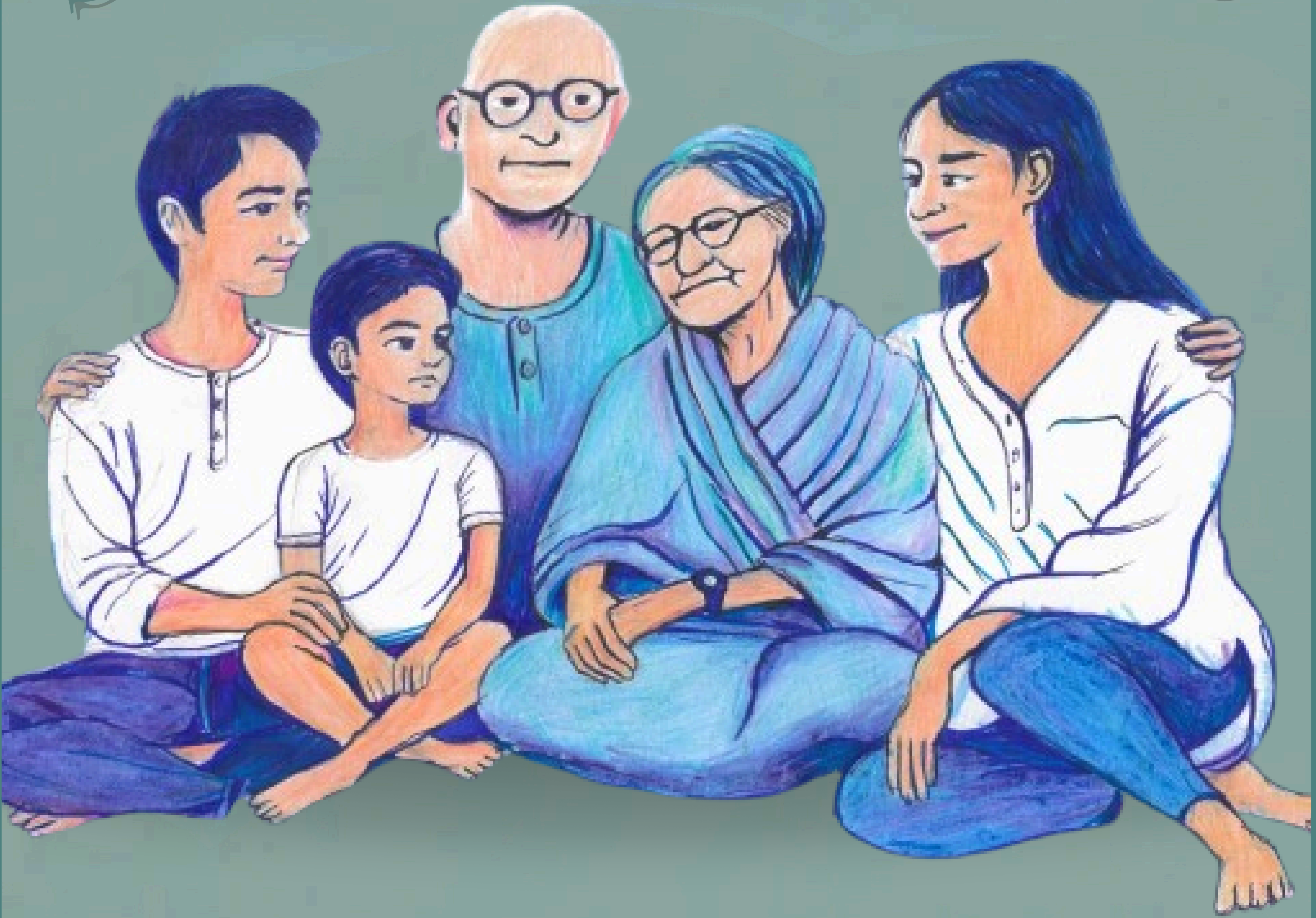
Caregiver
ADVOCACY GROUP
Caring your loved ones

CAREGIVER

"Supporting your loved ones through their journey"

SPECIAL NEEDS



Professional Insights ★ Community Voices ★ Upcoming Events

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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.

