TOTSGUIDE.com

Fundas of Parenting

April 2021

Hello all.
On the occasion of WORLD AUTISM AWARENESS DAY, we bring forward to you this issue focusing on AUTISM SPECTRUM DISORDER (ASD) . It gives me immense pleasure to introduce our guest editor for this issue of our newsletter.

Dr Kirthika Rajaraman. She is a developmental pediatrician with immense knowledge and expertise in the field of Autism. She has done various courses across the field and added many more laurels to her accomplishments. She is also the core planner and author of the patented SCoPE program. I am very happy to share her experience and invite her on board.

Dr.Kirthika is working as Consultant developmental paediatrician at Centre for child development and disabilities (CCDD) & Motherhood child developmental centre , Bangalore.She did her post graduation in Institute of Child Health (Madras Medical College) in Chennai & Dip. NB in Bangalore Baptist Hospital. Subsequently she pursued her interest in developmental paediatrics by doing an IAP fellowship in Developmental & Behavioural Paediatrics in CCDD, Bangalore. She is trained in Developmentally supportive care NICU(Development & supportive care foundation for Newborn & children) & completed her training in Prechtl's General movements assessment of newborn & infants (GM trust, Europe). She is trained & certified in administering development assessment tools and has worked along with a multi disciplinary team in delivering early intervention to at risk infants. She has done a certified course in Learning disability from Spastic society of Karnataka & Worked along with Resource room special educators in designing IEP for children with Learning disabilities & guided them in functional behaviour analysis. She has experience in early diagnosis of children in the Autism spectrum & has good knowledge in Applied Behaviour Analysis. She is trained in Play therapy (National Association for play therapy India) .She is a certified practitioner in PEERS for adolescent social skills training & certified in Social thinking curriculum. She is also Avaz certified Alternate & Augmentative communication Practitioner. She has been conducting parental training workshops & research analysis on Parent based early intervention for Autism (EDITT- SCoPE program) and has done paper presentations in international & national conferences. She is a mother of two kids, 10 yr old daughter who is in spectrum & 5 yr old neurotypical son

DR.KIRTHIKA RAJARAMAN.
MBBS, DCh, Dip. NB (Paediatrics)Dip Course in LD
FIAP (Developmental & Behavioural Paediatrics)
Consultant Developmental Paediatrician
Asst. Director, Centre for child development & Disabilities.

DR NANDINI MUNDKUR,
MD DIRECTOR CCDD
FOUNDER SANGAMITRA
CO-FOUNDER TOTSGUIDE

TOTSGUIDE.com

EDITORIAL BOARD

Over a course of time, we will be sharing knowledge on various aspects of child growth and development. As the previous year ends with a lot of despair, we hope this new year dawns great strength and builds more confident parents.

Editorial Board :

Dr Nandini Mundkur,
MD Director CCDD
Founder Sangamitra
Co-founder TOTSGUIDE

Dr Kirthika Rajaraman,
DCH, DNB, FIAP (NDP)
Consultant Developmental Pediatrician
Motherhood Hospital

Dr N Uday Kumar,
Associate Professor of Pediatrics,Head of KCDU, SRIHER

Dr. Priya Kuberan,
MPT Neurosciences
Consultant Physiotherapist

Mrs. Manju Bhargavi,
M.Edu, Director Sangamitra
Consultant special educator

Compiled and edited by :

Dr Haneesha Pinnamarju
MD Pediatrics, MRCPCH (UK) ,
IAP NDP fellow

Dr Anjana B.
DCH, DNB Pediatrics.
CCDD NDP Fellow

TABLE OF CONTENTS....

.01 **A WORD FROM THE GUEST EDITOR**

.02 **NORMAL DEVELOPMENT –AN OVERVIEW**

.03 **SOCIO-EMOTIONAL LEARNING – ROLE OF CAREGIVERS**

.04 **EARLY INTERVENTION FOR YOUNG CHILDREN AT RISK FOR ASD**

.05 **USE OF AAC IN YOUNG CHILDREN WITH ASD**

.06 **SENSORY INTEGRATION THERAPY**

.07 **SOCIO-EMOTIONAL DEVELOPMENT & MISSING LINK IN ASD**

.08 **COMORBIDITIES IN ASD**

.09 **CROSSING THE THRESHOLD INTO ADOLESCENCE AND ADULTHOOD-PARENT PERSPECTIVE**

.10 **WELL BEING OF CAREGIVERS**

.11 **INDIAN MUSIC THERAPY**

.12 **GFCF DIET**

.13 **SANGAMITRA -FRIEND OF SOCIETY**

.14 **QUIZ**

.15 **FEEDBACK**

A WORD FROM THE GUEST EDITOR

Greetings to all.

As we enter into a new month, we are ready with the April issue of our newsletter.

World Autism Awareness Day (WAAD) is observed globally on **2nd April** every year. This day is observed to highlight the need to improve the quality of life of those with autism so that they can lead full and meaningful lives as an integral part of the society. This year's WAAD Theme is **'Inclusion in Workplace'**. This theme draws attention to the adult people with autism & their unique talents. While putting a huge focus on the warm embrace and welcome, that these skills deserve to fetch them inclusive job opportunities.

In the recent decade, many advances have been made towards creating awareness towards early diagnosis and availability of early intervention services. However, a lot more focus needs to be given for empowering the children & adolescents with ASD through adequate life skills, providing training to enhance their social cognition, inclusive education focusing on functional literacy and training in interest-based vocational skills.

In the current issue we spotlight the need to look beyond speech and occupational therapy services for children with ASD. This is not to undermine the conventional therapies but to emphasize the need to have a holistic far-seeing empathetic view for their future independent & productive life as adults. We have focused in this issue on early intervention services for very young children at risk for ASD, socio-emotional learning for neurotypical children to create a more inclusive environment, the importance of AAC usage to provide the right of communication to every individual with ASD, social skills training for children with ASD focusing on establishing social thinking and changing intervention needs to embrace neuro-diverse brain of adolescents with ASD. We have also focused on the well being of the caregivers who care for these children 24/7 and a few Complementary & alternative management.

As pediatricians, let us pledge to diagnose & intervene these children very early (by 16-18 mths) when there is only a risk for social communication delay ,nurture their abilities & empower their parents. As socially responsible human beings, let us create more awareness of their unique abilities & enable the society to be more inclusive so that every individual with ASD can have an independent & productive life.

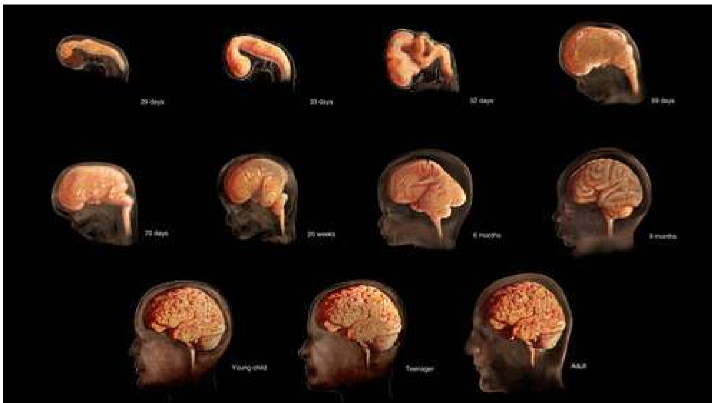
DR KIRTHIKA RAJARAMAN

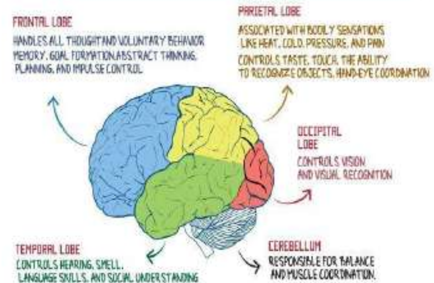
DCH, DNB, FIAP (Dev & Behavioural pediatrics)
Consultant Developmental Pediatrician
CCDD & Motherhood Child development centre,
Bangalore

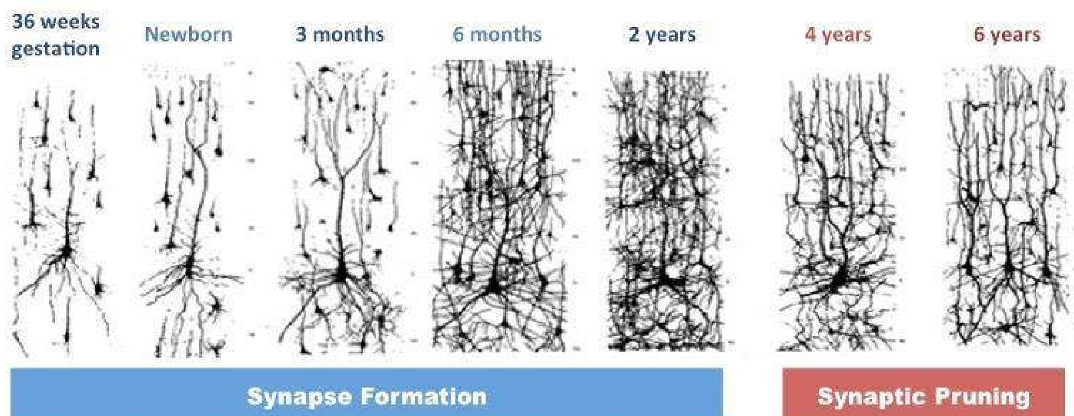
NORMAL DEVELOPMENT – AN OVERVIEW

Here is a bird's eye view of early development.

