Caregiver
ADVOCACY GROUP
Caring your loved ones

CAREGIVER

"Supporting your loved ones through their journey"

SPECIAL NEEDS

Professional Insights ★ Community Voices ★ Upcoming Events

SERIES-1

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DIRECTOR'S NOTE

DR. K. NIRAIMATHI
FOUNDER MEMBER,
CAREGIVER ADVOCACY GROUP

"TO CARE FOR THOSE WHO ONCE CARED FOR US IS ONE OF THE HIGHEST HONORS."

- TIA WALKER, THE INSPIRED CAREGIVER: FINDING JOY WHILE CARING FOR THOSE YOU LOVE

As caregivers, we often find ourselves in a role that we didn't anticipate - a role that asks for endless strength, patience, and understanding. Whether it's waking up in the middle of the night to offer comfort, understanding the complex medical care, or balancing the emotional demands of caregiving with our own well-being, the journey is one that requires immense resilience. And yet, caregivers are often the ones who go unseen and unheard.

This is why we felt a deep need to create something more - a space where caregivers could not only receive support but also feel validated, connected, and empowered. The Caregiver Advisory Group was born out of this very need. At Evidentia Research Solutions, in partnership with KK Charitable Trust, our goal is to provide you with the tools, resources, and community that you deserve.

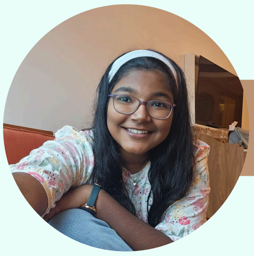
This newsletter, CAREGIVER, is just one part of our larger vision. We want it to be more than just an update or resource - it's a testament to the importance of your role, and a reminder that you are not alone in this journey. We hope it becomes a source of encouragement, inspiration, and practical guidance as you continue your caregiving efforts.

The decision to focus on caregivers, especially those caring for loved ones with cancer and autism, comes from a deep recognition of the unique challenges you face. For those caring for someone with cancer, the journey can be particularly heavy. You are often the backbone of support, managing everything from medical appointments to emotional reassurance. The toll it takes on your mental and emotional health is real, and we want to ensure you have the tools and support to take care of yourself as well.

Similarly, caregivers of individuals with autism face their own set of ongoing challenges. Autism is a lifelong condition that requires constant adaptation and understanding. Whether it's accessing educational resources, managing behavioral interventions, or simply finding time for self-care, the road can feel isolating. But through the Caregiver Advisory Group, we are committed to providing you with the guidance and community that can make this journey a little less lonely.

We invite you to be an active part of this community. Share your experiences, engage with the resources we provide, and know that we are here to listen and support you every step of the way. Together, we can build a stronger, more resilient caregiving network - one where caregivers are truly recognized for the vital role they play in the lives of their loved ones.

EDITOR'S NOTE



MS. PRAJNA.A
FOUNDER MEMBER,
CAREGIVER ADVOCACY GROUP

"**W**ill they be okay?" is the question that every caregiver ends up asking at some point in their lives. As a caregiver and a neurodiversity advocate, this is a question I've both asked myself and have had parents ask me, time and time again. While looking for ways to answer this question, I found myself asking more questions: "Why is this anxiety not being voiced out?" "How can we ensure that the caregivers are also cared for, seen, and heard in the long term?"

It was clear that the way to answer this question was not by temporary reassurance but by initiative. An initiative that would bring together caregivers from all over the state, who were asking themselves this question. An initiative that would give us a platform where we could voice out this question to experts and to other caregivers, and see our experiences reflected in others. This is how the seed for the caregivers' sessions was planted, nurtured by a powerful need for community and change in the way we approach care. This initiative was born out of a culmination of all our individual experiences as caregivers for family members with stigmatizing illnesses, disorders, and disabilities. It is important to remember that what we hope to address through this initiative is a human right. We're different in our own ways, but underneath our differences, we all want to be seen, heard, and supported something that most individuals with stigmatized disorders, disabilities, and illnesses, and their families are deprived of.

Progress is ultimately a process and not a destination. This initiative is only a small step towards a world that is accepting and inclusive of difference. We hope to watch this grow as a movement led by caregivers from all over the nation. Even if one caregiver walks away from these sessions feeling seen and heard - I count it as a step towards a better society and world.

Once again, the caregiver session could not be possible without the help of Dr. Niraimathi, co-founder, Ms. Soundarya.M, project co-ordinator and all the advisory board members, and last but not least, the caregivers themselves. You deserve to be cared for and supported, just as you do for the people in your life.

RAISING A CHILD WITH AUTISM

DR. JANAKI BALAKRISHNAN, COUNSELLING PSYCHOLOGIST

Parenting a child with disability can be a daunting task, with endless challenges and untiring hassles. One needs a lot of stamina and commitment in terms of time, efforts, and capability to nurture the child in the early years; more so, through their growing years. Never the less, the caregiving role and the exerting responsibilities will continue through the lifetime of the child.

Raising one would involve challenges and limitations that are controlled by various factors such as type and severity of the disability, age of the child, and age of the parents, family support, family income, socio-economic factors, community resources, and other cultural aspects. Furthermore, lack of awareness in society, poor family interaction, stigma, and misconceptions associated with the disability, can all make it worse for a parent to adapt to the new role.

Firstly, coming to terms with having a child who is not as perfect and as expected, in itself is a process of overcoming the grief. Then understanding the condition, seeking counsel and support, facilitating learning and development for the child, forging his or her path for progress and success, and lastly advocating in the best interest of the child for the needs and actions at the community level, are all in the gamut of parenting a special needs child.

Some of the questions a young parent might have are, “Can my child survive?”, “Will my child become normal?” “Where should I go for help?” “What will I tell my family and friends?” There will be different sets of questions at every stage as the child grows. Older parents might have questions like “How long will this continue?” “Can my child marry? or “Who will take care of my child when I die?” It may be difficult for any parent to know all the answers at once, and for the most part, they will find answers as the time unfolds.