MRS.JANAKI BALAKRISHNAN.,PHD IN PSYCHOLOGY
PSYCHOTHERAPIST AND BEHAVIOURAL COACH

As December is a World Disability Month, I intend to write something special about the people that we care and love. Often, we are very keen to notice what others cannot do, be it of goodwill yet fail to think about our own limitations. I started out thinking what could be the strengths of these people, who are afflicted with Intellectual Disability or Autism Spectrum Conditions.

Autism Spectrum Conditions	Intellectual Disability
Better focus or concentration when engaged	Helpful and friendly
Islets of special abilities yet to be tapped	Demonstrates emotional warmth
Oriented towards intrinsic rewards	Likes social rewards
Amenable when communication is established	Amenable to therapy or treatment
Structured	Good with routine, repetitive tasks
Suitable for individual work	Love to connect with people
Can perform better with shorter pacing guide or breaks in-between	Predictable
Reliable with right conditions	Reliable with training

I am filled with awe that I could come up with these attributes and how much I might have missed noticing. Getting stuck is universal to all, being unstuck is not permanent, yet many of us are blindfold to the fact that being stuck and unstuck is part of natural rhythm of life. The beauty of the ecosystem is how perfectly we can sync with each other, building on our strengths overcoming our limitations.

WEAVING THERAPY

GIRIDHAR, SPECIAL EDUCATIONIST

Weaving as a therapy for adults with developmental delays is a highly effective, therapeutic activity that offers a combination of sensory stimulation, motor skill development, and emotional engagement. It is a creative and structured process that can be adapted to individual abilities, making it a versatile tool in therapeutic settings.

Benefits of Weaving Therapy for Adults with Developmental Delays

1. Enhancing Fine Motor Skills

- The repetitive motions of weaving, such as threading and pulling, improve hand-eye coordination and fine motor dexterity.
- Strengthens hand and finger muscles, aiding in tasks like grasping and manipulating objects.

2. Promoting Sensory Integration

- Weaving involves tactile (touch), visual (color and pattern recognition), and sometimes auditory (sound of materials) sensory input.
- Helps individuals process and respond to sensory information in a calming and organized way.

3. Building Focus and Concentration

- The rhythmic and repetitive nature of weaving fosters sustained attention and focus.
- Encourages mindfulness by engaging individuals in the present moment.

4. Boosting Self-Esteem and Confidence

- Completing a weaving project provides a tangible sense of accomplishment.
- Positive reinforcement from caregivers or therapists builds confidence in abilities.

5. Encouraging Emotional Expression

- Selecting colors, textures, and patterns allows individuals to express their emotions and creativity in a non-verbal way.
- Weaving can serve as a calming outlet to reduce anxiety and stress.

6. Fostering Independence and Decision-Making

- Encourages autonomy by letting participants choose materials and designs.
- Develops planning and organizational skills through project creation.

7. Facilitating Social Interaction

- Group weaving activities encourage collaboration, communication, and social bonding.
- Participants can share ideas, materials, and celebrate each other's progress.

Types of Weaving Activities

- Weaving can be tailored to the abilities and preferences of participants:

1. Hand Weaving with Simple Tools

- Use frame looms or cardboard looms for basic weaving projects.
- Create small items like bookmarks, coasters, or wall hangings.

2. Finger Weaving

- Engage in simple, tool-free techniques where participants use their fingers to weave yarn or fabric.
- Ideal for those who may have difficulty handling traditional weaving tools.

3. Circular Weaving

- Use hoops or circular looms to create designs like mandalas or dream catchers.
- Encourages creative exploration with shapes and symmetry.

4. Basket Weaving

- Use natural or synthetic materials to create baskets, promoting a connection with nature.
- Develops problem-solving skills through structural design.

5. Tapestry Weaving

- Participants can create more detailed patterns and images using yarn of different colors and textures.
- Encourages artistic expression and storytelling.

6. Collaborative Projects

- Large weaving projects, such as group tapestries, foster teamwork and a shared sense of accomplishment.

Materials for Weaving Therapy

- Yarn, fabric strips, or ribbons.
- Soft, textured materials for sensory input.
- Simple looms (cardboard looms, wooden frame looms, or plastic looms).
- Beads or embellishments for added creative options.
- Natural materials like twigs, reeds, or grasses for eco-friendly projects.