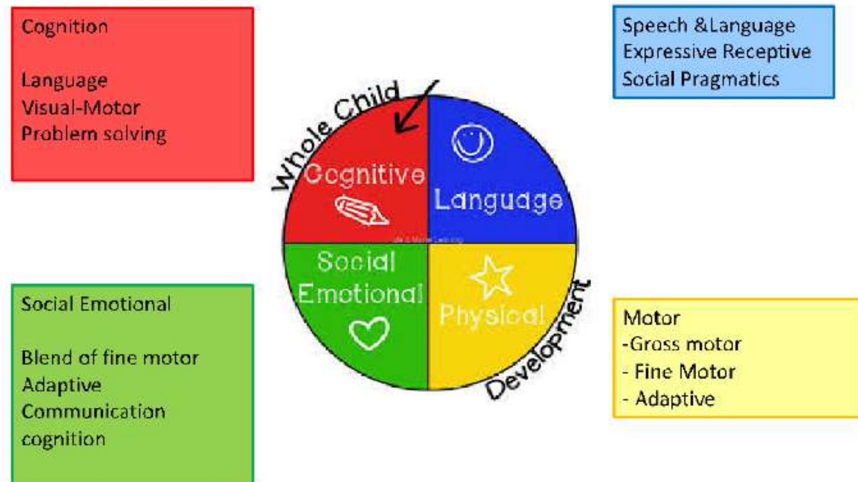
- Development also known as Neuro-development is the growth and maturation of the Brain and neurological pathways
- It starts right from ante-natal period and goes on until adulthood.
- However, the maximum brain development occurs in the first 5 years.
- It matures by formation of synapses and pruning.
- It is Measured as attainment of age appropriate developmental milestones across 4 domains.







Domains of developmental milestones



Facts on development (Gesell)

- It is orderly, timed, sequential.
- Occurs with regularity so predictable.
- All streams namely motor ,social ,cognitive and language more or less develop abreast ,they are related and overlap.
- Critical to track developmental milestones in every immunization visit
- Language , social and cognition easily missed or not given importance.

***Remember**, a child can fall behind in this timeline and still be within the range of normal, but it's best to discuss any issues/queries with your paediatrician.

Early social-language development:
In motor milestones, for a baby to walk, he/she must achieve prior stepping stones such as rolling over, sitting & standing. Similarly for a baby, before he/she really speaks meaningfully, the child must attain prior stepping stones of socio language development- **Joint attention**.

So, it becomes important for parents to track development of joint attention in their child. If a child hasn';t developed /any regression (disappearance of achieved milestones) in any of the below mentioned **early socio language development by 16- 18 months** and if your child can't understand common simple household instructions (pick up ball, give the glass) your child may be at risk for autism spectrum disorder. Consult your pediatrician immediately.

DON'T FOLLOW WAIT AND WATCH APPROACH

- Reciprocal eye contact – from 6 months
- Responding to name – from 7 mths of age
- Follows what you point at (both near & far off objects)- from 9 mths of age
- Imitating gestures (bye, clap, shake hands)- from 10 mths of age
- Point with index finger (to meet their needs)- from 12-15 mths of age
- Social Referencing (child shares his happiness by showing a toy to you/seeks appreciation for his/her achievement)- from 15-18 mths of age

Compiled by :

Dr Anjana B
DCH, DNB
NDP fellow
CCDD, B'lore.

Dr Haneesha P
MD, MRCPCH,
Fellow IAP NDP
CCDD, B'lore.

SOCIO-EMOTIONAL LEARNING – ROLE OF CAREGIVERS

- Social and Emotional Learning (SEL) is described as a set of skills that can be broadly classified into self awareness, self management, social awareness, relationship skills and responsible decision making.

- When children experience positive and nurturing interactions, a release of chemicals is activated in a child's brain that promotes neuronal connections resulting in socio emotional development (National Scientific Council on the developing Child 2004; Shonkoff and Meisels 2000). Connections are also strengthened when children have daily opportunities to practice their developing social competence and to interact directly with their environment (Wisconsin Council on Children and Families 2007).

Building Foundations for strengthening Emotional Quotient (EQ) at young age

- Are you familiar with a child who gets angry at the drop of a hat or gives up too soon? Or perhaps a child who does not know how to make friends or play with peers? On the other hand, have you observed an excited child who ends up losing his or her focus or a sensitive child who takes everything to heart. The connection between feelings and behaviour is evident in these illustrations.

- Feelings and behaviour together help children communicate and express themselves. It is important that children learn a variety of emotional and social competencies to be able to navigate complex social situations that they may face throughout childhood, adolescence and well into adulthood. It is more important to know that these skills can be taught. Research indicates- **'sooner the better'** so socio emotional learning can be inculcated from young age of **4-6 yrs**

- Caregivers play a key role in imparting social and emotional management skills to their children who then feel empowered to handle challenging situations, maintain friendships, take better decisions and reach their complete potential in all areas of life.

Emotional self awareness and self management:

- There are many important competencies to learn within our lifelong journey of social emotional learning. A few to mention- self awareness of our emotions, self management, social awareness, perspective taking, etc. Being aware of

one's emotions and appropriate usage of vocabulary & appropriate behaviors to express it are some of the skills under self awareness. Additionally, understanding another peer';s perspective and empathy are skills under the social awareness competency.

- Let's explore emotional self-awareness and self-regulation. When we human beings share space with others and/or engage in social interaction, we need systematic thinking and emotional-behavioral skills to attend to social emotional information, interpret our own and others' thoughts and feelings to make meaning of what is going on around us, and problem solve to make decisions about how to proceed in the situation. Ideally, we then produce an emotionally sensitive social response.
- For instance, why don't we just yell at someone, cry or throw something when we are angry in a park/shopping mall? Because we worry about how people will think of us if we behave this way **(social awareness- expected behaviors in social places)** & how our extreme reactions hurt the feelings of our dear ones with us **(perspective taking)**. So, we are expected to calm down for which we need to have **emotional self awareness**(that we are angry) and **self-regulation** strategies (Breathing/ drinking water/moving away) to manage our emotions and behaviors while we are in social situations.

- One of the best-known ways for children to learn these skills is for them to have good role models around them, who support and nurture them through their actions, communication and attitude.

- The Zones of Regulation (Leah M Kuypers) is a very helpful framework for parents to teach their kids as it helps kids to be aware about their emotional self & encourages kids to group emotions into one of four categories, each identified by a color:
  Blue Zone (low states of alertness or down emotions),
  Green Zone (neutral emotions and a calm, organized state of alertness),
  Yellow Zone (heightened state of alertness),
  Red Zone (extremely heightened states of alertnessor very intense feelings).

- Encouraging kids to **be aware of their emotions** & how to group emotions into categories is not enough. We need to teach about our expected social behaviors and how kids can learn to observe triggers that move them into specific zones, and related **self regulation strategies** that can help kids to manage their behaviors in that particular zone.

Role of Caregivers :

There will be many positive and conflict situations in our daily life that can be utilized to teach children these socio emotional skills. Here are a list of actionable steps that caregivers can take

1. **Provide opportunities to play:** During play, children develop resilience, solve problems, and manage their own behaviour. Converting the fights and conflicts into teachable moments helps children to develop values and healthy coping mechanisms. For instance, If your 5 yr old shares his toy with his peer but his friend doesn't share, your kid might feel unfair & frustrated and pushed down by his peer. Rather than just saying to your kid that it was wrong to push and ask forgiveness to his peer, In this situation/later at home parents can discuss about the **emotion** (How were you feeling- frustrated, so you were in orange zone), **expected behaviour and self regulation** strategies (Is it ok to push your friend? No. What can you do if you are in orange to move to the green zone? I think you could have tried slow breathing for 5 counts & said it's okay and moved away to another place) and **perspective taking** (might be that was his favorite toy, so he didn';t share. He would have felt sad when you pushed him down)

2. **Appropriate language usage:** The tone of our voice and the body language used while communicating with children is the secret to them accepting suggestions. Using positive reinforcements, praise, rewards helps' us in setting effective limits.

3. **Making your home a safe place:** Creating an environment where a child can express any feelings without being judged or scolded goes a long way in reducing unacceptable behaviour. Encouraging children to practice letting out anger, disappointment, sadness using their words, guides them in handing these emotions in a real life situation and really helps.

4. **Be hands-on:** Talking about your day's events not just at a factual level but by sharing your feelings through the events helps in leading by example. (I was tense during my meeting, so I did soothing self-talk that I can handle well and it went well too). Having a feeling related vocabulary words written on slips of paper or on the fridge or bedside gives a chance for children to rehearse situations.

Benefits of teaching Social and Emotional Competencies

There are innumerable benefits for children who develop their social and emotional competencies.

- Children learn to choose words that are helpful, not hurtful.
- They learn to apologize and forgive.
- They master doing the right thing when others do the wrong thing, as well as to re-do hurtful moments and recover after making mistakes.

- Socially, they acquire the skills of assuming the best in social interactions, they seek to be inclusive and get oneself included.
- Reciprocally, they become aware and recognize when others feel frustrated, mad, sad or left out and offer support. They allow others to try again.
- They become proficient in assertiveness and stand up for self and others.
- They deal with another's pride in a positive way and also respect others' feelings of fear, sadness.
- In a larger picture, they gain knowledge about handling emotions in relationships effectively and make decisions responsibly. They establish and maintain healthy and rewarding relationships based on cooperation and at the same time resist inappropriate social pressure; negotiate solutions to conflict, and seek help when needed.

