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Ummeed Child Development Center: A Hope for Acceptance

Abstract

This case study engages with the journey of Ummeed Child Development Center, a non-profit based in Mumbai, working in the field of developmental disabilities amongst children. Part of its story is closely wound up with the story of Vibha Krishnamurthy, a developmental paediatrician who, along with her team at Ummeed, has put in a pioneering effort to wean developmental disabilities away from the shadows of public and private conversations and to bring a holistic lens to awareness about them, interventions for them, and including others into mainstreaming the cause and seeking solutions for it. Remarkably, it has made what is often a solitary and anxious concern for parents into a collective and caring process providing a chance for parents themselves to participate in the development of their child. The result has been that Ummeed has become a point of reference when it comes to childhood disabilities.

This case-study, in tracing Ummeed's journey, also unfolds what it means to build and sustain a culture on which such a practice can stand: a culture that must deal with multiple interventions through multiple types of talent all the while holding true to what it means to care for a child. As far as case studies go, this case study aims to speak not only to learners and practitioners of management but also to parents of children with developmental disabilities, so that they too might find an echo of their concerns, and a hope for tomorrow; as well as to all of us as a broader society that contributes to the experiences of people with disabilities and their families.

Keywords: Developmental Disabilities; Biopsychosocial Perspective; Family-centred Care; Supervision, Narrative Therapy; Strengths-based Care

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A nascent sensibility

> The first person with disability I knew was my father's brother, Sambu Chitappa. I now know that he had an intellectual disability, but back when I was a child he was an integral part of my long summer holidays in Salem. He was always willing to play Snakes and Ladders, make helpful suggestions about my sister's future career ("Definitely the circus," he said) and was happy to accompany us to the movies despite having seen the film several times already. Candy loot from relatives had to be equally divided among the cousins and Sambu Chitappa. In the small town that was Salem then,everyone made sure he was part of the community. He was our representative for all marriages and sacred thread ceremonies, bringing back reports of the feast and the family. (Vibha Krishnamurthy, 2017)

Vibha's grandparents made sure their friends and members in their social circle accepted and loved Sambu Chitappa like the family did. That was Vibha's first lesson on acceptance.

Translating empathy to care had antecedents in Vibha's family. Her grandfather was himself a doctor and known amongst his patients for his kindness and care. Vibha, however, was only eight years old when he passed away, but his stories always were part of the family-lore and served to cement an inspiration. As if following in his footsteps, she appeared for All India Medical Entrance Exam at age of 17. Her own interests lay in paediatric care and her subsequent training in Delhi equipped her with necessary skills, but also left her yearning for better resources and a greater sense of bonding with the families, especially parents, of the children she was treating. Her marriage and her husband's move to the US offered her a chance to study child development and disabilities for which she served as a fellow at Children's Hospital, Boston (Ashoka, 2022).

Today (2023) Vibha is a practising developmental paediatrician, but back in Boston that choice was not as clear-cut. As she completed her specialisation and training in paediatrics, she found herself wondering what she should pick up:

> I am a developmental paediatrician. What that means is I am a children's doctor, but I have a special interest in children whose development is different. Children whose development doesn't go as their parents thought it would. How did I get into this field? It was actually quite by accident. When I finished my training in paediatrics, I thought to myself: "what do I know the least about?" I found that I had the answer in something that was quite different from what I thought it would be. I knew a lot about how to treat rheumatic heart disease, how to treat tuberculosis, pneumonia, asthma, but what I did not know is: how do children think? How do their brains work? How do their parents influence how their brains work? And most importantly, what happens when development doesn't go as you expected it to? When children have developmental disabilities? To find the answer to these things, I went to do a fellowship in Boston on developmental disability. (The Good Crusaders, 2016)

Following her fellowship, Vibha spent five years in Boston as a practising developmental paediatrician at Children's Hospital, Boston. She was struck by the number of children she met with developmental disabilities: children with speech delays, with Down syndrome, with dyslexia, autism, and it made her question: "Where were these kids in India? I had never seen these kids in India," she said. Perhaps it was because, as she says, "the eye does not see what the mind does not know" (The Good Crusaders, 2016).

An unacknowledged reality

"But what exactly are developmental disabilities and how prevalent are they in India?" It was a question which would stay with her for a long time, and even years later Vibha's concern is palpable in her voice:

> I was still plagued by the question, how big was this problem in India? … Let's begin with a statistic: at least one in every 10 children has a disability. That's a pretty startling statistic, at least, it was for me when I heard it. How can that possibly be? It couldn't really be one in every 10 children because if that was the case I would be seeing more children with disabilities, wouldn't I? But the operative word there is "see." Because when you're thinking of disability, you're thinking of things that you can see. And so when you think of disability, you think of a child with Down syndrome, you think of a person with a hearing aid, you think of someone in a wheelchair. But that's really not the end of it. Think of all the kids out there who are struggling to speak, the child in the classroom who is struggling to pay attention, the kid with dyslexia who's not able to write, the child with autism who looks like anybody else but is struggling to make social connections with people. That's also in the realm of disability that I'm talking about.
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> So, now that I've told you the gamut of what I'm talking about when I talk about early childhood disability, this statistic of one in 10 [doesn't seem so shocking] and in fact, in low and middle income countries particularly it is more like 1 in 6. We're talking about 15% of children being born with a developmental disability. What is that in absolute numbers, in India? 53 million. We are talking about the future workforce pipeline, we are talking of the limited potential of an entire country. (iimpactglobal, 2016)

As a corroboration: in 2018, India had the maximum number of children (1.15 crore) with developmental disabilities, out of 195 countries surveyed. This study found epilepsy, intellectual disability, hearing loss, vision loss and autism spectrum disorder to be the highest among Indian children (Azad, 2018).

Astonishingly, as per the World Health Organisation (WHO), the number of children with developmental disabilities is estimated at around 200 million (20 crore), running high especially among children in developing and underdeveloped nations. What compounds the burden uniquely for such countries is "toxic stress," of which chronic malnutrition is a major form, often caused by economic hardships. As a result, an estimated 45% of children under the age of three in developing countries are likely to experience "stunted" growth (OPENpediatrics, 2016). Even stressful situations in the family, and their effects on mothers (during and post pregnancy), could lead to the child's development being affected. Vibha spells out that:

> One in two kids in India is going to be malnourished. It's a real statistic in our country; 48% of children under the age of five are malnourished. The other

> statistic I know for sure is that 75% of children under the age of three are anaemic. Both anaemia and malnutrition change your IQ; they change the way you think and the way children develop. (iimpactglobal, 2016)

"Ummeed:" Sensing the tacit

The children Vibha saw or met in the US reminded her of Sambu Chitappa's affable laughter around friends and family. A striking aspect which she observed was the quality and number of facilities available to children in the US schools and hospitals, an infrastructure for disabilities that she had never seen in India. She also saw people with disabilities in restaurants, parks, movie theatres; again, something she had not seen happen in India where the children were typically only seen in hospitals, special schools, or restricted to their homes. These experiences left a deep impression on her and she was convinced that this was what she wanted to bring back with her: a centre that would provide high-quality services for the children in India who had or were at risk of developmental disabilities.

Upon her return to India in the late 1990s, she first started working with Jaslok Hospital in Mumbai. Alongside, she also connected with a number of nonprofit organisations and practitioners to understand the status of childhood disability in India, all the while reflecting on how best to provide Indian children and families the range of specialised services that they needed, and which she had seen being provided in the West. Soon enough, Vibha brought together a team of colleagues and coworkers to join her in building a new model for early childhood development and childhood disability care in India (Ashoka, 2022).

"Ummeed," which means hope, came into existence on 5 November 2001, with support from Vibha's husband, Ashish Karamchandani, then a partner at the (erstwhile) Monitor Group, a marquee management consulting firm, who too shared Vibha's sentiment to connect one's professional privilege to what deeply mattered to society. She began her journey with three associates and a belief that they, as a team, would look after the needs of children with disabilities, along with assisting their families and also advocating for them, all under one roof.

In 2001, however, the cause of developmental disability was not a mainstream concern for civil society, or indeed for the government. Notably, it was only in the 2001 Census, 54 years after independence, that a question on disability was first included: the first step to even understanding how many people in India were living with disabilities (Kannan, 2010). At the time, then, Vibha's effort was a pioneering one, and the support of her early team was crucial. Recalling those early days of Ummeed, she says:

> It was very important to me to have a team who philosophically believed in what I believed in: that families are the stronghold for each child; it's where the action happens, and that family-centred care is how we can address the needs of children. Secondly, that all families have strengths. The poorest of the poor families want the best for their children. If they were empowered with the knowledge that they could change their child's brain, they would do that. And lastly, [Ummeed] had to be about care for all, not just for those who could afford it. (iimpactglobal, 2016)

Armed with these principles but venturing largely into the unknown with little precedence to draw from, Vibha and her team proceeded to design and launch a model of clinical practice for developmental disability.

From a team of four in 2001, Ummeed has grown into a busy hub which brings together practitioners, specialists, parents and caregivers. It is connecting the dots for all to see, including what the data is indicating and why childhood disability should be a mainstream concern. It is also connecting civil society to the cause of early childhood development and childhood disability, creating awareness for early identification, early intervention, participation, and platforms for the voices of disabled children and their families—and a recognition of the long-term economic impact of these interventions for India's development potential.