Tips for Implementing Weaving Therapy

1. Adapt to Abilities:

- Choose simple techniques for beginners or those with limited motor skills.
- Use larger materials for participants who struggle with fine details.

2. Provide Visual Aids:

- Offer step-by-step demonstrations or picture guides to make the process easier to follow.

3. Encourage Creativity:

- Allow participants to experiment with colors, textures, and patterns.
- Celebrate individuality in designs and choices.

4. Create a Relaxing Environment:

- Play soothing music or ensure a calm atmosphere to enhance focus and relaxation.

5. Incorporate Progression:

- Start with simple projects and gradually introduce more complex designs as confidence and skills grow.

6. Focus on the Process, Not Perfection:

- Emphasize enjoyment and engagement in the activity rather than the outcome.

Therapeutic Goals of Weaving

- Improve motor coordination and sensory integration.
- Reduce stress and promote relaxation.
- Develop cognitive skills like planning, sequencing, and problem-solving.
- Foster emotional expression and self-esteem.
- Strengthen social and communication skills in group settings.

Weaving as a therapy is both accessible and adaptable, making it an excellent activity for adults with developmental delays. It provides a meaningful and creative way to develop skills, build confidence, and experience joy, all while addressing therapeutic

SELF-CARE FOR CAREGIVERS OF INDIVIDUALS WITH AUTISM SPECTRUM DISORDER

PADMA KALYANI, SUCHIRAM FOODS INDIA

Self-care is a conscious effort to maintain a healthy balance in one's life. It enables individuals to meet life's demands without experiencing burnout or exhaustion. This becomes particularly important for caregivers of persons with Autism Spectrum Disorder (ASD).

Providing care for a person with Autism is a lifelong journey that requires immense strength to face and navigate various challenges. Every stage in the life of a person with Autism presents unique situations and obstacles, necessitating continuous effort to support them effectively.

A collaborative approach is essential, involving professionals, family, friends, caregivers, and educational institutions working together to provide comprehensive support. However, the primary responsibility often falls on the caregiver, typically the parents.

The progress of a person with ASD depends significantly on the level of support and care they receive. As primary caregivers, their well-being is crucial for maintaining and enhancing this support. Caregivers themselves need care and support to sustain their journey effectively.

There have been instances where caregivers, lacking adequate support or self-care, experience burnout, leading to irreversible consequences. Therefore, the self-care of caregivers is as important as the services and support provided to the person with ASD.

Self-care can be addressed in the following domains:

Physical

The physical well-being of the caregiver is the foundation for this journey. Being aware of their health and taking care of it is essential. Maintaining a daily routine of physical activities, such as walking, exercise, and mindfulness practices like meditation and yoga, is important.

Emotional

Caregivers experience a roller coaster of emotions while supporting a person with ASD. Managing emotions positively is critical, especially handling uncomfortable feelings like fear, anxiety, frustration, anger, and sadness. Talking to a trusted person or engaging in leisure activities can help regulate these emotions. Emotional health enables caregivers to establish healthy relationships, particularly with the person with ASD.

Social

Caregivers should not limit their lives to supporting the person with ASD. Engaging socially with family and friends frequently helps them feel supported and not alone. This social interaction enriches their mental health and improves overall well-being. Connecting with support groups of professionals and fellow caregivers helps them stay informed about available services and address concerns and questions related to the person with ASD.

In summary, self-care is about being kind to oneself, preserving one's well-being, and investing in activities that bring joy and self-expression. Take care of yourself, for you are your best asset.

BUILDING BONDS: PARENTING AN AUTISTIC CHILD

MRS MALEEKA RIYAZ, COUNSELLING PSYCHOLOGIST

Parenting a child with Autism Spectrum Disorder (ASD) is a journey that brings both challenges and opportunities for growth. It requires not only patience but also a shift in perspective–learning to view the world through your child's eyes and finding ways to build a bridge of connection.

Children with autism often communicate in ways that don't align with typical expectations. Their behaviours –whether it's lining up toys, repeating a phrase, or becoming absorbed in a specific activity–are meaningful expressions of their inner world. Observing these actions with curiosity, rather than frustration, is the first step towards connection. For example, if your child enjoys spinning objects or repeatedly watching the same video, join in. These shared moments, though unconventional, send a powerful message: "I see you, and I value what's important to you."