In the case of autism, each child is unique and would present challenges that are very typical to that child and are transient in nature. With social and communication deficits and sensory issues, they may also present medical problems, fixedness, and a lack of motivation or interest in learning. This results in heightened frustration and maladjustment, which in turn presents severe challenging behaviours such as self-injury or aggression on others, as a disorder complex.

Caregiving for a child with autism differs from others in that it is fraught with uncertainty, unpredictability, and uncontrollability. It may be easy to control a young child, yet their behaviours would be unpredictableand developmental outcomes may be uncertain. As the child grows into adolescence and adulthood, parents may gain predictability and certainty of future outcomes to an extent, but controllability will be a challenge.

Albeit, it is not merely providing basic care, but involves that of responsiveness and emotional support. It is important for parents to be observant and sensitive to the child's needs and communication. Individuals with autism require a specialized environment that provides them a sense of structure, visually guided pacing, realistic expectations, and rewarding experiences. More importantly, safety and protection from harm should be a priority.

Notwithstanding, caregivers should attend to their own health and wellbeing while navigating this journey of caring for children with Autism. Adequate rest, exercise, a healthy diet and leisure are important parts of self-care for parents of children with autism so as to combat stress and develop coping strategies in order to become effective in their parenting role and to achieve an overall sense of contentment in their own experiences.

CAREGIVER TIPS

- *Acceptance of the diagnosis and and trust in doctors and therapists lead you towards the most effective care.*
- *Connect with other caregivers to learn how they've overcome similar challenges.*
- *Allow time for growth, as small changes in routines require patience and persistence.*
- *Nurture your own well-being, maintaining health to provide calm, and Compassionate care.*

10 STRATEGIES FOR MANAGING MELTDOWNS IN AUTISTIC CHILDREN

MS P.S.DIVYA, SPEECH LANGUAGE PATHOLOGIST

Autistic children are individuals who have Autism Spectrum Disorder (ASD), a neurological and developmental disorder that affects communication, social interaction, and behavior. Meltdowns in autistic children are intense emotional responses to feeling overwhelmed, frustrated, or anxious. Common signs of a meltdown in autistic children include screaming or crying, aggression, (hitting, kicking, biting), self-injury (head-banging, scratching), property destruction, running away, freezing, or becoming immobile, and increased heart rate and blood pressure. Various factors, such as sensory overload, changes in routine or transitions, communication difficulties, social interactions, emotional overload, physical discomfort or pain, and frustration or anxiety can trigger them.

Types of meltdowns

- Emotional meltdown: Triggered by emotional overload or frustration.
- Sensory meltdown: Triggered by sensory overload or processing difficulties.
- Tactical meltdown: A deliberate attempt to escape or avoid a situation.

Here are 10 strategies for managing meltdowns in autistic children

1. Stay calm and patient

Remaining calm and composed during a meltdown is crucial. Children often pick up on the emotions of those around them, and if you're anxious or frustrated, it can escalate their distress. By staying calm, you model how to manage emotions and create an environment where the child feels safe.

2. Identify Triggers

Understanding what triggers a meltdown is essential for both prevention and management. Triggers can vary widely among children and include sensory overload, changes in routine, or unmet needs. You can identify these triggers by observing patterns in the child's behavior and environment. Once recognized, steps can be taken to avoid or mitigate them in the future, such as preparing the child for changes or adjusting their environment to minimize sensory stress.

3. Provide a safe space

Creating a designated safe space, that should be quiet, comfortable, and free from overwhelming stimuli. It's a place where the child can feel secure enough to express their emotions without fear of judgment or further distress. This safe space allows the child to process their feelings in a controlled environment, helping them to calm down more quickly.

4. Use positive reinforcement

Positive reinforcement involves rewarding desired behaviors to encourage their repetition. When a child begins to calm down, offering praise or a small reward can reinforce these positive behaviors. Over time, the child will associate these behaviors with positive outcomes, which can help them manage their emotions more effectively in the future.

5. Offer choice

Simple choices, such as deciding between two activities or choosing a preferred item, can empower the child and reduce feelings of helplessness. This autonomy can help prevent meltdowns by addressing the child's need for control in a structured way.

6. Use visual supports

Visual supports, such as picture cards, schedules, or social stories, are effective tools for communication with autistic children, especially during times of stress. These tools can help the child understand what is happening or what is expected of them, reducing confusion and anxiety

7. Teach coping skills

Techniques such as deep breathing, counting, or using a sensory toy can help the child regulate their emotions. These skills should be practiced regularly when the child is calm so that they can be effectively utilized during a meltdown. Over time, the child can learn to self-soothe and manage their emotional responses more independently.

8. Use deep pressure

Deep pressure, such as a firm hug or a weighted blanket, can have a calming and grounding effect on many autistic children. However, it's important to ensure that the child is comfortable with this approach, as some may find it overstimulating.

9. Minimize sensory overload

To minimize sensory overload, identify the specific stimuli that distress the child and take steps to reduce or eliminate them. This might involve dimming lights, reducing noise levels, or avoiding certain materials. A calm, sensory-friendly environment can significantly reduce the likelihood of meltdowns.

10. Develop a meltdown plan

Having a personalized meltdown plan in place ensures that everyone involved knows how to respond consistently and effectively. This plan should be developed based on the child's specific needs and triggers and should outline the steps to take before, during, and after a meltdown.

Additional strategies for managing meltdowns in Autistic children

1. Communication

Use clear, simple language to help the child express their needs. For example, instead of saying, "Do you want to go outside or stay inside?" you might say, "Do you want to go out?" This simplifies the choice and makes it easier for your child to respond.

2. Emotional validation

Acknowledging and validating your child's feelings is essential for their emotional development. If your child is upset or frustrated, take the time to recognize their emotions. For instance, you might say, "I see you're feeling sad because your toy broke. It's okay to feel that way." This shows them that their feelings are valid and helps them learn to express emotions healthily.

3. Sensory integration

Providing sensory experiences is an important part of helping your child regulate their sensory system. Sensory integration activities can include things like playing with different textures, engaging in water play, or listening to various sounds. These activities can help your child process sensory information more effectively.

