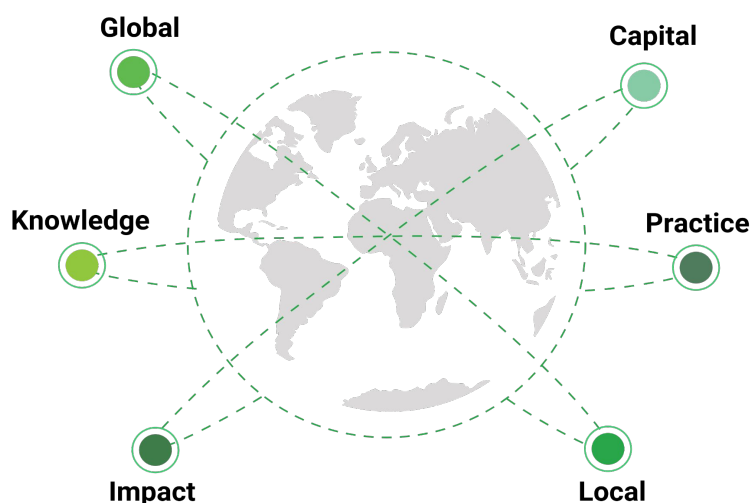
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