Communication with children on the spectrum can be complex and often extends beyond words. Speaking in simple, clear sentences and using consistent phrases can help them understand more easily. Visual aids, gestures, and routines are practical tools when verbal communication proves challenging. Active Listening is equally vital–pay attention to their body language, facial expressions, or even their silences. Often, these non-verbal cues reveal more than words ever could.

One of the most rewarding aspects of parenting a child with autism is recognising and celebrating their strengths. While challenges often dominate focus, many children on the spectrum possess unique talents in areas like art, music, mathematics, or memory. By concentrating on what your child can do–rather than on their struggles–you create an environment of encouragement that nurtures their confidence and strengthens your bond.

Children with autism thrive on structure. Predictable routines offer a sense of security and control over their environment, reducing anxiety and making daily life smoother. Simple tools, like visual schedules or providing advance notice about changes, can prevent potential stress. Even small adjustments, such as creating a calming sensory space or dimming lights, show them that their needs are understood and respected.

Play is a powerful way to connect. Whether through sensory play, building blocks, or engaging in pretend play, let your child take the lead. Enter their world on their terms–it's often in these shared, simple moments that trust and connection naturally flourish.

As you work to connect with your child, remember to care for yourself too. The demands of parenting a child with autism can be overwhelming, and seeking support is perfectly acceptable. Connecting with other parents, joining support groups, or consulting professionals can provide new tools and perspectives, while also reminding you that you're not alone in this journey.

KEY TAKEAWAYS

- *Engage in your child's favourite activities and embrace their unique ways of communicating.*
- *Use clear words, gestures, or visuals to make interactions easier and more meaningful.*
- *Focus on your child's strengths and talents to build confidence and deepen your bond.*
- *Establish routines that provide predictability and a sense of security.*
- *Allow your child to lead playtime, fostering trust and shared joy.*
- *Approach unusual behaviours with empathy and an open mind to better understand their needs.*

RAISING A CHILD WITH AUTISM SPECTRUM DISORDER

DR.S.ANAND KUMAR, CONSULTANT PSYCHIATRIST
DR. JANAKI BALAKRISHNAN, CONSULTANT PSYCHOTHERAPIST | MRS. DIVYA, SPEECH THERAPIST
MRS.PADMA KALYANI, CAREGIVER, FOUNDER - SUCHIRAM FOODS

The present article is the summary of panel discussion of Autism- Caregiver Advocacy Series – II. Mrs.Divya introduced the topic of the discussion by saying that caregiving of a child with Autism is for lifelong and that each one's journey is different while raising a child with Autism. Ms.Prajna introduced the panel members. Based on the predetermined questions, the discussion was led by directing the questions to the respective panel members and their responses are summarised and presented as follows.

What would you say about parenting of a child with Autism?

Mrs. Padma Kalyani, founder of Suchiram Foods, who is also a parent of a child with Autism responding to this question emphasised that raising a child with autism does not end after six, seven, or even twelve years and that it is a life long journey. She outlined that at every stage and age, new needs arise, and different kinds of support are required. She also stressed on the early intervention to play a crucial role in diagnosing early, within the first two years if possible, and that it offers the child a better chance at development. She said, "for my son, as soon as we received the diagnosis, we started intervention immediately. Many parents struggle to accept the situation and delay taking action, often hoping the child will 'catch up.' However, acceptance and seeking professional support early on make a significant difference in the child's journey as well as the parent's"

In this journey, building a strong support system is vital. Parent groups, especially those with senior parents who have older children or adults with special needs, offer invaluable insights and guidance. It helps to know we are not alone and that others have faced similar challenges.

How difficulty or easy was it for you in raising your child? What can you say about your perceptions, expectations or preferences that changed or persists in the growing years?

Dr. Janaki from her experience in navigating the challenges of caregiving highlighted that during the early years, awareness about developmental delays and autism was limited. Parents start out with a hope that the concern is temporary and will go away, but then they realise the chronicity of the condition only when the child is about 3 or 4 years of age.