4. Break tasks into steps

Divide tasks into smaller, manageable steps to reduce frustration. For example, instead of telling your child to "clean up the room," you can guide them through specific actions like "Let's put the blocks in the box" and then "Now, let's place the books on the shelf." This approach makes the task seem less daunting and helps your child feel a sense of accomplishment as they complete each step.

5. Offer breaks

It's important to offer regular breaks to help them regulate their emotions and prevent meltdowns. These breaks could be as simple as a few minutes of quiet time, a short walk, or a snack. By allowing your child to take breaks, you're allowing them to reset and return to the activity with a fresh perspective.

6. Seek professional help

If you notice persistent challenges in your child's development, it may be beneficial to consult with professionals such as an occupational therapist or psychologist.

These experts can provide personalized guidance and strategies tailored to your child's specific needs.

Key takeaways for caregivers

- Recognize the early signs of a meltdown and intervene effectively.
- Implement strategies to reduce the frequency and intensity of meltdowns.
- Create supportive environmental regulations.
- Develop a personalized plan to manage meltdowns in autistic children.

Conclusion

Understanding and supporting autistic children during meltdowns requires empathy, patience, and the willingness to adapt to their unique needs. Each child with autism is unique, and it’s essential to tailor your approach to their individual needs and preferences.

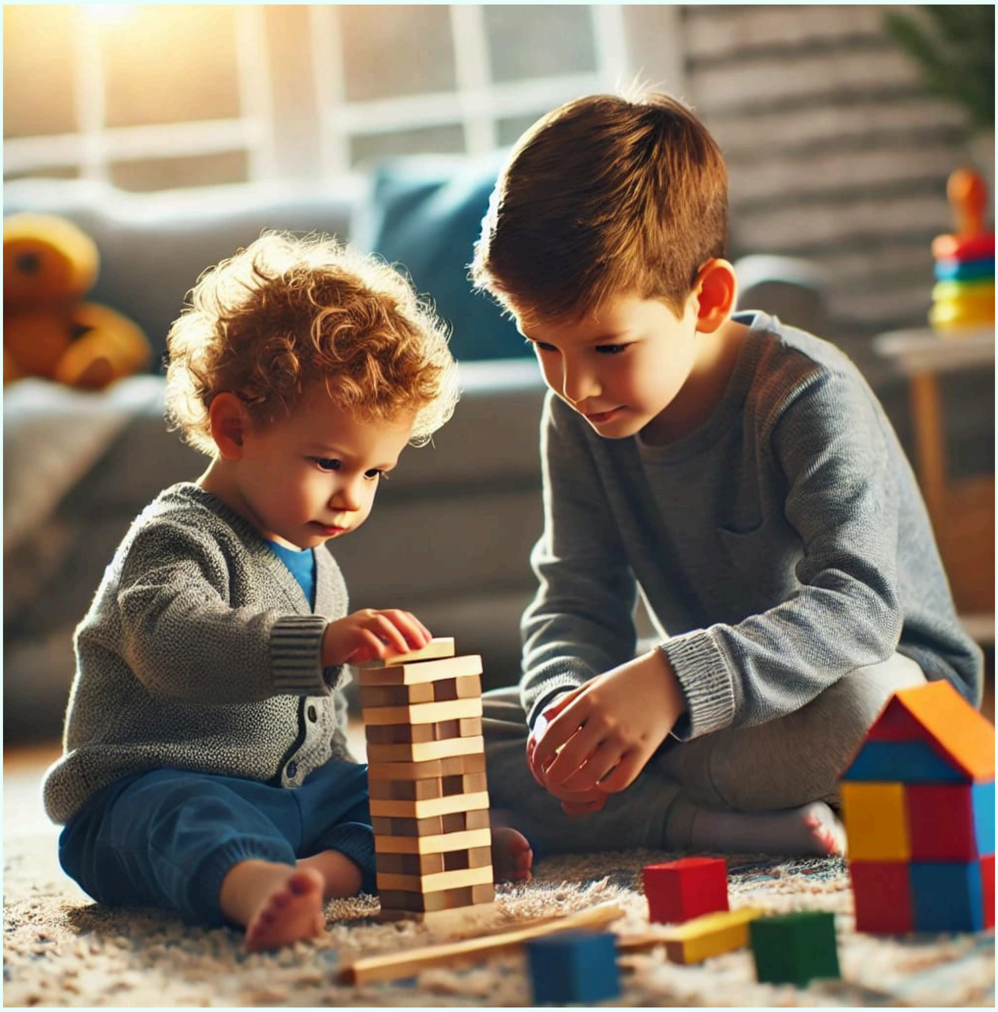
> *A meltdown plan is the blue print for turning chaos into calm*
>
> *-Anonymous*

SUPPORTING SIBLINGS OF CHILDREN WITH AUTISM

MR. VARUN MUTHUCHAMY, CLINICAL PSYCHOLOGIST,
INSTITUTE OF MENTAL HEALTH AND PSYCHOLOGICAL SCIENCES

Growing up with an autistic sibling can significantly impact the well-being of typically developing brothers and sisters. They may face a range of psychological and emotional challenges, including peer pressure, shame, rage, and loneliness. In some cases, they might even take on extra caregiving responsibilities, which can add to their stress. Family dynamics can also be strained, as parents may need to focus extensively on their autistic child, potentially leading to feelings of neglect or resentment in the typically developing sibling.