While caregivers strive to assist their children in reaching their fullest potential, for that they provide adequate nutrition, education and teach daily living skills. As parents, let us also start nurturing the social and emotional competencies too, so that our children are set up for independent living. Little efforts taken now will go a long way in helping children deal with social and emotional challenges of everyday life.

Compiled by :

Mrs Apoorva Deshpande
M.phil Psychology
Psychologist & Special Educator

EARLY INTERVENTION FOR YOUNG CHILDREN AT RISK FOR ASD

Autism spectrum disorders (ASD) are neurodevelopmental disorders defined by social and communication impairment, along with repetitive and stereotyped patterns of behavior.

With increasing awareness, the average age of diagnosis in India has come down to 2.5- 3 years. Pediatricians can detect the risk for developing ASD (delay in early socio communication skills- joint attention) in toddlers as early as 16-18 months. As soon as the risk for social communication delay is detected, children need to be started on intervention.

Why is early intervention needed?

Active self-generated interactive experiences are most influential in early learning than observation or passive experiences. However, infants diagnosed with ASD or at risk for ASD have atypical joint attention, engagement patterns and altered sensory and motor functioning that are likely to disrupt the quality and quantity of experiences they cultivate for themselves.

Early intervention services aim to accelerate the rate of child learning, foster new development and generalization of skills and attenuate effects of ASD on development, by maximizing the benefit of **experience-dependent neuroplasticity**.

Infants at risk of socio communication delay also need developmental enrichment programs (including parent coaching) to engage them in development-enhancing experiences at home to accelerate learning and generalization of skills.

Early Intensive intervention includes:

1. Naturalistic developmental behavioural interventions(NDBI)

- Children's Language therapist / Speech therapist must follow NDBI based strategies as a part of their early intervention Program.
- Recent early Interventions for autism are based on both developmental and behavioral principles (ABA) incorporating the strengths offered by both perspectives. These interventions based on combined principles are called Naturalistic Developmental Behavioral Interventions (NDBI)
- Skills in the NDBI approach are usually not taught in isolation. It is rather taught in the course of the child's typical daily interactions, experiences, and routines with a variety of materials and by many people. Research shows that teaching foundational skills such as joint attention, gesture, and shared affect facilitates the later acquisition of language. Thus NDBI focuses more on building these foundational skills rather than trying to teach language via verbal imitation alone.

2. Parental Training & Parent mediated interventions

- Caregivers are an integral part of early intervention. Hence parental training followed by parent- mediated interventions at home becomes essential.

- Parents must be provided with direct hands-on coaching rather than just psycho- education. They must be coached with a few child-responsive engagement strategies at a time and enough time must be given for them to practice these techniques with their child.
- Video feedback must be provided to parents for supporting their understanding of intervention strategies and to facilitate insights into their child's bonding & communication signals. They must also be provided with corrective suggestions to improve their skills.

3. Sensory integration therapy

- Sensory integration therapy aims to help children with ASD by exposing them to different sensory stimulation in a structured and repetitive way. The theory behind it is that over time, the brain will adapt and allow kids to process and react to sensations more efficiently & in an organized way.

- OT / Sensory integration therapist exposes a child to sensory stimulation through repetitive activities. Repetitive doesn't mean the same set of activities. It includes different activities to repetitively stimulate different sensory domains like touch, vision, proprioception, etc.
  This helps in the sensory modulation of the child.

- Parents will also be provided with a sensory diet - carefully designed and tailored activities to be done at home and accommodations to be done at other places to calm the child & also to improve his/her arousal and attention.

- Over time, activities become more challenging and complex to address balance and coordination, to enhance visual perception skills and spatial orientation, to improve motor planning, fine motor skills and augment sensory discrimination and interoceptive awareness of the child.

4. Oral placement therapy (OPT)

- OPT is an important addition to traditional speech treatment methods It is a tactile-proprioceptive based teaching technique that accompanies traditional therapy (which is primarily auditory & visual-based). OPT is only a small part of a comprehensive speech and language program and should not be done in isolation.

- Children with Apraxia and oro motor & sensory impairments benefit from the tactile and proprioceptive components of OPT because speech is a tactile- proprioceptive act.

- Children with ASD, under early intervention program, who has shown significant improvement in their social connectedness, receptive (understanding) language and imitation skills (gross motor, fine motor (rhymes actions) and object-based play imitation) but not progressing in vocal imitation may benefit from oral placement therapy.

In a fun way, OPT teaches oral structural placement to children who cannot produce or imitate speech sounds using traditional auditory or visual input.

- Parents can choose AAC (PECS/ speech generating devices AVAZ) to help the child communicate his/her needs along with it OPT can be used to enhance the childs' oral motor & vocal imitation skills to fasten the verbal communication.

5. Functional behavior analysis (FBA)

Children with ASD may have associated behaviour problems (self hitting, head banging, aggressive behaviors to others, flapping hands, chewing non edible items, etc) . A Child';s behavior always serves a purpose and the early intervention team must have expertise in analyzing the reason for the behavior & intervene appropriately. FBA is an approach to figure out why a child acts a certain way & then create a behavior intervention plan to teach and reward socially appropriate behaviors. Steps involved in FBA:

- Define the behavior- Define the child';s behavior in a specific and objective way (How often is the behavior occurring? How long does it take? Severity of the behavior)

- Gather and analyze information- After defining the behavior, gather information

1. **Setting Events**
   - ➢ When and where is this behavior happening? & Where is it not happening?
   - ➢ Who is around when it occurs?
2. **Antecedent**
   - ➢ What tends to happen right before the behavior?
3. **Consequence**
   - ➢ What happens right after the behavior?

- Find out the reason for the behavior- is it for tangential needs or for avoiding certain activities or for getting your attention or because of sensory deregulation or because the child is not able to accept change in the plan/ denial of his favorites.

- **Make a plan** - It includes making appropriate changes to see if the behavior changes & reward positive behaviors

5. Complementary & Alternative Medicines

- Complementary and alternative medical treatments (GFCF diet, Music therapy, Yoga, Omega 3 supplementation, Probiotics) are commonly used for children with autism spectrum disorders. Around 20% of parents are using at least one form of CAM-based intervention & 56% of parents did not discuss their usage with their pediatrician (Udayakumar et al 2020).
- The parents need to understand the evidence for CAM's efficacy (or lack thereof) and potential side effects before implementing them with their kids.
- CAM is often perceived by parents as "natural", without the side effects of conventional medicines & nutritional supplement is an important part of health maintenance. CAM therapies are perceived to increase attention, enhance relaxation, decrease gastrointestinal symptoms, regulate sleep, and promote general health. Parents also believe that a combined approach of CAM and conventional therapy is more likely to be successful & fasten their child's recovery.

But some CAM practices (Hyperbaric oxygen, Chelation therapy, Immune/stem cell transplant therapy) can cause harm to children's health & has evidence to reject their use and others have only emerging evidence but not been adequately proved yet to support their use.

Hence parents must be encouraged to have an open discussion with their developmental pediatrician on CAM-based interventions that they are pursuing or planning to pursue. This is very important for health monitoring of side effects.

Early intervention has positive effects on development in young children with ASD although extent of improvement can vary from child to child. Few predictors for better improvement are baseline reduced severity of autism symptoms, high baseline social engagement (actively seeking social engagement), better play level and play diversity, younger age to start early intervention and better rate of learning in the early stages of intervention. Hence it becomes essential for parents to regularly follow up with their developmental pediatrician to monitor the progress with early intervention and take necessary measures to enhance the progress.

Compiled by :

DR KIRTHIKA RAJARAMAN
DCH, DNB, FIAP (Dev & Behavioural pediatrics)
Consultant Developmental Pediatrician
CCDD & Motherhood Child development centre, Bangalore

USE OF AAC IN YOUNG CHILDREN WITH ASD

Full interpersonal communication substantially enhances an individual's potential for education, employment, and independence. Therefore, it is imperative that the goal of Augmentative and Alternative Communication (AAC) use must be the most effective interactive communication possible. Anything less represents a compromise of the individual's human potential." — American Speech-Hearing Association (ASHA).

AAC devices offer tremendous promise in helping nonverbal/minimally verbal children with autism overcome their unique communication barriers. AAC systems allow the child to become a proactive communicator, being able to communicate better with family and friends , increase participation and achievement in academic settings, decrease frustration and behaviour problems and also improve child's motivation and self confidence.

Yet, parents are confused when it comes to adopting an AAC system for their child successfully.

Different types of AAC

- Picture Exchange Communication System
- Communication boards/books
- Speech-Generating devices (AVAZ) – devices which have recorded voice output
- Sign language
- Communication by writing/typing

Advantages of speech Generating Devices

1. Auditory Output

- AAC facilitates enhanced receptive skills by providing a consistent speech model and multiple sensory words to make connections in the brain.
- When the child communicates a word through device and we provide a response, he can start attaching meaning to the spoken word.
- Because synthesized speech lacks the prosodic and intonation variations of natural speech, the consistent auditory signal might be easier for the young autistic child to register & recognize the word.

2. Increased Verbal Speech

- Studies and anecdotal reports indicate that AAC not only enhances communication effectiveness but also speech production and intelligibility, particularly if the AAC method has voice output.
- Increased interaction and participation allow AAC users to be introduced to pre-verbal skills such as turn-taking & different language functions such as commenting, requesting, and staying on topic.
- AAC decreases oro motor demands, relieving pressure to speak. As children with ASD are visual learners, AAC provides a visual representation of the language & makes it easy for them to communicate with others.