In the present day, with increased awareness, possibility of early detection and intervention is much sooner that it used to be. And parents are well informed about the condition of the child, thus making the referral and guidance easing into their journey. But caregiving is not mere basic support of providing food and protection, but also extending the emotional responsiveness and comfort to the child. This is more challenging to the parents in the early years as it is difficult to understand the child's communication and unique needs.

She said that through the years with parent counselling and connecting with parent network, she could learn a lot about her child, which gave her the maturity to handle the situation. She added that the importance of support networks in easing the caregiving journey is notable. Connecting with parents network help one to perceive the burden much less because parents see that they are not alone.

Moreover, it also helps them to find solutions to their specific problems which others before them have tried. She accounted that the journey helped her to gain more confidence and skills in caregiving, setting out realistic expectations for her child. Most importantly, it promoted acceptance and as a group, it paved a space where the child with special child is celebrated.

Have you ever felt lost as to how to deal with your child? What specific challenges you faced and overcame?

Mrs.Padma responded that every day brings new challenges, and while there is a mix of confidence and fear about whether we're doing the right thing, observing and adapting based on what works for the child is key. Further, she added that no two children are alike and that there is no common solution for all; what works for one child may not work for another, so balancing logic, observation and critical thinking helps us decide on the best approach.

As a caregiver, it requires lot of observation, reflection and personal judgements to arrive at the best course of action given the unique needs of the child. This process is a continuous trial and learning for both the parents and the child. She advised the need for self care for the parents, and not to make decisions or choices based on emotions.

In response to the question about parent support groups that are available, Mrs.Padma shared that there are two major parent groups - SCAN and Voice. The SCAN community is working on future living arrangements for adult individuals with Autism. VOICE group engages in shaping the public policy and also facilitates on Special Olympics. Both are available on social media and it is very much possible to connect with networks that prevail locally.

How does environmental modifications help to mitigate the challenging behaviours and facilitate the progress of the child?

Responding to this, Dr.Janaki said that the ultimate goal of rehabilitation is to integrate the child with the community. Any provisions that facilitates the integration and availability of support would definitely provide a safe space to the child to grow and live.

She emphasised the need for such community-driven models, such as group homes, where parents and children alongside in a supportive environment. These setups ensure dignity, quality of life, and practical care for individuals with autism as they transition into adulthood, while also addressing parents' concerns about their child's future.

When parents take initiatives to address the potential needs, there will be more clarity of the need and mobilisation and effectiveness of the resources would become easier. Such models exemplify how collective efforts can make caregiving more effective and sustainable.

What kind of knowledge, skill or qualities a parent should ideally have to deal with the challenges in caregiving?

Dr. Anand emphasized the importance of harnessing and encouraging a positive outlook when dealing with challenging situations such as autism. He explains that raising a child with autism requires community involvement, as the extended family and society play crucial roles in providing support. While he does not claim to be an expert in autism, his insights are informed by years of experience as an adult psychiatrist.

He underscores the need for caregivers to stay updated with the latest knowledge about autism, including scientific research, webinars, workshops, books, and social support groups. Reliable resources, such as authenticated websites and organisations like Autism India, can provide valuable information. Awareness of government policies, financial compensations, health insurance, tax exemptions, and rehabilitation services is also crucial for caregivers.

Effective caregiving, according to Dr. Anand, hinges on strong communication skills. Caregivers must adapt their communication to the child's level, using tools like picture exchange cards or other strategies that suit the child's abilities. He advises against imposing expectations based on neurotypical standards, as each autistic child has unique strengths and challenges.

Empathy and patience are foundational qualities for caregivers. Understanding the child's perspective can help decode behaviours and address sensory issues effectively. Dr. Anand also highlights the importance of a calm demeanour during challenging moments, such as meltdowns, and recommends strategies to defuse such situations without escalating them.

Caregivers should develop keen observational skills to distinguish between normal and abnormal behaviours in autistic children. For instance, rhythmic rocking might be a self-regulating behaviour for some, but in others, it could indicate sensory overload. Consistency in routines and behavioural approaches is equally vital, as many autistic individuals thrive on structured and predictable environments.