Vibha's original seed of an idea has today evolved into four verticals: Clinical Services; Training and Capacity Building; Awareness and Advocacy; and Research. Together, these four verticals are inter-related and aimed at creating ecosystems required to help children with and at risk of developmental disabilities reach their full potential and be included in society. Foremost amongst these verticals is the Clinical Services vertical, run out of Mumbai, forming the foundation of Ummeed's work.

This vertical provides direct diagnosis and therapy services to children and families spanning the entire spectrum of developmental disabilities, and of all ages and socioeconomic backgrounds (refer to Exhibit 3). More recently, services have expanded to offer fun and leisure to children, support groups to young adults and families, and a Family Resource Center that enables families to connect with and support other families. The Clinical Services vertical also serves as a sandbox for developing evidence-based, culturally relevant practices that are then taken out to the rest of the ecosystem through the Training and Capacity Building vertical. It also hosts interns, fellows and observers, so that they can learn from Ummeed's values and practices and take them out to their own practices and contexts.

Since inception, Ummeed has directly supported around 12,500 children[1] who either had or were at risk from developmental disabilities and provided training to around 6,000 medical, school, and community professionals who work with children with developmental disabilities and their families, such as doctors, therapists, teachers, special educators, and community workers across almost all states and union territories of India (refer to Exhibit 4).

The heart of the practice

The "form" of this clinical practice traces its origin to a period of research and introspection following Vibha's return to India. Once, while travelling through Rajasthan, Vibha had stopped in a village, where she met 10-month-old Prakash, who was being cared for by his 12-year-old sister while their parents were out in the fields all day. She recounts that as soon as she saw Prakash and learnt the circumstances in which he was born and being cared for, it was evident that he would grow up with some form of developmental delay or disability despite not being born with one. His sibling, however well-meaning, was herself barely an adolescent, and thus unable to meet the developmental needs of a child that young, such as nutrition, safety, stimulation, etc. Vibha lays out:

> Childrens' brains, in the first three years of life, are exquisitely sensitive to the interaction that they have with a caring caregiver. What does that mean? Not having a parent to care for him, this little boy—his mother works in the fields—not having that mother who talks to him, plays with him, interacts with him, means that his development was going to be less than optimal, and that is why this little boy was almost certainly going to have a developmental delay…
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> The first three years of life are so crucial because 80% of our brain's growth and development happens in the first three years of life. And the key thing that helps our brains develop is how you engage with the child. So have you heard the expression, "Your child's brain is a sponge?" It is my pet peeve. Your child's

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[1] In 2021-22, it supported 1,140 children at its clinic through 11,900 clinical sessions; around 60% of these children were below the age of 9 (Ummeed, 2022a).

> brain is not a sponge. It's not an empty box, it's not a vending machine. You do not stuff things into a child's brain. Your child's brain is like a game of tennis. When the child "serves," that is, when the baby "coos" and you "coo" back to the baby, and you respond, that's what makes a child's brain develop. That's when those neurons connect with each other and those synapses develop. That interactive response in the first three years is critical to the child's development. (iimpactglobal, 2016)

For Vibha, it was increasingly hard to turn away from the growing conviction that early identification and intervention could be the key to changing outcomes in such situations, because it could completely alter the child's future, even in the case of disabilities caused primarily by genetic factors, such as Down[2] syndrome:

> Even more startling is what we know through science, the jury is in on what works to fix this situation. We know what works. If you identify those kids—like little Prakash—early, and you intervene early, by teaching their parents how to stimulate their brains in the first few years, you can change the outcome. And what do I mean by outcome? The kids who are identified early and intervened upon early end up having better IQ scores, they end up doing better in schools, and they end up earning more money. (iimpactglobal, 2016)

In aiding this early detection, Vibha was certain that the "family" was pivotal (yet startlingly under-appreciated) in untangling the disability knot: its support, patience, care, love and playful stimulation would be of immense value in helping the child's brain develop further. The family was also the "institution" vested most deeply in the development of and outcomes for the child, but least empowered in contrast to healthcare, educational and the governmental systems when it came to disability. There were many ways in which this "dis-empowerment" played out, no starker than the fact that, as Ummeed found over the course of its work, "in many parts of the country, parents were not even being invited to observe their child's therapy session, let alone being consulted on goals for their child." (Limaye et al., 2023)

For Vibha and the early team, shifting this power dynamic and creating a new geometry of relationships was integral to their practice: a practice which aimed to bring together a system change. Leveraging the family was therefore the primary consideration in any programme they would design to address developmental disabilities in children. This notion of family-centred care also became the anchor around which Ummeed itself would grow.

Bringing the child and the family "into the room"

After bringing the "family into the room," Vibha realised,a further paradigm shift would be required in the roles of all involved:

> So typically, if you came into a room where there was a professional— whether it was a medical professional like a doctor or a medical professional like a physical therapist or a speech therapist, or if you went into a room with a special educator, the pattern is somewhat like this: first is, what is the problem? Why are you here to see me? What is the problem for which you are here to see me? And the second would be: what are your symptoms? So, listening to the story and trying to figure out from the story: problems and

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[2] Caused by the full or partial presence of an extra chromosome.

> deficits and things which point to what the issue may be what the problem may be. And the third is the sleuthing; the detective work. You examine your patient or the child to figure out: where is the problem? What is the disease? And then you have your diagnosis and then you treat it. It's so simple. Except that it's not.
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> When I started working with children with disabilities I realised that there was a problem with this "problem thinking" and the problem is that disability is not a disease. It's not even a deficit. It's the way that humans exist. It's part of our diversity and it's a complex issue. If we treat it like a problem and want to fix it and we treat it like a disease and want to cure it then we are never going to be able to move ahead and make a plan. You end up feeling helpless: both the professional as well as the person who's come to see the professional.
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> So, what is the alternative way of thinking or being? One of the things I've realised is that you need to invite a second expert into the room. A second expert who knows much more about the child, knows much more about the child's condition or strengths or likes and dislikes and about the child's family. And that second expert is the child, and by extension, the child's mother and father and immediate family. So, this is the second expert that we need to invite into the room. (India Inclusion Summit, 2020)

Formally weaving in a family-centred approach required surmounting a cultural stigma associated with being the parents of a child with developmental disability. The early shock from the realisation that one's child is unlike other children, not "perfect" or "normal," often led to disappointment, frustration and a perception of divide between the child's parents and the rest. A need to shield their child from the glare of the world and to protect themselves from the judgement of society could set in, all of which could take a heavy emotional and psychological toll on the child and the parents. For such parents, it could be a long, uncertain and "exhausting" road to acceptance.

Gopika Kapoor, mother of twins, was a former volunteer, trainer and a long-term therapist at Ummeed. The experience which altered the course of her family's life one morning in 2008 is quite fresh in her mind. Her son, Vir, was scheduled for an appointment with Vibha at Ummeed. Gopika had set up the appointment because she was certain Vir was exhibiting signs of dyslexia.[3] A few minutes into her meeting with Vibha was when she heard the term "autism."

Echoing the sentiments of many families with children who have developmental disabilities, Gopika shares:

> There are a few times in my life when I have had an intense sinking feeling, like the bottom of my stomach had fallen through my body onto the ground …When Vir was diagnosed, and I was looking for material to read, everything seemed to have been written from a Western perspective, which I couldn't relate to entirely. The [Indian] subcontinent is culturally different from the West, and it was important to have an Indian context when discussing and understanding autism [and other developmental disabilities]. I found that missing. (Borges, 2020)

The experience of coming to terms with Vir's diagnosis was for her a long process of "living through

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[3] A learning disorder characterised by difficulty in reading.

the five stages of grief," which begins with denial, and moves through anger, bargaining, sadness and finally acceptance. As a young boy, when relatives would comment that Vir was aloof, and incoherent or unresponsive to his name being called, Gopika recalls that she would get defensive. While autism is a "largely invisible disability," this denial, she says, prevents many parents from noticing red flags, and seeking out early intervention (Borges, 2020).

Years later, she joined Ummeed, training as a junior therapist. But the subject of Vir's disability was so difficult that even "when I joined as therapist [at Ummeed], I wouldn't tell my patients that I had a kid on the spectrum. I just didn't want anyone to know." It took Gopika 12 full years to come to terms with Vir's reality and to accept herself as the mother of an autistic child, eventually writing a book—Beyond the Blue[4]—for other Indian parents going through such an experience. On her time working with children like Vir at Ummeed,[5] she reflects: "It's almost as if you are trying to decipher this puzzle, and once you crack it, you just fall in love with these kids" (Borges, 2020).

For Vibha, who had long grasped the importance of helping the family move to acceptance and then further beyond to being empowered, healing this stigma became an important priority. And this required her, as a specialist developmental paediatrician, to go beyond a routine medical diagnosis of developmental disability. The approach she adopted along with her team looked to build up a detailed picture of the psychological and social environment of each child in its care: adopting what is referred to as a biopsychosocial perspective to disability (refer to Exhibit 1). In many ways, this went against prevailing medical thought.