3. Development of Literacy

- Young children need adequate language skills for literacy to develop. Language foundations for young autistic children are enhanced with the use of voice output communication devices.
- AAC devices that offer pairing of text with the graphic representation of a word and/or a text display of the spoken words provide an opportunity for developing word recognition and spelling skills.

Which system will work best for my child?

- It's important to maintain consistency when beginning communication with an AAC system. Starting with one type of system (communication board/PECS) with the intent of moving to a more sophisticated one (Speech generation device) when the individual "proves" they're ready means that the child will have to have to relearn (motor movements will be different & words will be in different locations.) how to communicate with the new system. Relearning places a greater burden on those with more cognitive challenges.
- So it is best to presume competence and provide a system that will allow growth to independent complex communication.

Is my child ready for AAC?

- There are no prerequisites to introducing AAC. In fact, using a device with speech output and consistent motor patterns to say words is an easier cognitive task for young nonverbal children. AAC can be introduced as young as 3 yrs.
- Learning can start at a cause & effect level, where the learner touches a button, hears a word, and experiences the consequence. For e.g. they touch icon "give" in speech generative device ,hears give and they get their favorite toy from caregiver
- With latest speech generating devices, we can modify to accommodate the user's current level of language, motor , visual and cognitive skills by using a larger screen with contrast background, key guard, key highlights, limiting available choices

AAC Myths

There are several myths, lacking factual information surrounding AAC usage, that cloud the judgment of parents, especially those of young children, when deciding for an AAC system.

- **Myth** : AAC will keep my child away from talking.
  Truth: AAC does NOT hinder speech but may actually increase speech production. (Increased speech production – 89%- Millar, Light & Schlosser (2006))

- **Myth**: AAC will socially stigmatize my child, making them "look different" from peers.
  Truth: AAC will actually help the child socialize, whether it is in the form of greetings, classroom participation, responding to questions, participating in social games, or getting the attention of others.

- **Myth** : My child will use only alternative devices and give up on natural speech.
  Truth: "Children will use the quickest, most effective, and most accessible way available to them to communicate. Speech will certainly beat any other AAC system if it is available to the child.

In conclusion, Functional communication goals are more than being able to express wants, need for help and pain. This is where AAC can come in and help the individual lead a fullest life. The goal of AAC is that the child should have quick access to a lot of language to say whatever they want to, whenever they want to and to whoever they want to, and in the quickest easiest way possible.....

It is also true that the quality of the AAC technology they have access to and the user experience, dedication and compassion of the therapist who provide AAC services paired with parental motivation and persistence play a pivotal role in the successful usage of AAC

Let us all join hands to give every child in spectrum, the right to communicate with the quickest & easiest way possible

Mrs. R. Niveditha

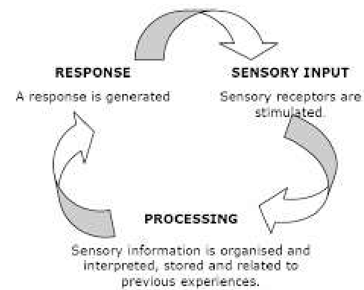
M.ASLP

Consultant Speech Language Pathologist

SENSORY INTEGRATION THERAPY

Autistic Spectrum Disorder (ASD)

Autistic Spectrum Disorder (ASD) or autism, is a developmental disability which affects how a person communicates with others and experiences the world around them. Children or adults with autism will have difficulties with social communication and interactions. Typically, they will have some form of restricted and repetitive patterns of behaviours, activities or interests. Children with ASD may have associated sensory processing disorder.



Jean Ayres was the pioneer in this field & she noted the importance of sensory processing & sensory integration in supporting our ability to use our body efficiently in daily routines. It helps us in developing good attention span ,sitting tolerance and also to develop emotional self regulation. Children with appropriate sensory integration will have adequate focus , good self-esteem and confidence & necessary prerequisite skills for performing academic skills.

Sensory Processing Disorder (SPD)

Sensory processing disorder (SPD) is a condition where children/ adults are overly sensitive or under sensitive to what they feel, see, hear & smell and a few others will have trouble integrating information from multiple senses at once.

The different parts of our body that receive sensory information from our environment (such as our skin, eyes and ears) send this information up to our brain. Our brain interprets the information it receives, compares it to other information coming in, looks into information stored in our memory and then helps us respond to our environment appropriately. This way sensory integration becomes important in all the things we do as getting dressed, eating, socialising, learning and working.

Apart from the main 5 senses like seeing, hearing, tasting, smelling and the sense of touch, there are other 3 internal and very important sensory components. They are Proprioception, vestibular and interoception.

<u>Proprioception</u>

- Sensations and inputs received from our muscles and joints to tell the brain where our body parts are. Your brain then uses this information to plan movements so that you can coordinate your body.

- Example : Eating- knowing how you are holding the spoon, how you pick the food and then taking the spoon towards your mouth without even looking at your mouth in the mirror

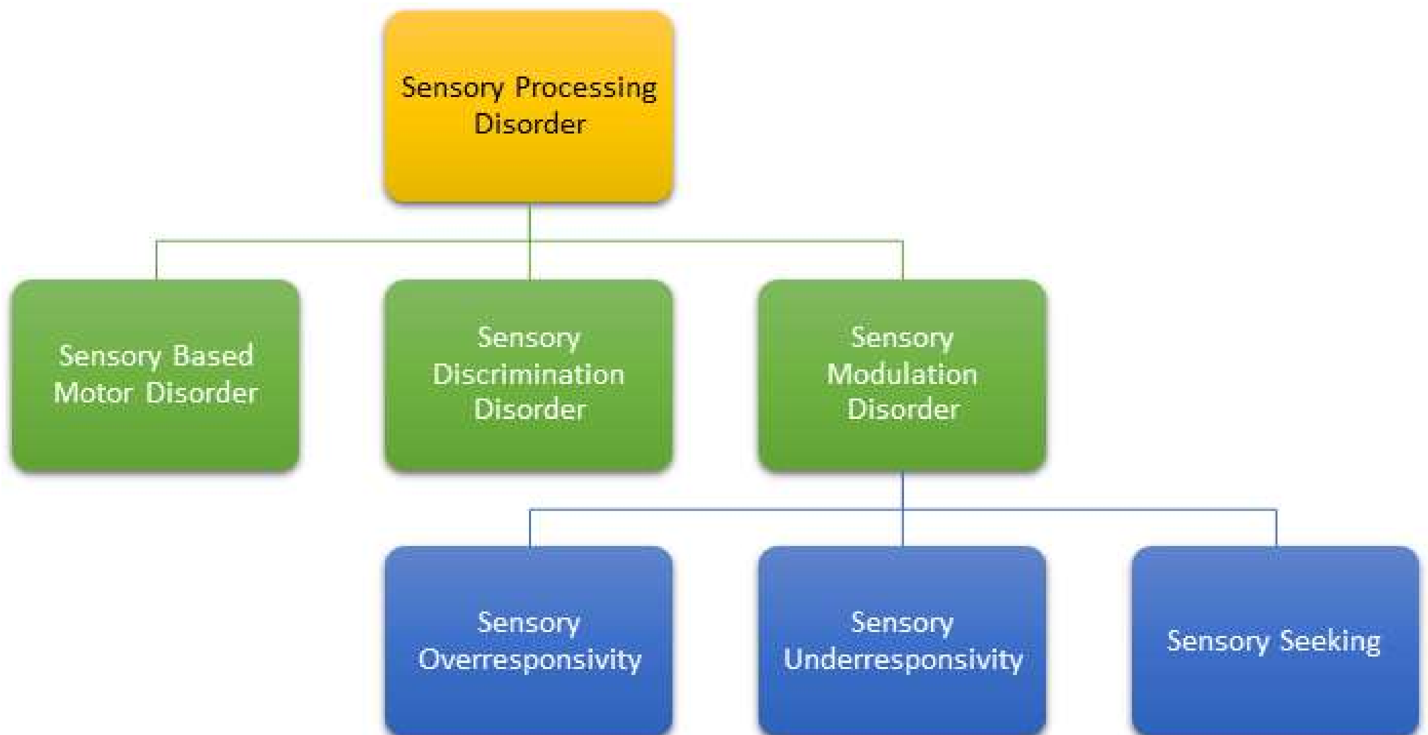
Vestibular

- Receptors in the canals present in our inner ear pick up the direction of movement and send this information on to our brain. So we know if we are moving forward, backward, side to side, tilting our head, turning round or moving up and down. Our brain uses this information to plan for movements and help us maintain our balance.

Interoception

- Interception is how our body tells our brain what is going on inside our body, when our bladder/bowel is full & we need to go to the toilet or when we are hungry or feel full, when our heart is beating fast or when we have that sensation of butterflies in the stomach.