The ordinarily developed sibling might struggle to understand their brother or sister's behaviors, causing further confusion and frustration. However, many siblings also report positive outcomes such as developing greater empathy, tolerance, and a sense of responsibility. In some cases, they assume a protective role and form a deep bond with their autistic sibling, which can strengthen the family's unity. The concept of "caregiver load" encompasses the physical, psychological, and financial challenges faced by those who care for individuals with special needs. While the focus is often on parent caregivers, siblings, particularly older ones, can also experience significant caregiving responsibilities. Researchers refer to this situation, known as "secondary caregiving," involves siblings supporting their autistic brother or sister through various tasks such as offering emotional support, managing meltdowns, and assisting with daily activities. The extent of these responsibilities can vary depending on family dynamics, the severity of the autism, and the availability of external support. Siblings who take on these roles may face increased stress, anxiety, and depression. They might also miss out on extracurricular activities and peer interactions, leading to social isolation. The long-term impact of caregiving responsibilities on siblings can be profound, affecting their mental health and overall well-being, especially if they begin caregiving at a young age. This highlights the need for targeted support to help alleviate the negative effects and ensure their well-being.



Strategies for Supporting Siblings of Individuals with Autism

1) Providing Emotional Support and Open Communication

Offering regular emotional support and promoting candid communication are two of the best methods to help siblings of autistic people. In particular, if they do not fully comprehend their sibling's condition, they may experience feelings of perplexity, irritation or guilt. It's important to create a safe space where they can freely express their feelings and have autism explained in age-appropriate terms.

Encouraging siblings to share their concerns without fear of judgment can help alleviate loneliness and emotional strain. Sibling support groups and professional counseling offer valuable resources, providing structured environments where siblings can connect with others who have similar experiences. These settings promote empathy, understanding, and offer coping strategies, helping siblings navigate their emotions and build a supportive community.

2) Promoting Individuality and Ensuring Equal Attention

Parents should ensure that the needs of their typically developing children are not overshadowed by those of their autistic sibling. If these siblings believe that their parents are unduly preoccupied with the autistic child, they may feel ignored or irrelevant. To address this, parents should schedule one-on-one time for activities with their usually developing sibling, emphasize their uniqueness and recognize and celebrate their accomplishments. Involving the ordinarily developing sibling in decision-making processes about their autistic brother or sister's care can also empower and uplift them. However, it's essential to strike a balance, ensuring that they are not burdened with responsibilities that could become overwhelming.

3) Offering Respite Care and Reducing Caregiver Responsibilities

Respite care can be an invaluable resource where respite programs offer expert care for the autistic person, relieving the temporary burden on maon caregivers This allows both parents and siblings to have more time for self-care and relaxation.

Siblings might feel pressured to take on caregiving roles, so employing professional caregivers or seeking help from extended family members can help ease some of this strain and lower the risk of caregiver burnout.

4) Encouraging Peer Realtionship and Social Integration

Siblings of autistic people may feel socially isolated, especially if their caregiving responsibilities prevent them from participating in regular social activities. Siblings' social and emotional growth depends on parents supporting them in extracurricular activities, establishing peer relationships, and pursuing their interests.

Including the autistic sibling in family activities can enhance relationships between siblings and foster enjoyable shared experiences. However, it's also important to recognize that the typically developing sibling may need time and space away from their autistic sibling to foster their own identity and social connections.

5) Educating Siblings About Autism

Educating siblings about autism helps improve their comprehension of their sibling's difficulties and actions. Age-appropriate materials can help to demystify autism and lessen emotions of irritation or uncertainty. Examples of these tools include books, films, and family discussions. Teaching siblings about autism can also help them to be more accepting and empathetic toward one another, which will improve their connection.

Supporting siblings of autistic individuals requires a comprehensive approach that addresses both practical and emotional needs. These siblings often face emotional strain, social isolation, and caregiving stress. With the right support, including open communication, emotional support, and reduced caregiving responsibilities, siblings can navigate these challenges and build resilience, empathy, and stronger bonds within the family.

ROLE OF PRIMARY CAREGIVERS

DR. SUBRAMANIAN, PEDIATRICIAN, DR. JANAKI BALAKRISHNAN, COUNSELLING PSYCHOLOGIST,
MRS. DIVYA, SPEECH THERAPIST, MRS. J. ARUNA ANGELINE, PGT ENGLISH TEACHER

"THIS IS A TRANSCRIPT OF A WEBINAR DISCUSSING CAREGIVERS PERSPECTIVES ON AUTISM, FOCUSING ON THEIR EXPERIENCES, CHALLENGES, AND INSIGHTS."

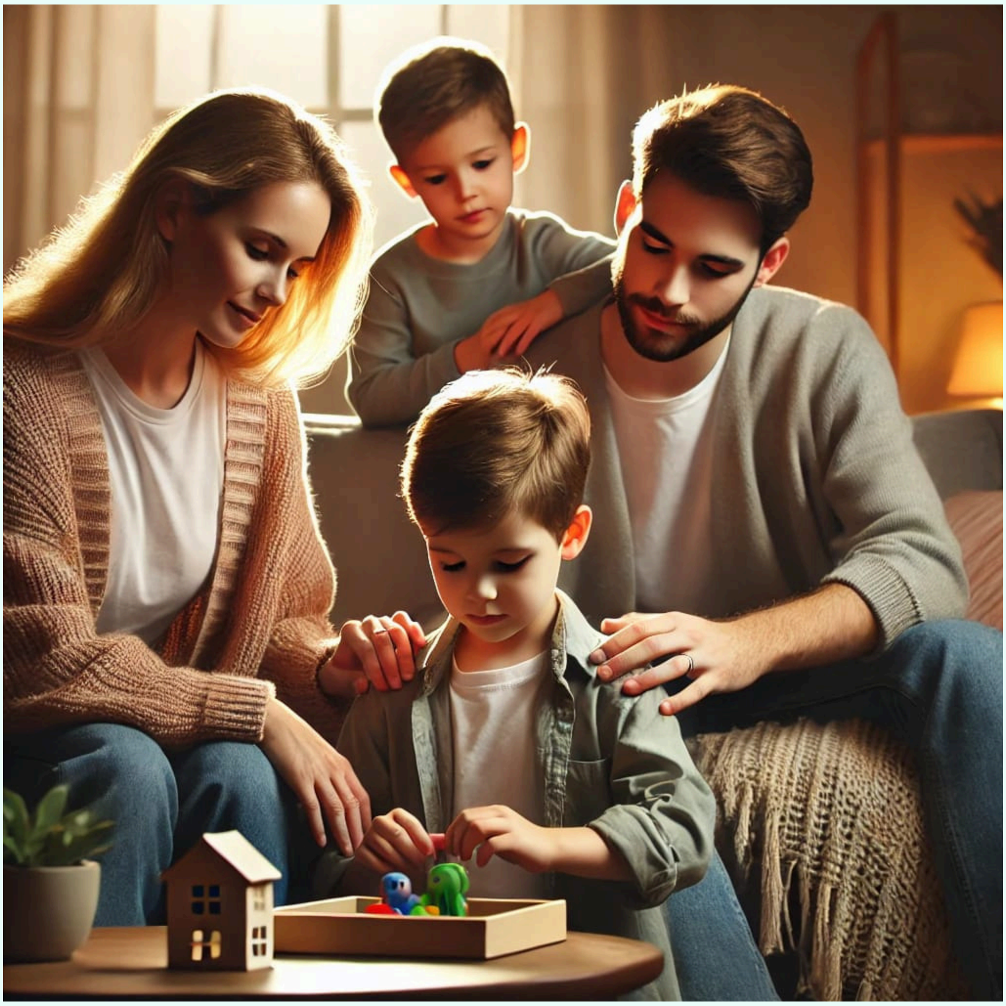
The present article is the summary of panel discussion of Autism- Caregiver Advocacy Series – I. Mrs.Divya introduced the topic of the discussion and introduced the panel members. Mrs.Divya began by sharing that caregiving is universal to all and that all of us have received or given caregiving support to someone in their life time. She reiterated on the theme of caregiving for individuals with Autism. Based on the predetermined questions, the discussion was led by directing the questions to the respective panel members and their responses are summarized and presented as follows.