Effacing the chasm early, holistically and collectively: A biopsychosocial perspective

In Ummeed's view, developmental disabilities had to be looked at with a very unique lens because it was a subject people approached and understood with many presumptions. It was not restricted to conventional understanding of "disabilities." Anita Limaye, CEO of Ummeed since 2017, and also a doctor by training (MD in Internal Medicine) succinctly strikes the all-important note:

> So, how do you balance a child who right now is still learning to have a voice of their own with the families' aspirations, which are still built on the society that they are participating in? The family needs to focus on the emotional care their child needs. Ummeed (therefore) believes that developmental disability is a biopsychosocial issue where disability intensifies or reduces or sometimes completely disappears, depending upon the context.

Under this perspective, developmental disabilities are no longer treated as a purely "biological" issue (i.e., a deficit that needs to be fixed in the child) but the result of an interaction between body, mind and environment, thus requiring other modifications as well, such as those in the environment to enable the child's participation.

"Narrative Therapy"

In its clinic practice, Ummeed fuses family-centricity with the biopsychosocial perspective through the use of narrative therapy (refer to Exhibit 2), a pioneering approach in its own right, to support conversations related to mental health. In particular, what Ummeed picked up on has been the ways in which mental health challenges both contribute to and get shaped by disability experiences of children and families (a fact whose recognition makes Ummeed stand out among disability organisations). Its narrative

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[4] So named as blue is often the colour associated with autism.

[5] She left Ummeed in January 2020, and currently consults with parents in Mumbai having children with autism.

practices thus emerged as a way—aligned to its core principles of family-centred and strengths-based care—of providing mental health support to children and families (in addition to other care needs of the child such as physiotherapy, occupational therapy, speech therapy, etc.). In Ummeed's words "these (narrative practices) have helped children and families to externalise problems, recognise multiple stories in everyone's lives and support the expression of preferred stories."

Through a sensitively facilitated dialogue, Ummeed thus gradually shifts the narrative of the child and the family's situation away from a "problem story" towards what is right about their child and about themselves, and builds on that to define their hopes for the future. The narrative therapist adopts a "decentred and influential[6] approach," creating a caring and respectful space which puts the children and their families at the centre of making meaning of their own situation and arriving at decisions. And in so doing, it offers children and parents an opportunity to shift the balance of power, or in other words, become empowered.

Vibha shares an example of the narrative process she follows with parents:

> To invite a second expert into the room is to acknowledge that someone else has the knowledge, that someone else has the know-how, someone else has the skills and it means training yourself to ask very different questions. And what might those questions be? So now, instead of saying, "tell me the problem for which you seek my help today," I have learned to ask: "what is your hope for what we're going to achieve in today's visit?" Immediately the question shifts from talking about a problem to talking about a hope and why is that important? It is really an important question because it tells you what the priorities of the family are or what the priorities of the child or the person with disability are.
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> The next question is not focusing on what the child can't do but what the person can do…if you ask: What are her strengths? What are the ways in which she is wonderful? What are the ways in which she is unique? It seems like an odd question to ask. Especially if you're a professional, you might cringe and say, "I don't ask questions like that" but trust me, it gets easier as time goes on.
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> So, I want to give you the example of one of my patients, let's call her Juhi. She's a 10-year-old girl with intellectual disability and when she came to see me with her parents and I asked them this question they were quiet for a minute. You see, Juhi attends an inclusive school. She has intellectual disabilities, she's struggling to read and write, she's still not able to do maths at the third grade level where she is but when I asked them what was unique about her and to tell me something wonderful about her, they thought for a minute and then they looked at each other and said: can we tell you a story? And I said, sure, tell me a story, and the story they told me was this: the previous week Juhi was at home with her grandmother alone. Her parents had gone out for a family function at night and when she was alone at home her grandmother went to bed before her. About half an hour later Juhi looked at

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[6] Decentred and influential are terms used to describe the approach of a narrative therapist while facilitating a session. A de-centred (humble, respectful, and caring) position is one which intentionally puts another person at the centre of meaning-making for an extended period. An influential (responsible and accountable) position recognises that despite de-centring, the therapist's participation in conversations is never fully neutral. Thus, it draws attention to the constant responsibility on the therapist for how they engage with someone, even when it is not the therapist at the centre of meaning-making (Gaddis, 2014).

> her grandmother and saw that her face was crooked and she didn't look right. She tried waking her up, she wouldn't wake up. She tried calling her parents but they wouldn't pick up the phone. She ran downstairs at 11 o'clock at night, rang the neighbours' bell and said you need to come now, my grandma's not okay. The neighbours came, the ambulance came and the doctor in the emergency room said Juhi probably saved her grandmother's life.
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> So, when I asked them further what this was all about, they said: "She's like that. She solves practical problems." She may not know how to solve a third-grade maths problem but she knows how to solve life problems and so that brought me to the next question: how did she learn that? What are some of the things that you both did to make that happen and in that came the story of their skills; how they focused on what was practical, how they focused on her learning emergency contact numbers, on knowing who to call in an emergency, on making herself breakfast, on making a cup of tea for someone. She was ten and she could do all of that right and her parents had the skills and she had the skills to achieve all of that. So, I'm proposing that we change the triad. Instead of talking about problems and symptoms of disease and signs of the problem or the deficit, we focus on hopes, we focus on strengths and we focus on skills because when we do that we change how we make plans. (India Inclusion Summit, 2020)

This approach of Ummeed attempts to reduce fear and anxiety and to create a much-relaxed disposition to the situation thereby creating the space for families to trust and to open up. In doing so, it is able to unburden the parents from the stress and anxiety that arises due to lack of information, absence of handholding and bring to greater prominence what the child's strengths are.

Over the years, its principles such as family-centred care, and philosophies of clinical care such as the biopsychosocial model and narrative therapy, have served as a common conceptual base upon which Ummeed has crafted many interventions, within and outside its clinical practice. One of its first interventions which directly included the family in the care of the child was the Early Intervention Centre, launched in 2007.

"Differently together"

Through a pre-school-like curriculum which emphasised parent-child play, the Early Intervention Centre looked to help children aged two to six with developmental disabilities become ready for entry into primary schools. Walking its talk, the programme was based on centring care for the child around its own family, and designing activities which leveraged the strengths of the family unit. According to Ummeed, the Early Intervention Centre is "a cheerful place, filled with laughter and is at the heart of Ummeed's clinical services" (Ummeed, 2017).

A natural extension of its work in preparing children for entry into the schooling system was a direct engagement with the subject of inclusion in education specifically, how to prepare children with developmental disabilities for schooling, and at the same time, how to support regular schools in their inclusion journeys. This was very much in line with Ummeed's belief in the biopsychosocial model, based on which interventions must focus not just on the child with disability, but also on the environments (such as schools) in which the child must not just survive, but thrive.

In its own words (Ummeed, 2022b): "inclusion is often associated with students who have impairments or students with special needs. However, Ummeed believes that inclusion involves the education of all children, not just children with special needs." Shamin Mehrotra (Director, School Outreach & Senior Counselor) led the initial efforts to increase Ummeed's focus on inclusion in education. Shamin continues to lead Ummeed's school outreach and inclusion efforts. Speaking in late 2021, she explains the backdrop:

> I've been working with Ummeed for a little over 18 years. So, it's been a long journey. My background is in mental health. So, that's my core area of work. That is what I love to do. I retain some part of that. And of course, being around for so long, and being part of their journey, I'm also part of the management team at Ummeed and part of the mental health team. But another team that got formed along the way, because I just felt that it was something that we were in some senses missing, was a team called the School Outreach Team.
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> It was something that, in my work as a therapist, I just felt was required. Oftentimes, when I met with families, I felt that the question that they came with was: "Is this the right school for my kid? Please come and talk to the teachers, they don't really get it, what should they be doing?" So, when that kept happening on almost like a loop, I just felt that maybe it's a space that we need to venture into. Six, seven years back, we got this team going called the School Outreach Team. So, that's a team that actually focuses specifically on supporting inclusion and getting schools to engage with diverse learners more meaningfully in ways that are more valuable. With respect to that team, inclusion in schools is really the core area that I'm working in.
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> If we look at the vision and the mission of Ummeed, it's really to try and get children and families of children with developmental disabilities to reach their maximum potential and be included in society. So, inclusion is a keyword. And, for me, the way I was looking at it is that it is a big picture. On a daily basis, inclusion starts in the home and starts in your community and starts in your school. So, I just felt that kids and families spend a lot of time in schools. And that's like a place to start in terms of supporting not only kids, but families to feel included.

Ummeed picked up on this need and the school outreach programme which emerged both engaged and advocated with schools to support learning and participation of children not just with developmental disabilities but with any kind of differences within the regular school context. This has included sensitising Bombay Municipal Corporation's 17 special schools in Mumbai (Ummeed's base) as well as working with regular low- and middle-income schools to build the capacity of teachers, special educators, and other school staff. By 2021, it had spread across schools in five states in India (Ummeed, 2021). In any new school it works with, Ummeed's short-term goal is to sensitise and create awareness of inclusion and inclusive practices. Deeper into its relationship with schools, it looks to build customised training programmes and develop inclusive culture, practices and policies.