Finally, Dr. Anand stressed the significance of collaboration with experts like occupational therapists, psychologists, and autism specialists. Establishing clear behavioural goals and maintaining consistency in their implementation helps reinforce positive behaviours and manage challenges effectively. This holistic approach ensures that caregivers and children navigate the journey of autism with greater understanding and resilience.

Do you have plans for your child's future? Do you have specific concerns about his future?

As for future plans, it's important to remain flexible and not impose conventional goals like schooling, college, or specific career paths. The focus should be on fostering independence. From an early age, teaching basic life skills—like brushing teeth, tidying up, or managing personal space—helps children grow into self-sufficient adults. These foundational habits can later support occupational or academic skills based on the child's capacity.

Moreover, providing structured engagement during the day, whether through a job, vocational training, or creative activities is essential. Unstructured free time often leads to distractions or reliance on gadgets. Encouraging hobbies like painting, gardening, or puzzles can help children find meaningful ways to spend time and reduce feelings of boredom or anxiety.

This journey requires adaptability, continuous learning, and a holistic approach to building a life of independence and purpose for the child while managing our own emotions and expectations as caregivers.

IMPACT OF CAREGIVING ON CAREGIVERS

MR. SRIRAM: FATHER AND LONG-TERM CAREGIVER | DR. ANAND KUMAR: CONSULTANT PSYCHIATRIST
DR. JANAKI: COUNSELING PSYCHOLOGIST

The third session of the Caregivers Advocacy Meet, titled Impact of Caregiving on Caregivers, brought together panelists and caregivers to discuss the challenges, strategies, and emotional resilience required in managing lifelong caregiving responsibilities for individuals with Autism Spectrum Disorder (ASD).

This section summarizes the panel discussion from the Autism - Caregiver Advocacy Series III. Mrs. Maleeka Riyaz opened the session by emphasizing that caregiving for a child with autism is a lifelong journey, with each parent's experience being unique. She then introduced the panel members. The discussion was structured around predetermined questions, with each question directed to the relevant panelist. Their responses are summarized below.

1.Briefly share your parenting experience of having a child with autism.

Mr. Sriram recounted his journey of raising his daughter, who was diagnosed with autism in the 1980s. At that time, awareness and resources were limited, and the family faced significant societal stigma. Over the years, they adapted their lives to her strengths and abilities, building a supportive environment.

2. What were the difficulties you faced in the early years?

He explained that the early years were fraught with challenges, including a lack of understanding of his daughter's needs and limited guidance. Managing her behavioral and communication issues required patience and persistence.

3. What are the difficulties you are facing now?

While his daughter has developed certain skills, ensuring her independence and planning for her long-term care remain pressing concerns. Mr. Sriram also highlighted the high cost of residential caregiving programs, which poses a financial burden.

4. What difference in terms of motivation, planning, and execution do you see in parenting between early years and later years?

Dr. Anand observed that the early years are often marked by confusion and emotional stress as parents come to terms with their child's diagnosis. Over time, however, parents tend to adapt, becoming more structured and effective in their caregiving approach.

5. In what ways do you see parents are challenged in special needs caregiving?

Dr. Janaki highlighted the chronic stress, social isolation, and emotional burnout that many caregivers experience.

6. In what ways has your health and well-being been challenged with caregiving?

Mr. Sriram shared that caregiving has been physically and emotionally demanding. However, he has managed to maintain good health through a focus on diet, exercise, and other lifestyle practices that benefit both him and his daughter.

7. How do you take care of your personal well-being and health?

Mr. Sriram stressed the importance of peer support, evidence-based practices, and proactive self-care. Staying informed and avoiding unproven treatments have been crucial in navigating his caregiving journey.

8. Do parents take care of their personal health and well-being? Is family counseling part of medical consultations?

Dr. Anand Kumar noted that most caregivers neglect their own health, often due to the overwhelming demands of caregiving. He strongly advocated for including family counseling in medical consultations to provide holistic support to caregivers.

9. What are the common health issues that parents are likely to report?

Dr. Janaki shared on the common health issues such as diabetes, hypertension, heart problems, alcohol addiction, anxiety, depression and suicidal ideation as being reported among primary caregivers. This is due to long term implication of chronic stress and burn out in parenting demands that poses health risks for parents, she added.