Can you describe the disability? When was it first identified? What is the current condition of your child?

Mrs.Aruna, parent of a child with Autism, responded that her son was born in 2009 and was diagnosed as having Autism Spectrum Disorder in 2012. Early in life, they had noticed the problem when her child's attention and speech regressed, and that there was no awareness at that time and the family was baffled and depressed about the situation. As they consulted various healthcare professions, they were confused about the diagnosis as ADHD or Autism. Later, when they pursued seeking help from pediatricians, neurodevelopmental specialists and psychiatrists, they received the correct guidance and support for their child at the age of five.

She said that she obtained more clarity when working with therapist and could identify her child's need for support, where focused intervention on sensory integration, speech and attention. She went on describing about tactile, visual and auditory integration in therapy. She shared that her son was more of a visual learner, and that he liked to use mobile, which recognized as her son's strength.

She recalled the efforts she had put in training her child during COVID period; consulting with her psychiatrist, she bought the needed equipment to train him at home. She stated that her son does have problems in learning, and that she hired a personal trainer who engaged him in activities throughout the day. As described by her, the boy is now able to read, having



increased attention, is able to ride bicycle.

She commended the support that she received from therapists, senior parents of children with Autism, and with the books that she read in dealing with Autism, in all, she could deal with the challenges better. She noted her personal journey as a process of discovering and resolving the challenges to which there is no definite end.

When is the appropriate time for diagnosing autism, and what factors influence the timing of an autism diagnosis?

When asked to Dr,Subramaniam about the early diagnosis, he stated that no two children with Autism are alike, therefore no broad generalization in terms of expectations or treatment plan can be envisaged. He emphasized on the individual approach to diagnosis and treatment, which is the most appropriate way to mitigate problems of self-referral, misdiagnosis or misconceptions about Autism. Further, he added that medical approach to Autism is not preferred and recommended for a bio psychosocial approach to diagnosis of Autism. Unlike in diagnosis of diseases, where investigations lead to presence of disease or not, the behavioral sciences often struggle to make correct diagnosis as the symptom presentation overlap with different disorders, because there is no categorical approach to giving a diagnosis based on symptoms. He elucidated that diagnosis is not important in behavioral practice, but the deficits that impacts the child's functioning.

Another issue in diagnosis is that the symptoms may present much later in life while adaptive functioning was adequate in the early years. Notions such as early diagnosis was missed or misdiagnosed, or parents brought them late, to be discarded. He finally surmised that the age of diagnosis for Autism depends on the severity of the symptoms and the adaptive functioning of the child, even though the global age of diagnosis for Autism is 3 or 4 years old. In India, the age of diagnosis is advanced further because of easy access to health care services. In developed countries, the waiting period for doctor's appointment is longer compared to India, which makes early diagnosis feasible, even though treatment options may be dearth. He also added that there may be children, who are identified as at-risk, but never reached through referrals for diagnosis and further management. To this end, he insisted for more awareness among health care providers, family and the community for making timely referrals as this could mislead the family.

Dr.Subramanian concurred with Mrs.Aruna when asked about how the parents receive the diagnosis, where he observed that parents and their family members gets very ruffled and upset about the information. He voiced out for a need for counselling as a process to prepare these families to overcome the initial shock, grief till acceptance. He reiterated that the focus should be more on deficits rather than the symptoms or the diagnosis of Autism; working on social communication, repetitive behaviors, or speech delay is more important than the diagnosis itself. In time, parents will learn to accept the diagnosis, which also is influenced by their education, family culture and the resources. Finally, he appreciated the effort and courage of the caregiver panelists for coming out to share their experiences in a forum.

In the same parlance, Mrs.Janaki commented that parents struggle to accept and cope with the needs of the child as it involves lot of daily life hassles, accommodating life changes, affecting personal health and wellbeing. From her own parenting of a special needs child, she briefly accounted her struggle and hands on experiences of giving care to a child with Autism. She noted the lack of full disclosure of the disability condition about her child, with a hope that her child will become alright if given physiotherapy. She expressed a need for counselling the parents by providing information on treatment trajectory while supporting them emotionally to overcome the grief. Finally, she emphasized that preparing the parents for life long caregiving is crucial to face the future challenges. She surmised on the role of caregiver as one of the many roles a parent would play in a family life, albeit, they will need to walk an extra mile in parenting a child with Autism facilitating the development of the child.