More generally, the practice of narrative therapy has allowed Ummeed to gain richer insights into the minds of families and it has taken pains to act upon these. For instance, feedback from parents led to the "Walk-In Family Support Group" (Ummeed, 2017), the earliest precursor to an addition to the Ummeed bouquet: the Family Resource Centre, another form in which family-centricity and a conversational approach to care took root.

Building the trellis: the Family Resource Centre

For Ummeed, a parent who has had a child with disability can be the best guide to another parent facing a similar situation, offering something a professional can't offer—sharing from their lived experiences. Caregivers are thus able to offer a trellis of real empathy and support: helping the other parents overcome hurdles based on practical experiences of navigating real-life situations, gaining confidence, and realising that they are not alone in their journey. It is based on this belief that the Family Resource Centre at Ummeed came into existence in early 2021.

Smita Pathak (Programme Manager, Family Resource Centre), a parent of a child with a disability, joined Ummeed as a staff member under the Family Resource Centre programme. She put her thriving corporate career on hold when her son was diagnosed with autism. She shares:

> We are part of the Family Resource Centre and have no background in being a part of the development sector. We are all parents of children with disabilities, we come in with very, very varied backgrounds. So, our motivation to join this place is to be able to help other families like ourselves. Just to be able to give back, you know, because we are sort of more experienced parents. We think we have some answers, and maybe not all but we can help new families with our own experience and things like that and that was the reason why (I joined the Family Resource Centre). And secondly, Ummeed has been something that we know of, from visiting it with our child. And it's always been an organisation that we respect because of the way the therapies and things like that were carried out or our conversations with doctors at Ummeed. So, it was always held in high regard, and then having an opportunity to be able to be a part of it was extremely exciting. So, therefore, I had put my hand up for it and it came through.
>
> Ummeed looks at disability not just as a medical issue, but also a social and psychological issue, which we call the biopsychosocial model. So, a child develops around the family, and the community is part of the larger society. And, therefore, it is felt that we not just work with the child, but also with the families, the communities, and you know, and hopefully, we try to educate them and that in turn leads to an informed wider society.

Narrating the idea of Family Resource Centre, she says:

> What was realised was that however inclusive and however respectful a professional is, families actually connect and open up more when they connect with another family like themselves, because you know what the challenges are, you know the struggles, and there is an instant empathy and bonding. And then there are families who have traversed the disability journey longer, they are older parents, more experienced parents, they have a lot to share on what worked for them, what didn't. So there's all this knowledge that families themselves have. So we wanted the Family Resource Centre to be a space in which families can connect with each other. You know, you can have support groups, but we wanted it to be a space where a newly diagnosed family can reach out and ask, what next for me? What should I now know? I'm told that my child has this, but I don't know what to do next. So, other families can guide them much better.

Through the Family Resource Centre, Ummeed also sought to carve out a new and important space within its walls: one where parents were also made aware of the rights of their children, and which gave due consideration to the long-term demands that caring for a child with developmental disability can place on caregivers. Smita carefully emphasises this aspect:

> We also want it (Family Resource Centre) to be a space in which we are making parents more aware of the rights of their child: making them more informed about what's legally mandated so that they can stand up for their children wherever it's required; helping them take a more rights-based approach. We also realise that, for families with disabilities, disability is socially isolating, you know. You tend to be just caught up in doctor visits and therapy visits. And so, we realise the need for leisure for families. We want to be able to provide spaces of recreation and leisure, and also spread awareness of the mental health of caregivers. Ummeed also offers mental health counselling services, we make that known to caregivers. Those are the aspects that we want to highlight, and that's what we're working towards within the Family Resource Centre.

Parents and family members, who have been long associated with Ummeed, believe they are ready to give back to the centre. They are experienced and are in a position to help the parents who are in the process of embracing the challenges they have come upon; parents who are new to the domain, who might be seeking answers, tools and resources. As of the end of 2022, the Family Resource Centre consisted of three full-time members and a small group of part-time members.

However, having family members as staff members of the organisation that they have interacted with, in therapy or through the intervention centre, could bring with it its own set of issues. Ummeed has accordingly brought in slow, gently placed, discursive onboarding so that the joiners do not get overwhelmed at any stage. Currently, the members of Family Resource Centre report directly to Vibha[7], and she is also the team's supervisor. Recounting her own experience, Smita says:

> When we were told that we would be directly reporting to Vibha, she being the founder of Ummeed, my fear was that she may not have enough time, that maybe we would get very little time from her and it would pretty much be us trying to find our own feet. But it's been totally different. She is a very hands-on supervisor; we have regular meetings with her. And she doesn't micromanage. She gives us enough cues for us to be able to pick on those and then run with it ourselves. And our team meetings sometimes aren't even about sharing updates. Sometimes it's about discussions, thoughts, feelings about, you know, a certain talk that we attended, or what we feel about a certain topic. So that makes you feel that it's not just time she's giving for the project, and the strategic aspects of it, but also time for us: seeing us, understanding us and also giving ideas and helping us come up to speed on this whole disability space, because we are not from it. That's not our background, but she spends enough time talking to us about it, recommending books that we could read. So it's a strong learning experience, and not just because she's directing us on projects but also because she's been able to open up a lot of space for how you can learn more and how you can think differently about things.

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[7] As of March 2023, the Family Resource Centre was undergoing a reporting structure shift from Vibha to another member of Ummeed's senior team.

> The HR induction that happened, it took its time, it wasn't something that was crammed in the first two weeks. Else it would be like trying to find your feet, and then having all this information thrown at you. So, it wasn't like that. It was very, very gently paced. And every week, we had a different team that was talking to us, that took about an hour to talk to us and there were probably just four or six new joinees, and even fewer sometimes. And yet, we had the leaders of that team, taking time out to talk and share, and not just share PowerPoint presentations about what that team was, but also share observation sessions or what they actually do with children.

Members of the Family Resource Centre are aware that with passage of time their role may expand from guiding, supporting, connecting to maybe doing other things like advocacy, lobbying with the government or some other related areas.

The Family Resource Centre added significant new depth to Ummeed's biopsychosocial perspective and foundation of family-centred care. Launched as the organisation turned 20, it hinted that its approach of continually and incrementally adding to its trellis, as it learnt more about itself and its domain, was showing no signs of slowing down with age. And in so doing, Ummeed itself had definitely grown much beyond being a clinical practice, or in its own words, it was "influencing society."

"Influencing society": Curating a collective

These efforts to influence are organised around a simple twin-track model. The first track refers to collectives or systems that engage with children (schooling, healthcare and communities) though it may not specifically be children with disabilities. Widespread awareness initiatives in the form of social media campaigns and events bring different actors together (through formats such as live events and panel discussions) and form the focus of this track.

The second track engages those groups that meet the specific needs of children with disabilities, such as parents, paediatricians, therapists and special educators. Working with these groups constitutes Ummeed's core expertise in the field of developmental disability. It provides them with training and capacity building initiatives developed in-house, so that they can become resources for children, families and professionals across the country (Ummeed, 2022a).

The team has also engaged with other civil society actors and community health workers to reach that part of the population which is involved in labour-intensive sectors and have no idea of developmental disabilities; who otherwise would be unable to spot it in their children or get help. Even today, it continues to seek new forms of collaborations. Towards this, Ummeed has hosted international conferences as well as local meets. One such collaboration is the "SELebrating Inclusion Summit", an annual gathering of stakeholders working with inclusion and Social and Emotional Learning (SEL), including "organisations, policymakers, schools, educational institutions, families, educators and any individuals working towards making the education system more inclusive, safe and focused on the wellbeing of those accessing it"(Apni Shala, 2022).

Ummeed's advocacy makes its presence felt even in its flagship fundraising activity, "Walk for Ummeed." The event is no stroll in the park, rather a demanding 55-kilometre challenge along the beaches of Goa. While each participant is given an aspirational fundraising target, the Walk has served as much more than a fundraising or even awareness event: it was during the Walk for Ummeed, 2015, that a serendipitous conversation between Vibha, her husband Ashish and one of their walkers—Anita Limaye—led to Ummeed finding its current CEO (Ummeed, 2016).

Over time, this growing bouquet of therapy and direct services, training and capacity building, awareness and advocacy, as well as the joining together of families, government, schools and mainstream practitioners and policymakers has helped Ummeed bring to fruition the biopsychosocial construct covering intervention, care, support, awareness, acceptance and inclusion. Anita, helming Ummeed since 2017, feels that:

> As an organisation, I think we are constantly balancing. I think the need is to identify early, mitigate risks and intervene appropriately; understand what this does to children when they become young adults and adults when they are developing their own identity. And we think this is happening a lot in the West, but it's starting to happen in India now, as disabled people are now having a voice around their identity, which is great. And so autistic people, you know, won't think of themselves necessarily as disabled and the challenge is that, unfortunately, they have to fit in a world that has been created by people who aren't autistic.

The dynamic behind this endeavour to expand its interventions is that in India, given the scale of the issue, all current efforts could always reach only a certain part of the affected population. Even if the country was looking at 15% of children having a disability or being at a risk of disability, that made it more than 50 million children to reach: bigger than the populations of several countries.