10. What would be your advice for minimizing the negative impact of caregiving for parents of children with ASD?

Dr. Anand recommended setting realistic expectations, establishing self-care routines, and seeking professional counseling when needed. He also emphasized the value of respite care and support networks in alleviating caregiving stress.

11. Are you able to make future plans for her?

Dr. Anand recommended setting realistic expectations, establishing self-care routines, and seeking professional counseling when needed. He also emphasized the value of respite care and support networks in alleviating caregiving stress.

12. How do we support the well-being and health of families?

Dr. Janaki emphasised upon the need for timely information and guidance, social support to access services, and most importantly the parents own self care.

Dr.Janaki stressed that respite care for parents is a much needed one. She added that it has to begin from father supporting the mother, who is usually the primary caregiver of their child. Next, parents as a couple need to take a break from caregiving by involving extended members of the family to provide respite care. Furthermore, families with children with Autism can support each other by taking turns to provide respite care for each other. Also, there needs to be community respite care service providers to give these families a break to meet out their personal care needs.

She noted that in the developed countries, parents of special children could avail additional paid leave for accessing care and support services for their children. As their children are life long dependents, parents seek medical and rehabilitation services, while continually caring and supporting throughout the adult years of their children.

Caregiver Advocacy Series - 4

CONNECTING WITH YOUR CHILD WITH AUTISM

MRS. MALEEKA RIYAZ, COUNSELING PSYCHOLOGIST,
MR. GIRIDHAR, A SEASONED SPECIAL EDUCATOR, MRS. PADMAVATI GANESH, CAREGIVER

The session, moderated by Mrs. Maleeka Riyaz, a counseling psychologist, featured insights from Mr. Giridhar, a seasoned special educator, and Mrs. Padmavati Ganesh, a dedicated caregiver. They addressed the following key questions:

1. Please tell us about your son briefly. What was your experience in the early years? What was your major challenge at that time?

Mrs. Padmavati narrated her personal journey, detailing the challenges she faced when her son was diagnosed with autism at the age of 3.5. Initially unaware of the importance of early intervention, she struggled with delayed milestones, sensory sensitivities, and communication barriers. Over time, with support and strategies such as structured routines and using music as a connection tool, her son made significant progress. She emphasized the value of early efforts in addressing key developmental areas.

2. Why is autism so hard to understand?

Mr. Giridhar highlighted the complexity of autism, explaining its diverse manifestations in social interaction, communication, and sensory processing. He elaborated on the varied nature of the spectrum, the impact of co-occurring conditions, societal stigma, and the lack of visibility, all of which contribute to the challenges in understanding autism. He emphasized the importance of building awareness and adopting an individualized approach to address these issues effectively.

3. What were your early fears about your child?

Mrs. Padmavati reflected on her initial fears, including concerns about her son's independence, societal acceptance, and long-term well-being. She shared how these fears gradually transformed into actionable goals as she focused on building her son's strengths and capabilities.

4. What are the common issues to be addressed in the early years? Why are early efforts important?

Mr. Giridhar emphasized the importance of early intervention, particularly in the first six years, which are crucial for brain development. Early efforts help address developmental delays, prevent secondary challenges, and lay the foundation for long-term independence. He highlighted the need to create structured environments and identify each child's interests to facilitate effective learning and engagement.

5. Where did you seek support and information to connect with your child?

Mrs. Padmavati shared how she sought support from family, special educators, and parent networks. She emphasized the importance of collaborating with others who have faced similar challenges, as well as leveraging resources like visual tools and structured schedules to connect with her child.

6. What is essential in engagement? How do we motivate the child to engage?

Mr. Giridhar explained that engagement must be mutual and tailored to the child's interests. He advised Care givers to use positive reinforcement, break tasks into manageable steps, and minimize sensory overload. Understanding the child's unique learning style and sensory preferences is key to fostering meaningful connections.

7. What has been your learning in this journey as both a parent and a teacher in dealing with autism?

Mrs. Padmavati reflected on her journey, emphasizing perseverance, faith, and adaptability. She highlighted the importance of celebrating small milestones, maintaining structured routines, and staying consistent in efforts. Her dual role as a parent and educator deepened her understanding of autism and shaped her approach to caregiving.