Subtypes of SPD



Examples of behaviors associated with sensory modulationdisorders:

Sensory Over responsivity	Sensory under responsivity	Sensory seeking
- Is upset by tags in clothing and the seam in socks and/or only wears clothing with particular textures - Struggles excessively to avoid grooming tasks such as brushing teeth or having nails clipped - Hates messy play (eg, finger painting). -Becomes very concerned when hands/legs get dirty or wet -Covers ears and/or becomes very distressed with loud or unexpected noises -Avoids movement activities such as swinging or climbing -Is picky about food textures and frequently gags on food or the smell of non-preferred food -Has extreme difficulty with changes in routine, novel activities, and anything unexpected	-Does not respond when name is called repeatedly -Does not react to injuries and seems to have a very high pain tolerance -Does not notice food left on face or clothing twisted on body -Difficulty with toilet training and has frequent accidents -Extreme preference for sedentary activities -Does not notice things going on around the room -Overstuffs food in mouth	-Is in motion from the moment of waking until falling into bed to sleep at night -Takes risks during play such as climbing too high, jumping off high surfaces, and moving too quickly for safety -Appears driven to touch everything in the environment -Frequently crashes and bumps into people and objects -Mouths non food objects -Makes non-functional noises -Likes spicy or flavourful foods - smells everything around - Likes to feel everything around and may be messy

Children on the autism spectrum, in particular, should be referred as soon as possible so that intervention can begin early. Attending to **warning signs** (Refer the table above) can allow for the provision of treatment for possible increases in functioning.

- Child constantly has a extreme behavioural response to a normal stimuli
- Inappropriate response to the demands of the environment

Beyond informal observation, the child sensory profile and toddler sensory profile is a quick and easy screening tool that can help to confirm clinical observations that point to a sensory modulation disorder. This caregiver questionnaire has questions that help parents report the frequency of the occurrence of behaviors related to sensory dysfunction.

Knowing the warning signs and investigating further with screening tools can facilitate appropriate referrals to Sensory integration therapists/ occupational therapists (OTs), who have training to treat sensory processing disorders.

Feeding issues in children with ASD :

Children with ASD are more prone to have feeding related issues (food selectivity, chewing issues) . A detailed feeding evaluation should be done to find out the underlying cause for not chewing the food/ extreme food selectivity .
It can be because of sensory issue (Child's oral cavity is over sensitive to certain textures & taste) or oromotor hypotonicity (muscles of chewing are weak and not adequately functional) or idiopathic/ habitual.

Thus the child with oral motor/ sensory issues (where he/she lag in the skills to manipulate the food like moving it from side to side in lateral transfer pattern and chewing it with their molar teeth) might get stuck in an immature oral motor pattern like suckling where in the child just mashes the food with tongue & swallow . These children want solids but prefer them as soft, mixer mashed food & choke/puke if any new textured food is introduced.

How professionals can help with sensory processing issues & feeding issues :

There are no medications for sensory processing issues. But there are professionals who can help your child learn strategies to cope with sensory challenges. The treatment is known as sensory integration therapy. But more often therapists might create what's called as a sensory diet.

Sensory Diet is a tailored plan of physical activities. It helps kids learn to calm themselves and regulate their behaviour and emotions. This can help the child by being more open to learning and socializing.

Classroom accommodations to help kids with sensory processing issues might include:

- Allowing your child to use a fidget & weighted vests
- Providing a quiet space or earplugs for noise sensitivity
- Telling your child ahead of time about a change in routine
- Seating your child away from doors, windows or buzzing lights
- Allowing your child to take exercise breaks to self-regulate

Therapy for feeding issues: Post detailed assessment, Feeding therapy with Occupational therapist/ SI therapist must be started to focus on improving chewing skills. Oral sensory issues should be handled differently by gradually desensitizing the child and slowly introducing to different textured and different flavoured food along with other sensory inputs to oral cavity.

Active oral exercises can be taught to the child in a play way method to build up the oral tone. There are also therapeutic tools available in the market to help the child in building up the tone and giving sensory input. It will take time to develop the skills needed for chewing including motor planning ,strength and coordination for chewing . So it is important to gradually wean the soft puree type of foods and slowly introduce solid foods , simultaneously working on the motor & sensory aspect of chewing skills.

Treatment can ease the burden of this disorder for children and their families

Compiled by :

Dr Supriya Sachin
MPT pediatrics,
Senior pediatric Physiotherapist,
Sangamitra Early Intervention Centre

Dr Rashmi R
MPT pediatrics,
Pediatric physiotherapist,
Sangamitra Early Intervention Centre

NORMAL SOCIO EMOTIONAL DEVELOPMENT & MISSING LINK IN CHILDREN WITH ASD

The seed of socio-emotional development is sown for all human beings as young as 3-6 months. Infants by 3 months develop social awareness towards their caregivers and their voices. By 6-7 months babies start understanding their family members to be his/her people & start crying when they encounter a stranger which is termed as stranger anxiety. By the same time, neurotypical babies like to observe & interact with human faces more than inanimate objects.

In the second half of infancy, babies' locomotor skills drastically improve and he/she becomes more independent as they acquire walking skills. This more independent toddler, to reassure his/her safety, keeps his caregiver as his/her base of reference and does social referencing (referencing at parents to see what he/she thinks about and decipher it from their facial expression and body language) before exploring anything new in his/her social environment

When the child is about 1 year, sensory regulation kicks in and it helps them to modulate all the different sensory experiences. At the same time, Joint attention evolves to the social environment around him/her. As the toddler grows up, he/she starts expressing his/her needs in a more sophisticated way - not just by crying but by using appropriate gestures (such as pointing for needs, nodding his head for protest). He/she not only enjoys looking at things pointed by his caregiver but also likes to share his/her enjoyment with the caregiver by pointing out something he/she like (pointing at his/her favorites & looking back at the caregiver) or by showing his/her toys to the caregiver. All this takes place while the child acquires early communication skills as he/she participates in increasingly longer circles of engagement with their near & dear ones.

By 2 yrs, we can see the child representing his toys as real objects and making appropriate sounds as they play with them (Vroom...as he pushes the car) and imaginatively symbolizing one object for another (stool can become a car he drives). As children go from their late 2s to 3s we notice children more actively pursue reciprocal engagement, not only with adults but with their age-matched peers. Between 3-5 yrs, typical children engage in Cooperative imaginary Play, where they imagine together as teachers, parents, shopkeepers, mechanics, etc. They adjust their play plans based on their own and others' shared thinking. Despite how simple it may look to outsiders, cooperative imaginative play requires a lot of social problem-solving skills. It involves reading other children's intentions, understanding shared goals & play within unsaid rules and being willing to go with the flow based on the interest of the group. By practicing all these social problem-solving skills playfully, neurotypical children acquire all the prerequisites to survive in the world. They already know how the social world works & its unsaid rules. They go to school only to learn to work in the social world.

Missing Link in children with ASD

Autism spectrum disorder (ASD) is a developmental disability that can cause significant social communication and social interaction challenges. Most of us are aware of this definition of autism. But do we know really what is the real hidden difficulty? Let's look into it

1. Weak Theory of mind (ToM)- ToM is the ability to understand others' mind. Joint attention serves as a building block for developing ToM. Children by 4-6 yrs start understanding that others have thoughts different from their own and their actions may affect others thoughts. They also get to know that their thoughts are very personal unless it is expressed. Thereby humans can create false beliefs or manipulate others. In ASD children , irrespective of their good Intelligence, ToM is affected from the very beginning.

2. Weak Perspective taking skills: Perspective taking is a process of understanding differing thought and emotions & changing one's behaviour accordance with that knowledge. Empathy takes a very active role in perspective taking. The ability to predict other's intentions and adjust one's behaviour is a very vital skill , if not acquired , may significantly impact social development.

3. Weak central coherence: One important skill of humans is the ability to connect to the bigger picture. Human brain has the ability to filter out unwanted sensory inputs that we receive each moment and process only those inputs that are relevant to the bigger picture. In ASD, as this ability is affected, the child gets into details but misses the bigger picture

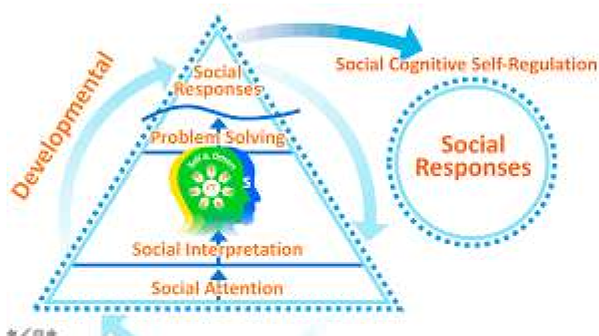
4. Executive function deficits : the moment a thought happens to do some action, immediately the brains makes a plan & starts giving the instruction for how to do it in sequenced steps and while executing the action plan, it prevents us from getting distracted or get us back to the plan even if we get distracted. Children with ASD may have associated executive function deficits and this may affect the child's play and academic functioning

Some Children diagnosed with ASD around 2 yrs, with intensive therapeutic intervention & with growing maturity, their language skills and cognitive skills would have become almost age appropriate by 4-6 yrs. However their Theory of Mind & perspective taking skills persists to be still low compared to their overall intellectual level. This may make parents feel that their children are smart but clueless in the social circle.

SOCIAL COGNITION DEFICITS IN ASD

(Michelle Garcia winner,https://www.socialthinking.com)

Social communication process is dynamic, complex and constantly evolves with age. To be efficient social communicator, we need to have strong social attention skills (ability to observe other's facial expression, body language, and tone of voice, to observe what people are looking at so that the child can predict their thinking), proficient social interpretation skills (able to read the context & situational cues, think on prior existing knowledge about the communication partner, figuring out the group plan of others in the social group) and flexible social responses (consider one's own and other's emotions & adapt responses).