As Anita points out, although Ummeed is directly working with around 1,200 children a year, it becomes important to constantly ask:

> So, what's happening to the rest? And how do we reach out to them? So, that's when we took on training and capacity building as a pathway to scale. We knew that our models work, why they work; and the values that are important to us. So, we thought about how we take this outside and beyond. We offer training today to doctors, to therapists, teachers, to community workers and to caregivers.

Shamin adds further detail to the strategic considerations behind Ummeed's chosen pathway to scale: The priority generally has been to see how we can scale in a way that's meaningful:

> 15 to 17 years back when we thought about this question, the thought was, "Okay, we open many more centres." But soon, we realised that there's only that much that you can reach through a centre and which is why we consciously decided that our pathway to scale would be through training. And so, why reinvent the wheel? If somebody already has leverage in the community, if somebody already has a connection with people, I would like to train 10 such people who can reach out to 10,000 instead of trying to find 10,000 of my own, which will take me much longer. If someone already knows those 10,000, I might as well work with that one person. So, I think the priority pathway to scale has been in terms of training so that we can reach more people. Having a centre is one thing, but the point is that most vulnerable families don't even know how to access our centre, or don't even know that a centre like ours exists. So, it's not about people reaching us, it's about us reaching people to sort of build that awareness and sense of wellbeing in communities.

Thus, with time, training alongside advocacy has come to be integral to Ummeed's way of working and its approach towards building inclusive ecosystems. (Ummeed, 2022c).

Seeking people

But curating a collective outside puts its own stresses and strains on maintaining the bond within, as such bonds too have to be based upon the same principles advocated outside. Anita lays out these principles: "We believe in biopsychosocial approaches; we believe in family-centred care; we believe in strengths-based approaches; we believe in evidence-based care and culturally relevant care. These are the five broad principles." Unfurling these principles demands bringing together a striking variety of specialists under one roof. Enumerating this eclecticism she says:

> So, our team of 125 has about 80 doctors and therapists, which includes developmental paediatricians, physical therapists, occupational therapists, autism intervention specialists, counsellors, speech therapists and social workers: pretty much everyone who a child with disability or their family may need to consult along their journey.

This group of specialists and professionals have to be solicited against opportunities on offer in medical schools, lucrative private practices or various international opportunities. But there are other considerations, including those of finding the right orientation and compensation that compound matters. Anita explains:

> Family-centred care, strengths-based approaches, disability as a biopsychosocial construct, evidence-based care and culturally relevant care. Now, all of these draw into all areas of our work, because, fundamentally, if I'm hiring an occupational therapist who's very oriented towards the conventional medical model that doesn't fit. I mean, even the unlearning journey is too painful in that case. And so, you just don't want to hire those kinds of people. And we've learned over time about how to screen out such people and get people who may not use the same words as us, but are fundamentally value-aligned, because then you can get the terminology and build the skills further while in the organisation.
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> Speaking of the plain challenge of recruitment, I remember recently, we were trying to hire for a position and our consultants told us that "the competencies you are expecting and the salary you're offering are not on par with each other;" basically that "you're expecting competencies that an international organisation typically expects from their staff, but you're paying what an Indian organisation pays, and that's not going to work." So, I think, since I joined Ummeed, we've revised salaries three times. Significantly revised. Not revised by [standard] 8% increments, but given larger chunks and jumps. And that's in the five and a half years of me being at Ummeed.
>
> I think we recognise that our competition when it comes to doctors and therapists isn't the social sector, it's the private medical sector, and it's international, because so many of these people go abroad after they've studied; they get further degrees and many of them settle down over there. Somebody recently was reminding me about how few people in the first place get churned out by the Indian medical education system. So, the number of

> doctors and therapists that are coming out of India are not enough for our population in the first place. And then, the majority of them are going abroad. We are now searching from a talent pool that is still in India, and then from them, we have to look for people who will be value-aligned, right? And then you have to coach them, train them, and then offer them a career ladder. So, we're looking at a pool which is really, really small. We're also based in Mumbai, which is an expensive city, which means if I find someone who's really good but who doesn't come from Mumbai and says, "I can't afford Mumbai." then I'm caught up by my salary structure, which means I can't offer that person more than I'm offering someone in Mumbai. So, on the doctor and therapists' side, I think that's been a challenge.

Added to this litany is also Ummeed's own resolve to not poach talent from other organisations. After all, as Anita says, "we are all here trying to do good work and it doesn't help if we eat into each other."

And if these constraints were not enough, Ummeed has also tried hard to integrate neurodiversity[8] and other forms of diversity into its workforce, like it has done with parents through the Family Resource Centre. Anita points out: "It has really worked for us, when we've had candid conversations with a person who, let's say, is on the autism spectrum. It's about what this person can do, and how we give them a role that they will succeed at." Trying to formulate a policy and approach of integrating individuals with disabilities as well as other forms of diversity into their team, however, remains a struggle, and the organisation is currently implementing a Diversity-Equity-Inclusion initiative to help do this in a more thoughtful way in the years to come.

Binding together

A combination of these challenges mean that those who become part of the team at Ummeed are invariably entering into a myriad mix and have to find a means to steady their footsteps. Counter-intuitively, the diversity of the work itself provides a refreshing means to find one's footing. As Anita shares:

> Once people decide to stay in the organisation, what Ummeed offers them is, firstly, that they don't do just clinical care, they can also get into training, they can also get into research, they can get into awareness and advocacy. So, I think they enjoy the diversity of exposure they get. We have a lot of international collaborations, so they enjoy getting that exposure. We publish quite a lot—we've been published in Lancet Global Health and other paediatric journals—so, there is writing experience and publications that one gets to their names. And we also present in a lot of conferences; we are invited, or we apply, and we present. So again, there is national and international exposure on that count.

But of far greater import is what at first appears a seemingly innocuous and ordinary term that has acquired a special meaning and function at Ummeed: supervision. Anita says: "I think supervision is a strong point. During the majority of times, when we've asked people exiting Ummeed, 'What's been right?,' they have said: 'Supervision is amazing.' I think that the culture here is really, really strong."

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[8] Neurodiversity describes the idea that neurological differences have always been a part of humanity, and as such are to be recognised and accepted like any other human variation. Thus, in the language of neurodiversity, neurological differences such as autism or learning disability are considered the result of normal, natural variations in the human genome, rather than "disabilities."

Regina Khurana, who heads HR at Ummeed, explains:

> At all times, everyone at Ummeed has a supervisor. We believe in supportive supervision throughout. People will meet their supervisors once a week, or once in two weeks, depending on the need. And the kind of support that the supervisors provide to each person to reach the best of their abilities is amazing.

As Anita elaborates further, it also closely reflects an important element of training in most medical schools, whereby medical students or junior doctors build experience through close, case-by-case mentoring with senior doctors :

> In the corporate world, we were managers. We managed people. I think it was at Ummeed that I heard the word "supervisor." I think it comes from the medical context where when you do physiotherapy or occupational therapy, or even me as I was doing my MD or MBBS, there's just so much that happens which is on-the-job, with people giving you ongoing learning or experiences while you're working with patients. So, that I think is what supervision is about, while management is also so much about managing people, managing your resources, managing time; you're managing. There's a side to supervision which is not about managing, it is more like mentoring and really investing in the person (supervisee) and trying to build the person along certain value sets and skill sets. It may be terminology, but I think it's more than management.

In particular, as Anita explains, supervision is really the “binding agent” that helps a person, whatever be her background, to orient herself more fully with the meaning and mandate of Ummeed:

> And so, when an occupational therapist joins Ummeed or an autism intervention specialist joins Ummeed, they come with a certain qualification; but they will still go through three to six months where their sessions are supervised, so they understand what's going on at Ummeed, they receive feedback during and after sessions. After that, a certain amount of supervision continues throughout their career. So, there is group supervision, where during meetings, people bring their cases, and we talk about them. It's not easy, right? You know, there's a saying that "no child with autism is the same; no person with autism is the same.” In the first place, each child and each person is different; and then their social context is different; then their family situation is different. So, you will never know everything about this, right? And you're always going to learn. Like even Vibha will sometimes come to the UMT (Ummeed Management Team) group of developmental paediatricians and she'll put out a question asking everyone: "what have you done in a situation like this?" Now, Vibha is probably the foremost, or amongst the foremost developmental paediatricians in the country. But in supervision, you're feeding off of each other: "have you faced this before? That before? I haven't, so what did you do when you faced it?” So, at Ummeed, there is peer supervision, there's group supervision, and there's individual supervision.

It is not about (only) pointing out the right or wrong but in fact creating space for all activities to be observed by the next senior level individuals or by peers so that the nuances of Ummeed’s practices can be transmitted, understood and embodied in a contextually appropriate way in different situations.

Supervision also remains critical to Ummeed's relationship with its parents and children. It enables its family-centred, strength-based therapy to be imbibed by all staff, in turn ensuring the right environment for its children and their families where they are dealt with empathetically, without "mechanistic" approaches creeping in. All agree that in Ummeed supervision is carried out with a sense of openness, transparency and handholding at all levels. It is also by no means restricted only to Ummeed's clinical practice. Supervision spaces also allow mentors and mentees to connect on personal levels, and for supervisees to open up on any aspect of life at Ummeed they may be struggling with, as Daisy Daruwalla Bhathena (Senior Therapist and Mid-Level Manager at Ummeed) emphasises:

> A supervisor is also a go-to person, which is really, really helpful. You can brainstorm, you can talk about personal things, you can talk about work-related things. So, that is something which is very therapeutic. You're brainstorming together, you're working on projects together, you're not individually doing anything.