8. What are we aiming for? What should be our preparations for the long-term care of a person with autism?

Mr. Giridhar outlined the need to prepare for long-term care by fostering independence and life skills from an early age. He stressed the importance of structured engagement, building support systems, and creating environments that ensure dignity and quality of life for individuals with autism.

PARENT PERSPECTIVE

MR. SRIRAM

Born in 1981, Aishwarya Sriram a.k.a Aishy was diagnosed with autism at the age of three. She was enrolled in Vijay Human Services, a special school in Chennai run by Professor P. Jeyachandran, from the age of five onwards. An incident at this school when Aishy was about ten years old proved to be a turning point.

When a box of jigsaw puzzles accidentally fell out of a cupboard, Aishy, who had been crying to get attention until then, quickly assembled the pieces of the puzzle, much to the surprise of her teacher. Since then, she has assembled hundreds of jigsaw puzzles of various sizes and levels of complexity. Interestingly, she never looks at the original image on the puzzle box either while piecing together the puzzle or after she has completed it.

In an endeavour to spread awareness about the special skills of persons on the autism spectrum, Aishy's puzzles have been displayed in exhibitions, sold as artwork, and published as desktop calendars.

Aishy was also a part of the vocational centres at Vidya Sagar, Chennai and Sree Sakthi Academy, Chennai but did not show much interest in the structured skill-training programmes offered at these schools. Since 2010, she has maintained a daily journal in her mother tongue Tamil which began with jotting down to-do lists and grew into a space that housed her thoughts and reflections on everything she observed around her. This was published as a book titled Avalukkendru Or Manam (Amarabharathi Publishers, 2016). We plan to host the English translation of this book in instalments in a blog for the benefit of parents of special children and others interested in research on neurodiversity. Currently she spends her time at home where she is closely involved in all the daily household chores, especially preparation of lunch with millets and vegetables that she cuts herself, under the supervision of her parents. In fact, her journal also includes simple recipes that she has written down which can be prepared using an induction stove and microwave oven instead of a gas stove.

Late Girija Sriram, Aishy's mother, is a trained special educator. A Tirukkural enthusiast, she also has a flair for learning languages and is well-versed in Hindi, Malayalam, Kannada and Telugu apart from Tamil. She worked with the Early Intervention Programme at Madhuram Narayanan Centre for Exceptional Children, Chennai for ten years (1991-2001) and with Sree Sakthi Academy, Chennai (2009-2014). "Girija miss" is a much-

B. Sriram, Aishy's father, retired as the General Manager of Rallis India Limited, Chennai after serving the company for forty years. A student of Ramakrishna Mission School and Vivekananda College, he has always believed in the motto of selfless service and "never ask, you will earn what you rightly deserve". It was his initiative, along with Girija Sriram, to compile and edit Aishy's diary jottings and publish it in book form. He is a tireless champion of autism awareness and acceptance. He believes that just like neurotypical children, persons neurotypical children, persons on the autism spectrum, too, can be trained well according to their individual aptitudes and talents, be it in art, music, cooking, sports, computers and so on. He is a practitioner of yoga, which he performs daily along with Aishy, and believes that a diet free of processed/refined food goes a long way to ensure good gut health for all.

Aishy's music therapist Smt. Lakshmi has written two books about Aishy. Beach Peter Sir...Lollypop, released in Dec 2013, is a crime thriller which highlights her puzzle solving ability. The second one Live. Love. Laugh out Loud, released in Jun 2016, is about how Aishy brightens lives with her sense of humour. Both these books are in Tamil and translated to English.

Smt. Mythily Chari, Educationist specialised in Autism, has devoted a chapter on Aishy in two of her books, Masters and Mythily and Autobiography of an Autism Entrepreneur.

VEERAPANDIYA KATTADOMMAN

Yogesh, Nava Jothi Trust

--UPCOMING EVENTS--

“Helping with activities of daily living: Handling and Mobility”

DECEMBER
31
2024

“Myths, Facts, and Best Practices in Cancer Nutrition”

JANUARY
7
2025

TIME

6.00pm – 7.00pm

ZOOM MEETING	YOUTUBE LIVE
Meeting ID: 863 4222 5932 *Passcode: 524556*	*www.youtube.com/@CaregiverAdvocacyGroup*

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