Children with ASD are deficient/very slow in processing these social cognitive skills resulting in

- Difficulty in group learning due to lack of observing and figuring out group plan. Because of lack of social attention, they also don't know to modulate their behavior according to group needs. Eg: talking out of turn, talking for an extended length of time and inability to work as group without adult facilitation.
- Though they desire social interaction, they struggle to figure out how to enter into peer groups and initiate communication because of inability to track what others are talking about and make related comments or asking appropriate questions. Some may initiate but they may be off topic.
- Not able to recognize others' communication intentions and therefore they are at risk for being easily tricked & bullied. They also have poor self-awareness about how they are being perceived, there by not realizing that they are being bullied.
- Weak at understanding hidden social rules & adapting their behaviors according to the situation expected.
- Difficulty with transitions & accepting the change in their schedule due to their rigid thinking style (expect the world to work in the way they think)
- While most are able to learn how to read and comprehend factual information, with an apparent lack of social problem solving skills along with deficits in central coherence , these children might find it extremely difficult to comprehend social based information in their academics. In preschool & primary school, they might do very well (excellent rote learners) however they may face learning issues from 3rd/4th grade when they have to engage with the characters of their academic lessons, understand the character's perspective & emotional responses, interpret the motives and identify main idea of the lessons.
- They may struggle to organize and convey thoughts through written language in a way others can easily understand (though they know facts, they lack perspective taking skills)

<u>How to address these deficits ?</u>

- Children with ASD needs social skills training after they acquire good joint attention skills, basic sensory regulation skills and receptive & expressive language skills equivalent to functioning at the age of 3.5-4 yrs.
- Social skills training Program must not focus on person's outward social skills (such as make eye contact, scripted conversation, greet your friends) because social skills are dynamic and child has to adapt skill based on context , place & person (the way I greet my friend in the restaurant must be different from the way I greet my boss in official meeting or greeting my relative in a funeral)
- Focus must be on establishing social thinking (not on just what to do, but on why & how to do). In other words, child must be taught the skills to socially attend , to predict other's thoughts and plan of action and respond flexibly to the situation.

Dr Kirthika Rajaraman

DCH, DNB, FIAP (Dev & Behavioural pediatrics)

Consultant Developmental Pediatrician

Motherhood Child Development Centre, Indiranagar, Bangalore

CO-MORBIDITIES IN ASD

Autism Spectrum Disorders (ASD) have moved from being known to have specific clinical characteristics and core symptoms to being a widely heterogeneous complex disorder with regards to the clinical profile, etiology of the disorder, and its neurobiology. It is however important to identify these comorbidities early and address them in order to improve short term developmental gains and long term quality of life in individuals with ASD. Here I list some of the most common comorbidities of ASD and some tips to address them.

- **Seizure Disorder:** Prevalence of seizures in children with ASD can range from 5-30%. Identification of clinical seizures may not always be easy in many cases where children can present only with abnormalities on EEG. These findings may simply reflect the neuropathology seen in ASD, without a straightforward implication for treatment. But a subgroup of them (with significant sleep disturbance, regression) may potentially benefit when treated with anti-epilepsy medication even for EEG abnormalities.
- **Sleep disorders:** 40-80% of children with ASD can have sleep issues ranging from problems with sleep onset and maintenance to more severe parasomnias, and circadian rhythm disturbances. Sleep disruption can lead to aggression, hyperactivity, irritability and self-injurious behaviours in ASD. Melatonin hormone & sleep hygiene practices can be beneficial in some, while others may need a detailed exploration into the psychopathology of these problems and appropriate treatment for the same.
- **Gastrointestinal issues:** Though the prevalence of GI issues is not well known, literature in the last decade is paving a path towards the mounting evidence of the presence of constipation, chronic diarrhoea, abdominal pain and symptoms of reflux disease in ASD. Diet modifications, correction of motility dysfunction and sometimes pharmacotherapy(Probiotics) may seem to benefit in the particular subgroup of children with ASD.
- **Neurodevelopmental disorders:** Children with ASD are also known to have comorbid neurodevelopmental disorders such as Attention Deficit Hyperactivity Disorder, Intellectual Disability, Motor developmental delay etc. These disorders will need detailed evaluation to understand the degree of severity and appropriate intervention is needed. For some children with ADHD, medication along with behavioural intervention techniques will be augmentative.
- **Anxiety disorder:** Though challenging to differentiate, individuals with ASD can have an independent anxiety spectrum disorder which needs to be skilfully teased from the social and communication skills deficits seen in ASD. Anti-anxiety medication and supportive therapy can be particularly beneficial in these individuals.
- **Mood disorders:** Adolescents and adults with ASD are known to have mood issues with depression and suicidal symptoms being more common. This can result as a primary psychiatric disorder or can occur as a consequence of negative life experiences through the developmental years. Medication and aggressive therapy for the severely affected individuals may be mandated due to cognitive and social challenges that exist as part of the ASD spectrum.
- **Schizophrenia:** neurobiological studies in the past years have proven time and again that there is a common genetic basis for ASD and schizophrenia. Many children with ASD can develop schizophrenia during adulthood and will need closely monitored pharmacotherapy.
- **Self-injurious behaviours, aggression and irritability:** Negative problem behaviours such as aggression, self-injurious behaviours need proper exploration into the antecedent, behaviour and consequence(Functional behaviour analysis) of the episodes. Many of them may have these behaviours as a consequence of inability to verbalize/ non-verbally express emotions, as part of attention seeking behaviours or as a consequence of underlying medical comorbidities listed above.

Though comorbidities may not just be limited to the conditions listed above, it is important for clinicians and parents to note these behavioural changes and support individuals with ASD and their families. These comorbidities make it difficult for people with ASD to be diagnosed because of the difficulties to express their own feelings or problems. Unfortunately, there is still little clarity on how best to assess other psychiatric comorbid symptoms in this population and the direct impact on the ASD severity. Appropriate referrals and maintaining a support system outside of routine therapy will go a long way in helping these families.

Dr. Sowmyashree Mayur Kaku
MBBS, PhD in Clinical Neurosciences and Child and Adolescent Psychiatry (NIMHANS, Bangalore),
Centre for Advanced Research and Excellence in Autism and Developmental Disorders (CARE-ADD),
Unit of Hope, Dept of Psychiatry, St John's Medical College Hospital.

CROSSING THE THRESHOLD INTO ADOLESCENCE AND ADULTHOOD

A perspective for parents and families of persons with Autism

Teenage or adolescence is a period where a person comes on to their own and discovers their unique identity. It is a period of exploration where the person experiments many paths so they can discover their life's purpose. It is also a period where they need to interact with peers and the community and understand relationships, responsibility and boundaries.

Adolescence is not an easy time for anyone and add Autism to the mix and there are a host of additional issues to deal with which make it even more challenging for them. Many experience sensory issues all over again, the gaps in their social and communication skills become more evident and as they try to break the dependence on the parents and teachers they end up in power struggles and meltdowns.

Parents and families of young adults and adolescents with Autism need to tread carefully in this crucial period as it will in some ways "make or break "; the future of the person and they may not have the skills to navigate this stage on their own. I am sharing some focus areas that I feel are important to come through this phase successfully.

CELEBRATE DIVERSITY

From the time the child is diagnosed with Autism to when he is about six to seven years old, parents tend to focus on therapies and treatments. The goal is to help the child catch up on the developmental lags or gaps like speech or motor skills as well as schooling and academics.During this period, we tend to constantly look to the "neurotypical" population for milestones and aspirations for our child. Somewhere down the line we start realizing our child is "neuro diverse" –Their learning styles & abilities, their interests, their communication and behavior patterns, their needs and preferences are different. As parents we need to understand and embrace these differences, and adapt our strategies specifically for our child, only then we will be able to support our child better towards their holistic growth and development.

ENABLE COMMUNICATION

While academic performance is important, even more crucial is for the child to have a clear form of communication. We tend to focus on the "Verbal/Non-verbal" labels but tend to overlook the communication patterns of the child.

We need to ask ourselves the following questions - Is the child able to communicate their needs and preferences? Is the child able to communicate their feelings and emotions? Are they able to make a choice about day to day stuff like what they want to eat or wear? Can they say "No"? Can they ask for help?

They need to achieve these basic communication skills whether it is through speech or pictures (PECS) , technology aids - Avaz(https://avazapp.com)

& clicker (https://www.cricksoft.com/uk/clicker/8/special-needs) or any other mode. We need to create a climate where open communication is encouraged in the home and school. These Are crucial skills that help them to become more independent and assertive as they enter their teens. Without these skills they are sure to use other inappropriate behaviors to get their point through as teenagers

FOSTER INDEPENDENCE

Another important area is to get them to get as independent as possible with their daily Living skills such as Eating, Toileting, Brushing, Bathing, Grooming. They also need to be able to sleep on their own and have some way of engaging themselves for short periods of time. We can train them to use visuals or other technology based adaptations (iprompts app, visual timer- https://www.goodkarmaapplications.com/visual-schedule-planner1.html) to become more independent.

As they grow older they will not want us to constantly be in their spaces and we need to value their privacy. We need to observe ourselves if we are overly prompting them and reduce our physical and verbal prompts.

We can also help to organize and structure their spaces in such a way that it fosters more independence and reflects their style and preferences also.

As they grow older (by 6-8 yrs, earlier the better) it is important to involve them in household chores & responsibilities and help them to become more independent with managing a home which they may need to do later on.

Another important skill is moving around safely in the community, knowing to travel independently, manage money and shopping etc. Even if they cannot be 100% independent, it is important that they are aware of what needs to be done and able to ask for help when needed.