In its own distinctively fashioned culture of supervision, perhaps lies Ummeed's secret sauce: of finding ways and means of safeguarding a sensibility towards a child with disability and her parents, while holding on to practices that are rooted in evidence. And it is on the back of the strength of this cultural sensibility that it has endured against a societal sensibility which is much at odds with its own. Not only has it endured, but it has also grown. At the end of two decades of its journey, Ummeed today has a team of 125, channelling funding commitments to the tune of INR 12 crore per annum (refer to Exhibit 5). Much of this growth has happened in the past five years during which time the team has nearly doubled.

For a sensitive, bold and creative non-profit, sailing against the winds, harbouring all shades of stakeholders, such growth is both pleasing and discomforting at the same time. The discomfort is understandable: a growing organisation demands a firmer, more formal and codified hand to manage, while the very ethos of the organisation, for instance as embodied in its narrative therapy practices, is structured yet emergent, organic, empathetic and inquiring. Wherein then lies the balance?

Structuring

An early side-effect of a growing team is everyday miscommunications or misunderstanding, especially in a diverse talent pool. Frictions and competitive undercurrents are inescapable in a house of highly qualified doctors, specialists, scientists, young graduates and those working in all kinds of non-medical roles. Adding to these under-currents is that the pedigree—of education and experience—can often prevent unlearning.

Compensation is often where these frictions can converge if prudence is not adequately exercised. At Ummeed, for example: the need to recruit for a particularly rare specialism can result in a newly joining specialist (in that area) being offered more than those who have been around much longer. In such instances, the need for the specialist to fulfil Ummeed's own mandate to the children can override a sense of fairness to those in the team who have been with it for longer. Ummeed, like many, is forced to walk a tightrope on a case-by-case basis in this regard.

Further, as Anita puts it, Ummeed is a place where medical science, social sciences and the practice of management must all meet. For its core team of medical staff, especially those who have reached the "middle management" level in terms of their experience and responsibilities, the managerial side of the job can start to become a disorienting experience:

> This (middle management level) is the place at which you start to get into this space where you're feeling pretty sandwiched across multiple points of view. And I don't think we've supported them enough in navigating this space; again, because a lot of people who moved into these roles were people who are doctors and therapists, who were never trained in management in the first place. And so, all of this felt new and we were also finding our way around supporting them.
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> I think, as we've grown from 55 to 125, we've also started bringing in people with project management background at the organisation, because our programmes have grown, which means that we now have a structure within which to deliver them. As medical people, we are not trained to be project managers, we work with one patient at a time, we don't know how to work on a programme. So, that's a skill that Ummeed's doctors and therapists, who are about 80 of the 125, have had to learn on the job. Supervision is something they've learned on the job; management is something they've learned on the job. So, bringing in this talent pool, and then managing them, has been a learning journey, I would say. We are generally a collaborative organisation but there's always that conflict between "I want to do what's right by this child and family," and, "okay, there are a lot of other things to get done that we promised donors. So, when is that going to happen?" So, those are some of the things that we are navigating.

The antidote to these challenges and stresses will not be found amongst canons of management theories and practices. Perhaps though, it is to be found, in some part, front and centre within Ummeed, as Vibha shares:

> I recall times when my patients have reached out to me with concern and care. Children who have experienced the anxiety and fatigue of juggling many difficult things can recognise the symptoms in others. One hectic day, I greeted my 12-year-old patient, who had attention deficit hyperactivity disorder, somewhat distractedly with “How are you doing?” He gave me a once-over and said gently, “I’m okay, but how are you?” We did a little check-in on how our respective days had been and, quietly, my day became lighter.

For those in or from Mumbai, the city of Ummeed’s own birth, Vibha’s anecdote may well remind them of the saying etched beneath the mural in the middle of Mumbai’s expansive traffic junction of Mahim: “A child gives birth to a mother.” When in doubt, when confronted with strains, Ummeed always has the luxury of not needing to look afar: within its precincts are those it serves, who will continue to inform its motivations, means and methods, and continue to inspire. They will provide the vitality to retain its mandate, provided it continues to nurture an attitude to pay heed to the space within, even against odds that have at times been stacked against it.

Maintaining an independent resolve

Ummeed has over its lifespan resolutely journeyed down paths less travelled: be it Vibha’s first steps with it as a young medical professional setting up something with little precedent in India at the time, the establishment of family-centred care, the biopsychosocial model, the narrative therapy approach, focusing on “shifting ecosystems” or even looking deeply into workforce diversity and inclusion.

Throughout, Ummeed has always found a way to create a model which is striking, innovative and yet not opulent in terms of implementation. It is done with a warmth and understanding which is driven only by passion for caring about, accepting and bringing into society a group of children who are often overlooked, ignored or labelled unfit. As is often the case with pioneering approaches which go against established norms, these efforts have, in Anita’s words, led to it becoming a bit of a “pariah” in the wider medical community:

> We want to influence the medical system to become biopsychosocial. That's not an easy journey. You know, doctors will bring their children to us when they want a diagnosis or a second consultation, but they may not call us to a conference because we are pariahs in a conference: we are talking about stuff that the majority of the medical community does not ascribe to. At the same time, we are working with partner organisations that may not have the kind of medical expertise we do. So, how do we help upskill them to be able to still support early identification and intervention? How do we work with caregivers to understand their own voices, to first make their voices heard, and then for them to go through some of these journeys that we are going through? And then, to do the same at some point with the government. We do that right now more with international agencies because our voice is more easily heard over there. In India, we are waiting to be invited to the table. Sometimes we are, sometimes we are not.

Anita’s own journey in Ummeed, and indeed of much of its senior leadership, has been one of staying on in a “pariah” land. For Anita it started on the “Walk,” then with volunteering for six months and that soon morphed into six years, which continue. She recalls her early days at Ummeed and reflects on these six years:

> Vibha, our founder, at that time felt like she had brought Ummeed as far as she could, and she now needed someone to come in who brought in skill sets that would help the organisation grow. Vibha thought at that time that she would hand over and leave, but we realised we work very well together. Vibha is the content person, she's the face of the organisation, she's an amazing person. So, she's the ideator, I’m the feet on the ground. We strategise together, and we use our collective, complementary skills to think about how to move forward with Ummeed. We are supported by a very strong leadership team. And the reason why I decided to continue at Ummeed, after my volunteering, was because I loved the people.

To love means to accept and there is perhaps no greater teacher than a disabled child. Vibha, reflecting on her journey along the road less travelled thus far, adds:

> So, when I think about this kind of two-expert thinking [involving the families along with the professionals], and I think about what I want to say to families, it is this: everybody's good at something, but you are the expert on your life and no matter how big and how qualified and how smart the professional is in the room with you, there's only one expert on your life and that is you. The second part of what I want to say is for professionals. What's in it for you? Why would you want to work this way? You remember that initial burden that you

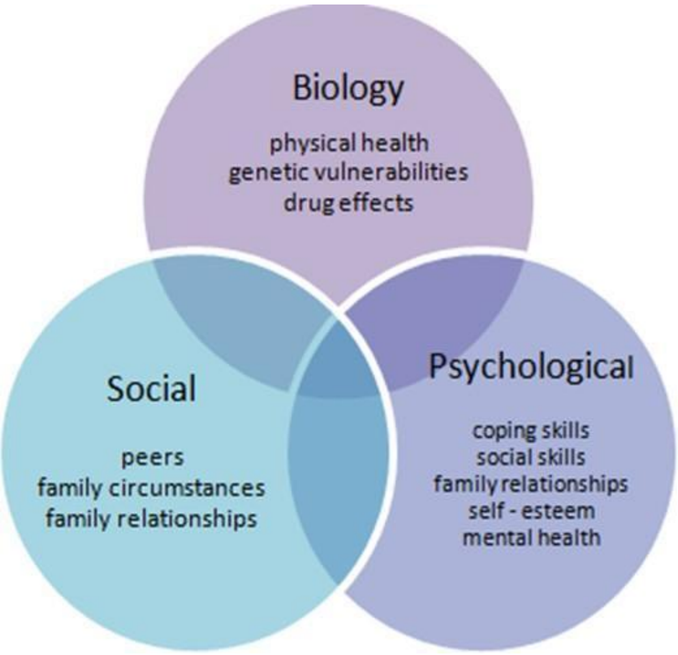
> had of needing to know everything: you need to solve every problem, you need to know all the answers, you have great responsibility and you have great power. Guess what? That can change. You can have permission to bring yourself into the room as a whole with your patient, not just your professional persona but your whole persona. You finally have permission, one, to be curious about the child as a person, not just as a disease or a diagnosis because that's not what it's all about.
>
> Secondly, you have the opportunity to say: “I don't know, but we'll find out together” because many times when families ask me: “Do you think he'll go to college? Do you think she'll ever get married?” I don't know the answer but I know that I can partner with them in the journey to find out. And, lastly, to be vulnerable. I have laughed with almost all the families that I work with and I have cried with some of them. I have comforted many of the families I worked with and many times I have been comforted by them and this is because to be vulnerable does not mean to be weak. I think being vulnerable makes me a better physician, it makes me a better human being. (India Inclusion Summit, 2020)

In closing, she reminds of a quote near and dear to her by Leonard Cohen, saying: “Ring the bell that still can ring, forget your perfect offering. There is a crack in everything, that's how the light gets in.”