"What level of support is required for your child in day-to-day activities, and what are the areas of support that you provide?"

Mrs.Aruna responded that as her son is a single child, she and her husband could focus on his development much more than others could. She shared that her son was moved around five to six schools before he was accepted and could adapt with the school environment, and that she had to resign her job to help her son make adjustments in the school. She remarked that a mother is the first therapist to a child with Autism even though professionals could help with more technical support and guidance. She agreed with Dr.Subramanian that elders in her family were reassuring that he is just having a delay and that will succeed and learn soon like his same age peers. As parents, they were in confused state as to what to expect or whether to seek professional help or not. Later with the timely diagnosis and especially with the support from the therapy, she was able to teach self-care skills like brushing and bathing until independent functioning. She noted that potty training was the most challenging part, which took seven years to train; more importantly, she advised that parents should keep in touch with the therapists beyond sessions to refine and improve the help at home. As she found difficulty in providing support all day, she hired a personal trainer to impart self-care skills. Continuous monitoring and shaping of the behaviours helped her son to improve on-seat behaviours in school. Mrs.Aruna also cautioned not to compare one child to another, or make a broad generalization that inability in one task may translate to inability in many other tasks. It is important to identify the strengths of a child and develop the potential. She also shared about her decision to pursue a career so as to reduce over attachment with her child; and that her embracing the acceptance of her child's condition has given her the courage to openly share her experiences. Finally, she insisted on being positive and optimistic about future.

Asking about the care demands for people with Autism, Mrs.Janaki responded that it depends on the intensity and duration of the support that the child requires. She noted on more the support intensity, more the hardship and difficulties the parents face. As in the case of individuals with Autism, she added that some of them will have islets of special abilities, but will not be able to perform simple self-care. She insisted on training in self-care as priority to protect them from neglect, abuse or exploitation in future; recreation and daily routines are important areas for providing support and training. She further observed that individuals with Autism lack abstract thinking, and therefore need environmental structures to connect them with daily routines and the timeliness of the tasks that they have to perform. Adding further, she said weaning the support gradually is also important to lead the child towards independent functioning. Parents tend to over protect their children with special needs because of the emotional attachment as duly noted by Mrs.Janaki. Also, providing care is easier than imparting training in daily life as it requires less time and efforts; it may be easier in the early years, but later in life, providing physical care is strenuous as the child has grown bigger and stronger. She reiterated that training in self-care is of utmost importance to avoid potential harm. On the other hand, she noted that some children may need lifelong support in self-care, and it may be harmful for caregivers to continue to providing such support instead can hire paid help or social support for such care.

“Are there other children? Are you able to divide your attention among all of them? Do they understand and help with this child?”

Responding to the involvement of siblings, Mrs.Janaki shared that as a parent having a single child, she drew from her professional experiences about having siblings playing a crucial role in caregiving of a child with Autism. She added that involving them will be more beneficial as they are better role models and exert peer buddy influence over the brother or sister with Autism. In rare few cases, there may be incidences of sibling rivalry as some kids do not take it very well when the parents give more attention to the child with Autism in the family. It is very important to foster acceptance and right attitudes in siblings towards special needs. Parents also need to divide their attention between both, special needs and the able body children in the family. Even though, it may be micro support or micro interactions, it will be beneficial to a child with Autism and to the parents when they involve siblings in the caregiving role. Further, she added that it promotes acceptance for the siblings,who will also be involved in the long term care of a brother or sister with Autism later after their parents’ time.

In this regard, Mrs.Divya added that in her professional work, she involves siblings in therapy sessions based on the age and the maturity of the siblings as it has proven to be very helpful to carry over training in the home situation.

Do you find the care demands increasing? In which areas—such as household tasks, self-care, mobility, emotional, social, and economic support, health and medical care, or advocacy and understanding—do you face difficulties? Could you describe these challenges in more detail?

Mrs.Aruna responded that the support systems in the family plays a major role in exerting the caregiving role as easy or difficult. She shared that she faced awkward questions from the family members about the behaviours of her child in the early years to which she attributed as lack of awareness. With more familiarity, some members are able to understand, accept and facilitate the role of caregiving, while others may pose a dilemma. For her, the support from the therapists was significant and more helpful, she added. She posited that realistic expectations for a child with Autism differs vastly from that of a typical child,which the family has to accept and that there need no botheration to social stigma or wrong notions. Mrs.Aruna also shared about her personal initiatives in sensitizing the community towards the needs of a child with Autism. Finally, she emphasized the importance of networking with other parents of a child with Autism for guidance.

Conclusion---

Dr.Subramanian concluded that focus on intervention areas would be more on communication, self-care and academics in the early years, while later years will demand intervention in challenging behaviors. He advised on the need for parents to be adaptive to future potential needs and the responsibilities associated with it. He stressed on involving other family members in caregiving role to reduce the burden and negative impact on the parents. More importantly, he voiced out for more community and social support to aid families in exerting their role in caregiving. Adding further, he expressed the need for awareness and advocacy for the child, and sharing of success stories. Finally, he pointed out to embrace the child with Autism regardless of the limitations that is posed.

RETHINKING EDUCATION: CREATING SCHOOLS THAT EMBRACE NEURODIVERSITY

MS.PRAJNA.A, STUDENT, EINSTEIN PUBLIC SCHOOL, COIMBATORE

“**E**ducation is the most powerful weapon you can use to change the world,” said Nelson Mandela. Yet, for many neurodivergent students, particularly those with autism spectrum disorder (ASD), the current education system can feel more like a battlefield than a pathway to empowerment. With the prevalence of ASD rising—now affecting 1 in 36 children, according to the CDC (Center for Disease Control and Prevention, USA)—it’s crucial that we rethink how our schools are structured to ensure every student has an equal opportunity to succeed.