HELP THEM DISCOVER THEIR UNIQUE IDENTITY

As much as we look to the neuro typical population for benchmarks, we need to also observe our child keenly and help him/her explore and express. We need to help them towards creating a unique identity for themselves and move them closer towards finding their life's purpose.

It is important that we let them experience and explore many areas including the arts (apps- doodle buddy, dexteria), music, movement, sports, drama, cooking, modeling, photography, adventure etc. from a young age. Some of them may be interested in facts, numbers, wildlife, nature, movies, politics, geography, law or science and it is important to help them with the resources and guidance to delve deep into these interests. Often this may help them find their interests that later may become their vocation too.

We need to remember sometimes these interests are a passing phase and may change over the course of time. At least they would have experienced it first hand to decide this is not what they want to do. Many of these areas can also ensure later on the person has very interesting hobbies to pursue in their leisure time. This is important given the fact that many of them may not have a very active social life overall.

Amaze interns baking and cooking

BUILD A SOCIAL CIRCLE

Social skills are most challenging for persons with Autism. Even the most communicative persons with good language skills find it difficult to have a large social circle they can connect to on a regular basis. For many, family is the only circle where they are understood and accepted and some have a few friends.

However, as these individuals may need support for life, it is important to constantly expand their circle of support within the family to cousins, uncles and aunts, family, friends and also to the community. So it is important that they interact and involve with the community around them where they live and also the school /college or workplace. One way is to join in with community activities such as celebrations, attending camps like adventure camps, art camps, summer camps & also find volunteering opportunities in the community. This will also help to build a social circle for them and become more independent from their primary family and build systems that support them in the future.

It is also important over time for them to be involved in awareness and advocacy groups and empower themselves to fight for their own rights.

Nishant @ the Adventure camp at Coonoor , Nilgiris

USE POSITIVE BEHAVIORAL SUPPORTS

Setting clear rules and expectations – Setting the expectations ahead in terms of behavior and outcome is very important. If required one can use visuals and videos and social stories to clarify and remember the expected behaviors and outcomes. Reinforce positive behaviors.

Sensory supports - Puberty is the time when some sensory issues may reappear and they may need adequate sensory supports in place to regulate themselves. These include a sensory diet consisting of massages, exercise and other activities relating to the teen's specific needs, sensory breaks and some sensory safe spaces in the environment, like their room, a rocking chair, some music or tactile /fidget toys as the need may be.

MANAGE CHALLENGING BEHAVIOR

In Spite of the measures taken and steps to ensure a smooth transition for teens with Autism, they may still have some challenging behaviors self-harm, aggression, avoidance, oppositional behavior, destruction of property and have what we generally call a "melt down".

It is important to

1. **Do not get into direct power struggles or arguments with the teen** - instead redirect them to a safe area or calming routine. Safety of the person and others around as well as safety of property is most important at this time. Minimum eye contact, simple instructions to be given. Gentle physical guidance if at all to be given.

2. **Be very matter of fact** – if we react or raise our tone of voice or get physical with them it will only aggravate the issue. Being passive or trying to comfort the teen at this point also may not be appropriate as it may reinforce the undesired behavior. So it is important to stay calm, in control and matter of fact.

3. **Coregulate** – It may help the individual if we model the behavior that they need to follow, so rather than giving verbal instructions, we have to model what is needed to be done. For example, we want them to do some deep breathing/stretching, we could start off the deep breathing/stretching ourselves and pause and look expectantly at them to join in . Over time this will teach them to self-regulate using these routines.

4. **Behavior intervention plan** – It is important to plan ahead to understand the triggers for some behaviors and avoiding them as well as having a plan to handle them when they get into a "meltdown" stage becomes essential. This plan must be consistent across people and environments.

Compiled by :

Mrs. Akila Vaidyanathan
Founder-Director Amaze charitable trust
Parent to Nishant sriram, an adult with autism

WELL BEING OF CAREGIVERS- LET US FILL OUR POTS BEFORE OFFERING OUR CHILDREN

Stress is a relationship between an individual and his/her situation that is perceived by the person as exhausting or exceeding his /her tolerance limits, which endangers their well-being. In simple words, an individual feels stressed if there is an imbalance between the demands of his/her life and protective coping resources.

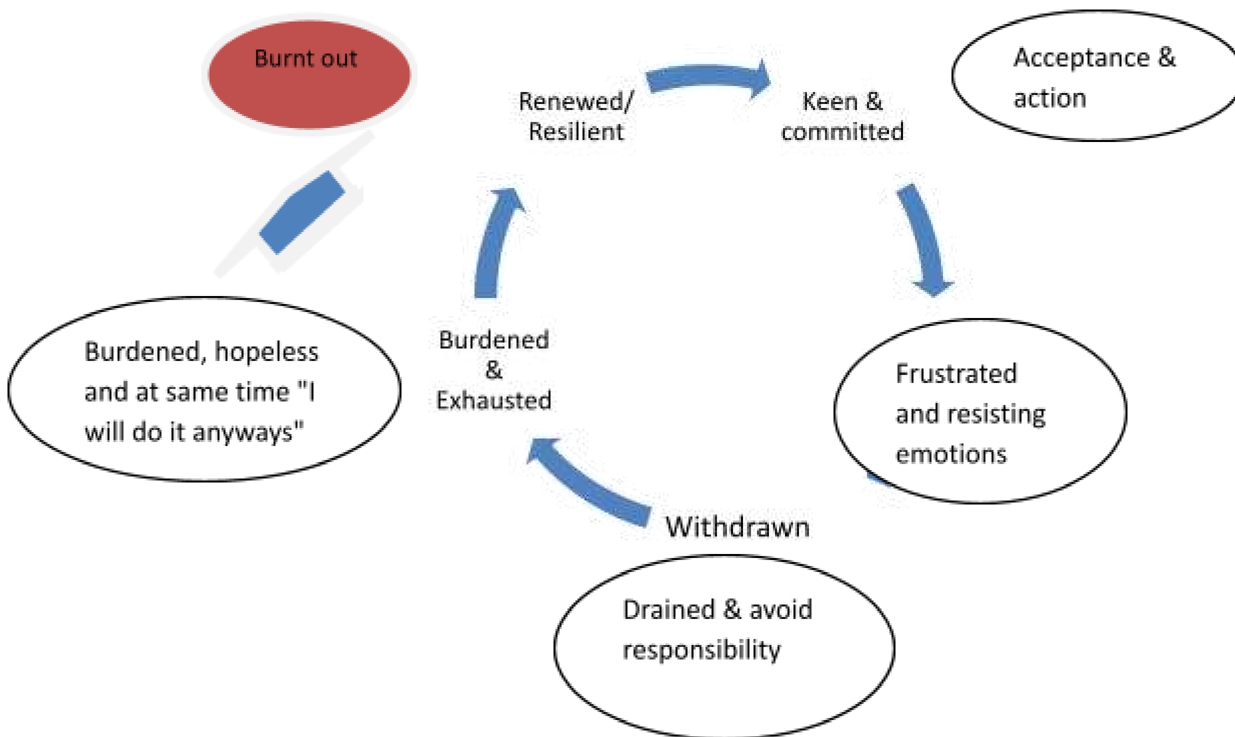
Is Parenting role stressful/ Blissful?

- Parenting a child is indeed stressful. There is some level of anxiety (am I doing my best), exhaustion (from the additional responsibility), and stress accompanying the parenting role (what I do differently from my parents, is it correct for my child). However, it does bring in unique joys - Our child's first smile, first step, first gesture, first word, first scribble, first day to school & such so many firsts.
- If the parenting role goes well, most parents feel accomplished, appreciated, and have a positive self-image. They are satisfied with their role as caregivers and enjoy parenting as a blissful experience.
- However, parenting children with special needs is difficult. Research shows that compared to parents of neurotypical children, parents of CWD experience a greater amount of stress, physical health difficulties, mental health issues like anxiety and depression. (Yun Ju et al 2017)
- The relatively higher stress could be attributed to factors such as:
    - ❑ Spending a lot of time caring for the child (frequent travel to the therapy centers, handling challenging behaviors)
    - ❑ Worries about future of the child
    - ❑ Financial burden
    - ❑ Lack of respite
    - ❑ Inability to participate with society (due to lack of awareness, acceptance, and inclusion of their child in the society)
    - ❑ Self-criticism (Am I not able to do my parenting role properly) leading on to self-blame (I am not good enough)
- The fatigue caused by the constant stress can lead to burnout.

Stages of Parenting fatigue (Georgina Robinson et al)

- Most of the parents pass through these stages of parenting fatigue and the final stage can be burnt out (or sometimes rejuvenation) . Burnt out means feeling depressed and hopeless. Whereas renewal or resilience is the ability to bounce back to acceptance & being in full action
- Parents must understand parental fatigue is inevitable and can't be avoided or resisted.
- Some parents may stay in one stage for a longer time when compared to others . It is not necessary that one has to pass on every stage to reach the final stage.
- Some may feel the emotion of that stage to an extreme degree & some at a lesser degree

- But having awareness & acceptance towards which stage of fatigue currently the parent is in and taking actions would facilitate in faster renewal.



How to build resilience?

1. Take care of yourself

- As a parent you might feel guilty for spending time on your own pleasures. But self-care increases your well-being and equips you in helping others better. Fill your pot first to pour for others.
- Have a scheduled dedicated time for leisure activities with your friends. Get help to take care of your child when you are with your friends.
- Invest on your fitness - Choose an activity that you would enjoy. (Ex: Zumba, Yoga, Walking)
- Make time for your hobbies or doing things that you value (any art form, gardening, reading a book). Your child picking up your hobby as their own self engaging skill is an added advantage
- Find your own suitable method (meditation, mindfulness, being with nature) to grow spiritually & finding your purpose in life.