Exhibits

Exhibit 1: The biopsychosocial perspective

Fig. 1: The biopyschosocial perspective



Source: The Albert Team, 2022

Exhibit 2: Narrative therapy

The exhibit below is an article which appeared in Mid-Day (Chandrasekharan, 2016).

Narrative therapy, which aims to empower the patient with self-generated coping skills inspired by fables, is finding eager practitioners at NGO Ummeed.

Daisy Daruwalla Bhathena, senior therapist at Ummeed, and Jehnazeb Baldiwala, head of the mental health team, say narrative therapy encourages the patient to describe their circumstance and what's ailing them on their own terms.

"While earlier I would tell her what to do, which school was good for her, etc., now I listen to her to understand what she wants," says 46-year-old Sonali Jain, a community worker with city-based RA Foundation. The NGO connects with children from less privileged backgrounds and funds their education at residential schools in order to help educate them in a protected environment. The girl Jain is referring to is an orphan who was brought to the attention of the foundation when she was eight years old, as she was being sexually assaulted by her maternal uncle with whom she lived. Jain became her counsellor and is now her unofficial guardian. Her more recent conversations with the young girl, now in Standard 10, revolve around the teenager wanting to find a part-time job. But, the way the conversations are patterned have shifted in the last 11 months. This is after Jain took a course in Narrative Therapy at the Chinchpokli-based Ummeed Child Development Center. "From telling her what is right for her, I have changed focus to figure out what she wants and why she wants it, and how best she can achieve it," says Jain. The teenager is now discussing what measures she can take in order to ensure that she has time to spare for a part-time job that won't interfere with her education, and whether it's something that she is able to, and willing to.

This involvement of the patient in how the problem should be viewed and dealt with is central to the idea of Narrative therapy. Developed in the 1980s by New Zealand-based David Epston and Australian social worker Michael White (who passed away in 2008), it's a form of mental and emotional healing in which the therapist is expected to play the role of the "influencer" through conversations. A quote by Epston—"every time we ask a question, we're generating a possible version of a life"—exemplifies this.

Jaffer and Singham

Narrative therapy shies away from using labels that have become part of common mental health parlance, such as depression, bipolar, bully, etc. This, says Jehnazeb Baldiwala, head of the mental health team at Ummeed, encourages the patient to describe their circumstance and what's ailing them on their own terms, while steering clear of internalising the problem. As Daisy Daruwalla Bhathena, senior therapist at Ummeed, says, "The problem is the problem, not the person."

For instance, in an interaction with five-year-old Jaffer Khan (name changed), an Ummeed community worker said, the senior KG student would mostly be seen outside class. Mischief and aggressive behaviour—troubling kids passing the corridor by teasing and hitting them, slamming or kicking the doors—came to the social worker's attention.

In a blog for the NGO, she writes that her initial work with Jaffer was done by building a rapport. A typical narrative therapy conversation goes like this:

When anger comes, what does Jaffer do at that time? How does Jaffer feel when anger comes to him?

How does it look? What is its colour? Can you draw it for me? Do you want to name it?

Jaffer, writes the Ummeed team, named his anger “Singham” after the character in the Bollywood movie. He drew pictures of a man bold and strong, red in colour and called him Singham. Jaffer told the Ummeed team that when Singham came to him, he would hit, run, slam the door and not listen. Due to this he said that his friends went away from him and said he was a bad boy. Whenever Singham came to him, Jaffer said, his anger would increase and so he would trouble his teachers and the rest of the class.

The solutions, too, had to come from Jaffer. The questions then turned to “Do you want to keep Singham as a part of your life?” “How should Singham go out of your life?” To reinforce a positive time, questions also lean towards looking at times when the situation or the negative reaction to it are not present. Therefore, “Are there any situations when Singham does not come to you?” Now a model child, Jaffer is often used as an example for other kids who misbehave.

Paediatrician, Dr Vibha Krishnamurthy, also the founder and medical director of Ummeed, says that Narrative therapy became the predominant form of therapy at the centre as it was the training that Baldiwala had received. “However, soon, through anecdotal evidence, we realised that the families that received this therapy said they felt empowered. In traditional sessions, they felt they were being given *gyan*,” she says, adding that the previous year, she too, enrolled for a course. With the children and their families being taught to identify problems and develop the skills they can use to counter them, Dr Krishnamurthy believes that the therapy also ensures less dependence on the therapist.

Some drawbacks

Narrative therapy, however, has some rough edges, admits Baldiwala. While there are some questions that a therapist can start with there is no three-step solution that will help the therapist reach a conclusion. There are maps, outlined over the years, that act as guides.

The other issue is that while it encourages patients to identify why certain behaviours won’t work in the long term, they don’t try and identify why the patient responds to situations a certain way. For instance, traditional therapy would try and probe what about a classroom situation made Jaffer angry. If, for instance, he was being told to do homework, what about the homework was upsetting.

Cross-disciplinary programme

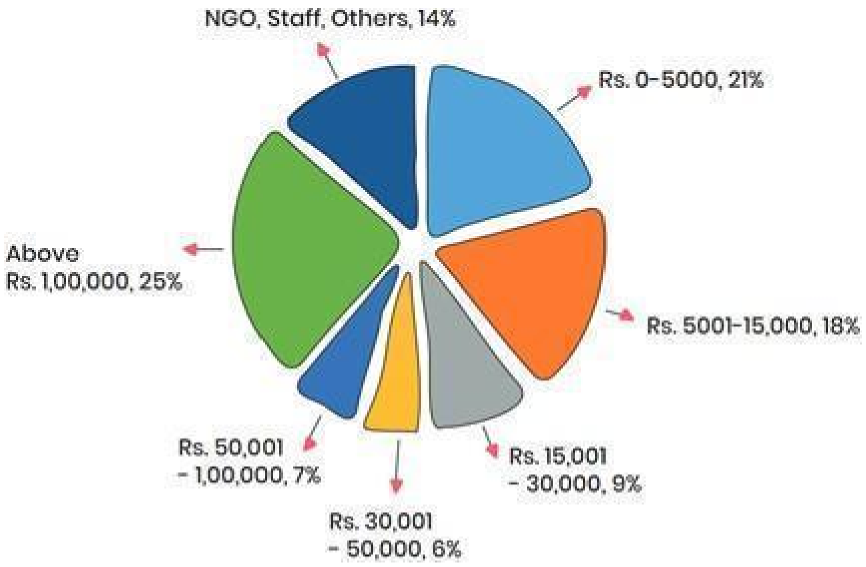
Yet, feels Dr Krishnamurthy, it is an approach that more and more health experts must adopt, and move away from the “expert model.” “As paediatricians, we believe we know all and we tell the patients what to do. We do this, because we are not taught any differently. But, I see a shift in that people want to participate in their healthcare and want to choose better. When patients pick their goals, they are more likely to stick to the therapy,” she adds.

Peggy Sax, a Vermont-based psychologist, says this form should be seen as a cross-training programme among various disciplines such as those involved in social work, speech therapy and even parenting.

Shona Russel, a practitioner at Narrative Practices Adelaide, says: “Often problems that are very serious and difficult push people apart, but this approach enables people to work together to find solutions that are practical and fit for a particular family. The approach helps children and families uncover novel and creative ways of managing the problems they face.