Understanding Neurodiversity

Neurodiversity is a term that acknowledges the natural variations in how human brains function. Within this spectrum, "neurotypical" refers to individuals whose cognitive and developmental processes align with what is traditionally considered typical or "normal." On the other hand, "neurodivergent" refers to individuals whose brains function differently from what society typically considers "normal," encompassing a range of conditions such as ASD, ADHD, dyslexia, and more.

While neurotypical students often thrive in conventional educational settings, neurodivergent students face significant challenges.

The Struggles of Neurodivergent Students

Neurodivergence reflects differences in cognitive or neurodevelopmental processes. While many neurodivergent students wish to attend schools and colleges, similar to their neurotypical peers, they face unique challenges. The conventional school environment, designed with neurotypical students in mind, often fails to accommodate the needs of those with autism. The result is a range of difficulties, from sensory overload in overly bright and noisy classrooms to feelings of isolation and shame due to a lack of understanding or support.

Despite their best efforts, many neurodivergent students struggle to access the help and services they need. External discrimination and feelings of self-doubt make the situation worse for these students. They are left to navigate an educational system that often doesn't seem to care about their specific needs.

Building Inclusive Support Systems for Neurodivergent Students

To truly support neurodivergent children, schools need a comprehensive plan that addresses their unique needs and offers practical solutions. This plan suggests creating a special unit in every school to manage all services for neurodivergent students, ensuring they receive the help they need without unnecessary obstacles. The focus should be on making the academic environment more inclusive by incorporating flexible learning options, trained teachers, and smooth transition programs. Additionally, schools should create environments that respect neurodiversity, with smaller class sizes and peer support groups to foster social connections. Mental health support through counselors and regular awareness programs can further promote understanding and reduce stigma.

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The Path Forward

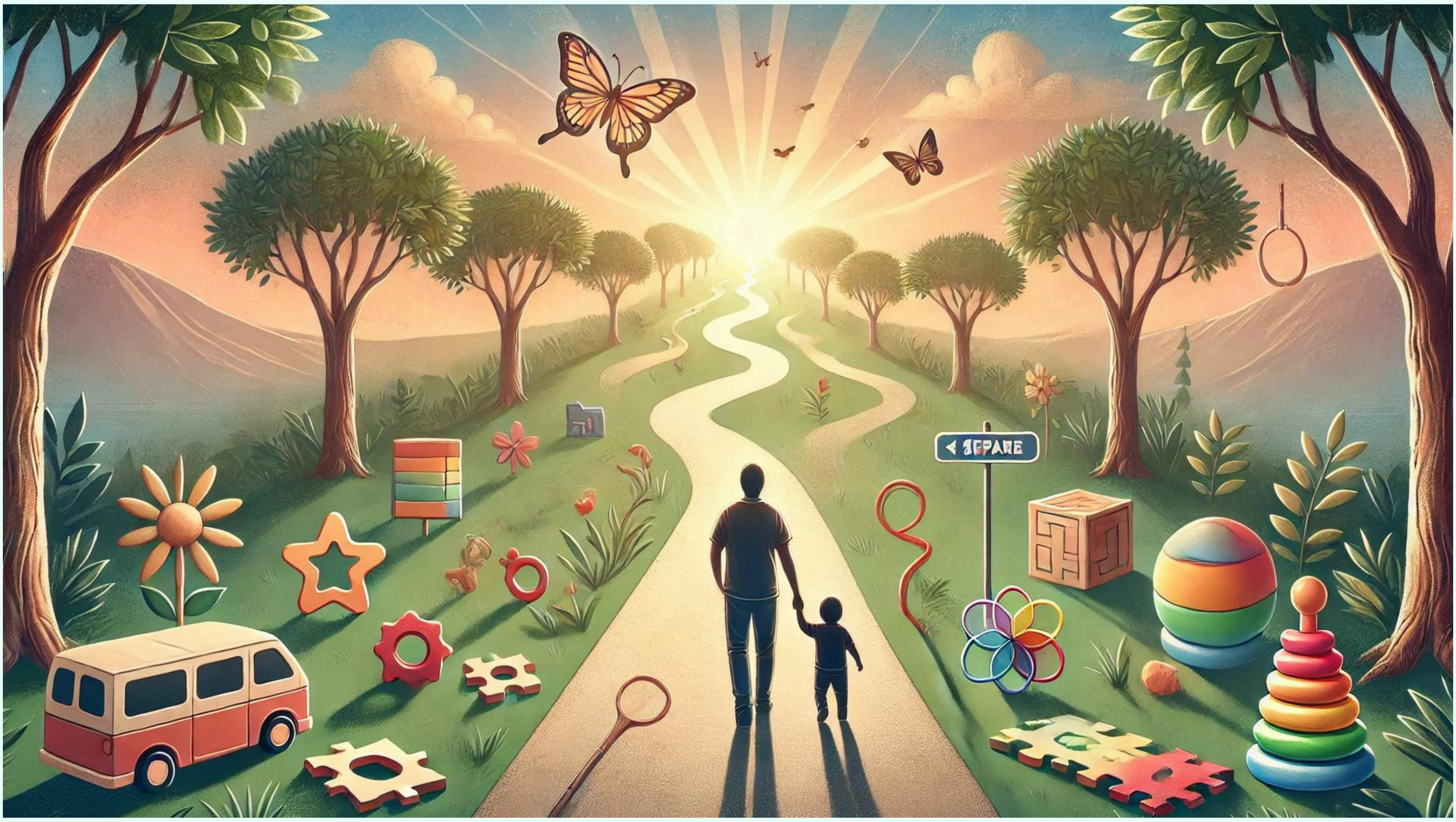
"As our understanding of neurodiversity deepens and the number of neurodivergent students grows, it's more important than ever that we establish dedicated support units in every school and college. These units will not only help recognize the unique strengths and needs of each student but also create an environment where they can truly thrive, feel valued, and be seen for who they are."

> *There is no one-size-fits-all approach to education.*
>
> *— Ken Robinson*

> *When a flower doesn't bloom, you fix the environment in which it grows, not the flower.*
>
> *— Alexander Den Heijer*

A JOURNEY IN RAISING AN AUTISTIC CHILD

MRS. VAIDEHI KRISHNAN, MAITHREE MEMBER (ASSOCIATION OF PARENTS OF EXCEPTIONAL CHILDREN)



Raising a child with autism presents unique challenges that require patience, love, and unwavering dedication. Each step in their development, especially in teaching essential life skills, can be a slow and sometimes frustrating process. However, these small victories whether mastering toilet training or learning to wash hands independently bring immense joy and fulfillment to both the parent and the child. This journey is one of learning, adaptation, and perseverance, where the right combination of love and discipline paves the way for progress and independence.

When it comes to raising a child, especially one with special needs, patience is the golden rule. Handling situations with love and care is equally important.

At the age of three, I began my son's toilet training. We started every morning after having milk. I would show him his father and brother going to the bathroom, and initially, he understood that it was his turn to try. However, if I called him, he would run to the balcony or another room, crying louder when I placed him on the toilet. After just two minutes of trying, there were negative results. When I left him alone to do my kitchen work, he would spoil his shorts or his white loincloth. We didn’t see success for three months. During a check-up with our psychiatrist, she prescribed Sodium Valporate, although his EEG was normal. I then began documenting his behavioral disturbances, including his diet, visits, and social interactions.

The doctor recommended an early intervention school, emphasizing that it would be a team effort. I discovered that my son didn’t want to talk about his struggles with teachers or family members and would often pull me away from conversations. In our free time, I frequently talked to him about using the toilet and eating vegetables to ease bowel movements.

After six months, there was a change in his behavior. He finally tried sitting on the toilet seat, and I celebrated by buying him chocolate. That reward system worked, as he began using the toilet regularly, motivated by the chocolates he received after each successful visit. However, teaching him to clean himself was a challenge, but his teacher patiently helped him. I am deeply grateful for her dedicated guidance.

We then worked on other life skills. Since we both needed to be at school on time, I set a condition: if he wanted chapatis, one of his favorite foods, he had to clean himself after toileting. Otherwise, I wouldn't have time to make chapatis. He understood and cooperated, and after a year of training, I was relieved.

Life skills like independent brushing, toileting, dressing, and packing his lunch bag took four years to develop. He even learned to fetch biscuits or other items from nearby shops using a list. Throughout it all, the key was communication, patience, and love.

The Challenges and Triumphs of Toilet Training

In the beginning, if he soiled his pants, I would punish him by taking away his favorite things and making him wash his shorts, expressing my unhappiness. Whether he fully understood or not, it was mentally exhausting for both of us. My husband found the process boring and wasn't always happy with my methods. Sometimes, I became emotional and cried when things went wrong, feeling overwhelmed by the situation.

After a year, the struggle began to ease. I made sure to express my happiness daily, and my son started expecting my praise for his efforts. Thankfully, his bowel system only required him to go once or twice a day, which made the situation more manageable.

We need to be mindful of what and how much we feed children like him, as they are often sensitive to smells and textures. His early intervention teacher did a wonderful job teaching him how to apply soap and wash his hands. Those skills became even more important during the COVID-19 pandemic when hygiene was critical.

If the bathroom closet was wet, my son would show hisdispleasure, so I always carried a cloth or tissue to dry the area. Traveling presented additional challenges. During overnight train journeys, I would tie a towel around himand help him from outside the toilet.

Even today, when we travel, he becomes agitated if other passengers ask him questions. I usually explain his condition, though some people don't seem interested in understanding. However, I remind them that children like my son are silent and happy in supportive environments.

We travel to many places, but if he becomes tired or upset, I make sure to stop and prioritize his comfort.

Each child is different and has their own set of challenges. I've seen children from wealthy families who still need assistance with basic tasks. My message to those caring for children with special needs is to be patient. Never discuss their difficulties in front of them. Their brain may not always cooperate, but with patience, love, and firm guidance, they can achieve small but meaningful milestones.

--UPCOMING EVENTS--

“Handling Treatment Modalities and their Effects”

OCTOBER
1
2024

“The Impact of the Caregiving on the Caregivers”

OCTOBER
29
2024

TIME

6.00pm - 7.00pm

ZOOM MEETING
Meeting ID: 884 3153 0745
Passcode: 262840

YOUTUBE LIVE
www.youtube.com/@CaregiverAdvocacyGroup

--COLLABORATORS--

EVIDENTIA RESEARCH SOLUTIONS
KK CHARITABLE TRUST
Reinventing Life RAMANA REHAB CENTER (An Integrated Center for Holistic Care)
Dr.GVN CANCER INSTITUTE @RIVERSIDE Enhancing Life
MARY ANNE CHARITY TRUST
UVAKAI RESEARCH FOUNDATION

--ACKNOWLEDGEMENT--

We extend our deepest gratitude to Mrs. J. Aruna Angeline , Teacher and Primary Caregiver, a caregiver, for sharing her empowering journey as a guest speaker in our webinar. Her courage, resilience, and dedication have touched the hearts of many, offering hope and strength to those facing similar challenges. We are truly honored to have had her as part of our event and are thankful for her invaluable contribution.

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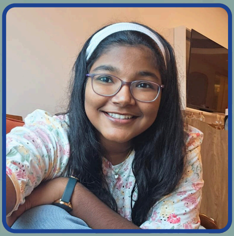

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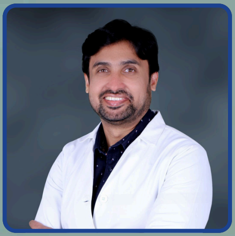

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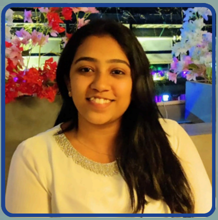

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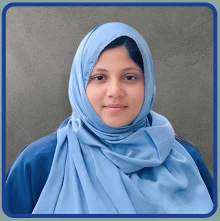

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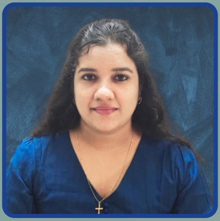

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