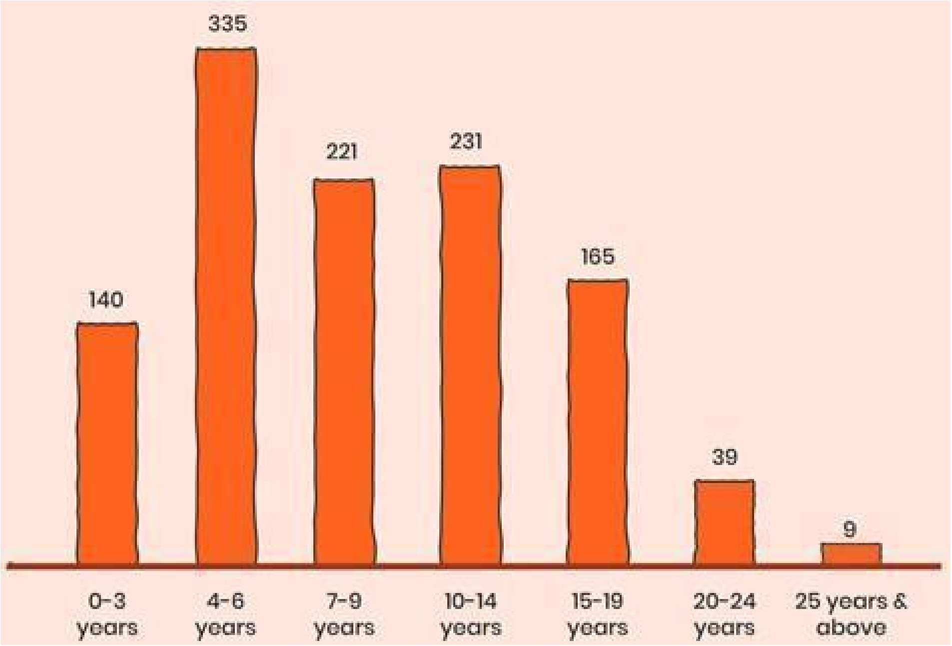
Exhibit 3

Fig. 2: Monthly income of families supported at Ummeed's clinic



Source: Ummeed Annual Report 2021-22

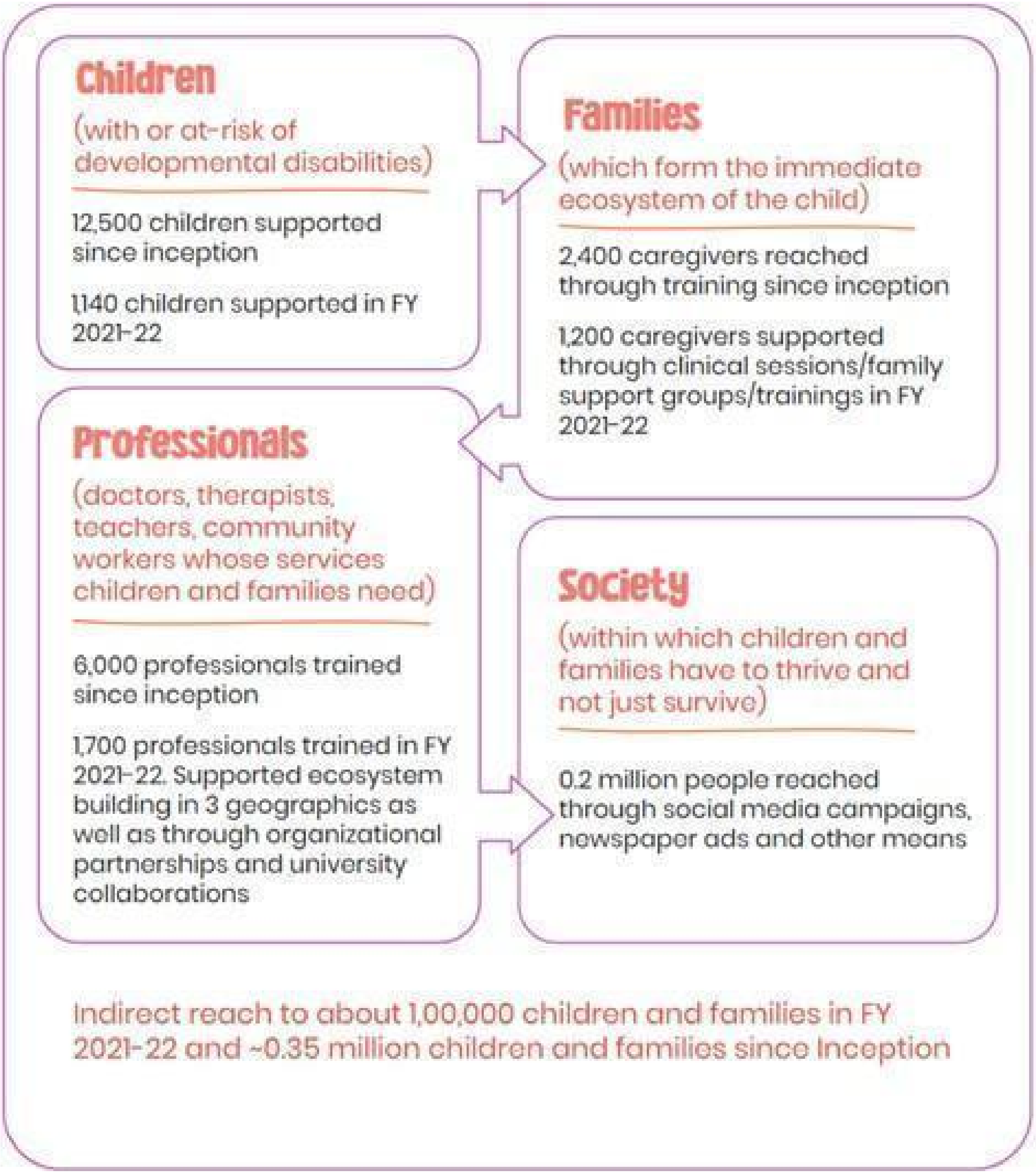
Fig. 3: Age distribution of children served at Ummeed clinic



Source: Ummeed Annual Report 2021-22

Exhibit 4: Ummeed's reach and impact in India

Fig. 4 & 5: Ummeed's impact in 2021-22



Children

(with or at-risk of developmental disabilities)

12,500 children supported since inception

1,140 children supported in FY 2021-22

Families

(which form the immediate ecosystem of the child)

2,400 caregivers reached through training since inception

1,200 caregivers supported through clinical sessions/family support groups/trainings in FY 2021-22

Professionals

(doctors, therapists, teachers, community workers whose services children and families need)

6,000 professionals trained since inception

1,700 professionals trained in FY 2021-22. Supported ecosystem building in 3 geographics as well as through organizational partnerships and university collaborations

Society

(within which children and families have to thrive and not just survive)

0.2 million people reached through social media campaigns, newspaper ads and other means

Indirect reach to about 1,00,000 children and families in FY 2021-22 and ~0.35 million children and families since Inception

ACTIVITIES

Individuals and organizations

- Sensitization and skill-building workshops
- Long-term trainings
- University partnerships for internships/observerships, course/curriculum delivery
- Organizational partnerships for Early Childhood Development and Disability
- Peer partnerships for program co-delivery

Ecosystems

- Three geographies (Jalgaon, Hyderabad, Guwahati+)
- Pilot program for implementing inclusive ECD in the anganwadi system
- Pilot program for Inclusion Fellows in schools
- Conferences for stakeholders associated with the school inclusion and inclusive early childhood development space

REACH

- ~1,300 professionals trained through ~100 sensitization/skill-building/advocacy workshops
- ~350 professionals trained through 19 long-term trainings
- New engagements with organizations such as SNEHA (Mumbai), Bethany Society (Meghalaya), CORD (Himachal Pradesh)
- Partnership with Azim Premji University for diploma design and delivery; interns and observers from other universities
- 2 initiatives run jointly with peer partners (ECHO-ADHD, and caregiver survey on impact of COVID-19 pandemic)
- 10 research papers published
- 16 oral and poster presentations in national and international fora/conferences

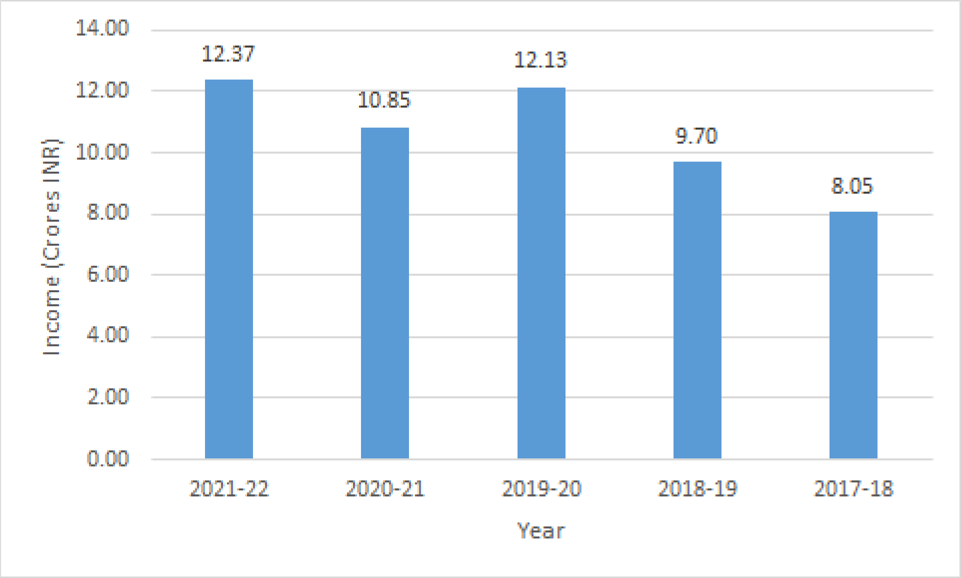
OUTCOMES

- Average post-training knowledge scores for long-term trainings between 70-87%
- ~15% of children monitored through the early childhood development program identified with delays/disabilities
- Co-delivery of programs and initiatives with peer partners piloted
- Representatives from partner organizations and geographies at advocacy events
- Exploring possibility of expanding to one new geography
- Ummeed invited to be part of Integrated ECD Network in India

Source: Ummeed Annual Report 2021-22

Exhibit 5: Ummeed's financials

Table 1: Ummeed Annual Income, 2017-2022



Source: Ummeed Annual Reports 2017-2022

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