2. Be a part of parent support groups

- It reminds us that you are not alone in this journey of special needs parenting and your experience is not unique.
- Other parents can empower you with strategies on how to handle judgment/criticism of the society or reassure you that the stressful situation you face currently shall too pass away (as your co-parents must have experienced a similar situation prior).
- Parent support group may provide social connections for both parents and the child.

- It is not just that the individuals with Asd need to acquire knowledge to be part of this society but the society also need to be empowered on how to be more inclusive. As being a part of parent group, parents can build awareness about autism & empower the society.

3. Practice Letting go

- Let go of perfectionism. Accept that you are not the only person who can do this for your child. Take a break and allow someone else to deal with it. Be brave to ask for help.
- Let go of that stranger's haunting look/daunting words in a public place when your child was throwing a huge tantrum
- Let go of something that you can't control

4. Be grateful :

- Look into your stressors & protectors in your life and be grateful for your protectors (can be your child's strength, your characteristics, your family support system, support from your child's school/therapy center)
- Start building more of your protectors.
- Daily be grateful for one good thing that you have in your life. Practice maintaining a gratefulness journal.

Though it is difficult and stressful to parent a child with special needs, it does bring along unique joys - enjoying minuscule achievements, better able to understand and experience the feelings of others & being more empathetic, and being a better human being. Remember you mean the world to your child and taking care of your wellbeing is your responsibility too.

Happy & Resilient Parenting

Dr Kirthika Rajaraman
DCH, DNB, FIAP (Dev & Behavioural pediatrics)
Consultant Developmental Pediatrician

INDIAN MUSIC THERAPY – BEATS THE DIFFERENCE

- There has been a fairly improved awareness about autism as a developmental disorder across societies over the past decade, however an understanding of the cause, outcomes & prognosis has been elusive to the medical and scientific community. Many complementary and alternative methodologies are being practiced in the treatment of children with ASD along with standardized evidence based treatment protocols (speech therapy, ABA and occupational therapies). Of which a few therapies are able to showcase a distinct change in the behavior of persons with autism.

- Among those few, Music therapy is fast gaining universal acceptance. Music therapy is a time-honored intervention in which music is used within a therapeutic association and deals with physical, emotional, cognitive, and social requirements of an individual. Music is a form of human communication and a musical response is possible for a child who has severe physical, intellectual, or emotional handicap (Gresham et al 1998)

- The Cochrane Collection reviews of randomized clinical trials (RCT) showed evidence about the positive effect of Music therapy on ASD and emphasized about the possibility of Music therapy to increase social adaptation skills in children with ASD (Geretsegger et al 2014)

- Children with autism have difficulties with direct social engagement; hence, musical activities in the social context provide valuable opportunities for interactions with social partners (Bhat et al, 2013) . ASD children manifest impairment in applying nonverbal behaviors which is needed to regulate interaction and communication. Music therapy helps in improving the nonverbal behaviors of ASD children and thereby enhance their social skills.

- Music therapy contributes to improvement of behavior, communication, motor imitation abilities, sensory issues and confidence among autistic children and adults. It is also important to note that Music therapy is a complementary and alternative methodology that has no known side effects.

- Music seems effective as both group therapy and as individual intervention. Beyond the therapeutic goals musical experiences create personal bonding between the therapist /caregivers and the recipient

- All the more in India where music is an inseparable part of culture and daily life, added with strong and large family centered relationships, it is little surprise that a unique genre of Indian music therapy has grown in stature. Indian music offers a whole range of well-structured components of Raga (melodic pattern), Tala (rhythmic forms),and Krithis (songs and compositions) to be modelled and utilized in treatment plans.

- Svarakshema Foundation for Indian music therapy has been conducting music therapy sessions for the past 5 years with growing synergies and gratifying success stories. Certain children have shown remarkable improvement in attention span, sitting tolerance, verbalization, along with marked stress-relief for the caregivers. The effect of Indian music on enhancing caregiver experience is observable and remarkable. Further, as it is distinctly noticeable that many autistic children have a natural flair and liking for music, Indian music therapy is able to create an enjoyable ambience for the children and help in their emotional coping during meltdown/stressful states.

Compiled by :

Mrs. Sowmya
Music therapists
Svarakshema Foundation
Bangalore

Mr Sanak

GFCF DIET – GLUTEN FREE- CASEIN FREE DIET

This is the diet that restricts on proteins "Gluten" (found in wheat, barley, rye) and "Casein" (found in dairy products). These restrictive diets are classified as "Complementary and Alternative Medicine" meaning, these diets are still not proven. Dietary interventions in children with ASD are very popular but could be potentially harmful too if practiced without doctor's advice.

Children with ASD already exhibit picky eating behaviors . Restrictive diets further limit the variety of food intake, so it can result in macronutrient and micronutrient deficiencies (Santocchi et al,2016)

Idea behind trying GFCF diet is based on Gut- brain Axis & effect of dietary interventions on the gut-brain axis. Children with ASD have a disruption of their gut epithelial barrier (which is involved in controlling the passage of molecules from the GI tract) leading to altered gut permeability. This "leaky gut", may allow the passage of bacteria, toxins and metabolites (undigested gluten & casein metabolites too) that activate the immune response. The activated immune system releases inflammatory chemicals which can modulate the CNS and contribute to the pathogenesis of autism (Li Q et al 2017)

Due to the heterogeneity of children with ASD, Currently evidence supports trying GFCF diet only in those children who have significant GI problems (severe constipation) or food allergies leading to increased intestinal permeability (celiac disease). These children may respond to and benefit from a GF/CF diet, resulting in improvements in both GI and neurobehavioral symptoms (Desbonnet et al 2008)

HOW TO START GFCF DIET

It is important to identify the sources of gluten and casein in foods your child eats and eliminates them from their diet. If the child primarily eats gluten and casein containing foods, it is important to first work on expanding food options and then try on a GFCF diet.

It is very important to include all the other nutrients other than gluten and casein (containing foods), like wheat is high in fiber and is great for gut health, so it is important to ensure that the child's diet still contains high fiber from vegetables, green leafy vegetables, fruits and whole grains.Since dairy is good source of calcium, ensure the child's diet has plant- based calcium sources like green leafy vegetables & millets like Ragi .

INGREDIENTS AND FOODS TO BE AVOIDED

Gluten containing foods: Wheat, rye, barley, semolina, oats (not labeled gluten free), wheat bread, asafetida, durum-pasta or semolina-pasta, energy bars (not labeled gluten free), baked foods, wraps (made with wheat).

Casein contains foods: Cow milk, goat milk, sheep milk, curd, cheese, butter, ice cream, milk chocolate, dairy based sauces, pastries, cupcakes, cookies, chips, biscuits.

INGREDIENTS AND FOODS TO INCLUDE

While there are many on the avoided list, there are also abundant options that can be included in GFCF diet, like,
Grains: Rice, oats (gluten free), millets, corn, quinoa, any flour from above sources, puffed rice, corn flakes, bread (gluten free), gluten free sweets.
Milk: Nut milk (almond, cashew), oat milk, coconut milk, curd set from almond milk, cashew milk, coconut milk, plant based cheese, butter, ice cream.
There are quite a few cook books available online to have solid recipes to make.

HIDDEN SOURCES OF GLUTEN

Medications, lipstick, lip gloss, nail polish, paints.

EATING OUT WITH GFCF DIET

There are restaurants that cater gluten and casein free menus. It is important to give a detailed order, as there are very high chances of cross-contamination with flour, cheese and butter.

HOW TO TRANSIT TO GFCF DIET

Each child is different with their own set of restrictive eating patterns, no umbrella rule applies. We need a lot of deliberation before it is decided to keep the child off gluten and/or casein or not. It takes a lot of time, intervention and effort.

Few kids with autism struggle with big changes, so gradually replacing their gluten and casein foods with alternatives may work best. Texture, color, presentation play a major role in pleasing the child. Few kids do better with an "everything at once approach". You know your child best, try and choose the one that suits better.

SOY AND CORN

Protein structure of soy is similar to that of gluten and casein, leading to challenges. If you suspect any sensitivities (abdominal symptoms like diarrhea, vomits, constipation, repeated bloating)to soy or any other products (ingredients), it is important to eliminate them from the child's diet and observe the child for a period of 3-4 weeks, on any noticeable changes. If eliminating the particular ingredient eases the child, it is better to eliminate it further, but if not, then reintroducing it gradually is important.

Getting your child used to eating alternatives to some of their favorite foods, isn't easy and definitely troublesome, but worth a try.

NUTRIENT DEFICIENCIES

Low intake of vitamins or minerals is mainly caused due to the restrictive diet pattern. Many children with ASD, also have "Sensory Processing Disorder", that is having difficulty in receiving and responding to information from the five senses- sight, smell, taste, touch, hear. Texture, color, presentation of food plays a major role, as eating is a very sensory activity.

When children have fewer food options, it is usually compromised on Nutrients like vitamin A, vitamin-B, vitamin-C, vitamin-D, calcium, iron, zinc, magnesium, potassium, omega-3, if unmonitored. So supplementation of these nutrients in a balanced diet & supplementation as medications becomes essential while following the GFCF diet.

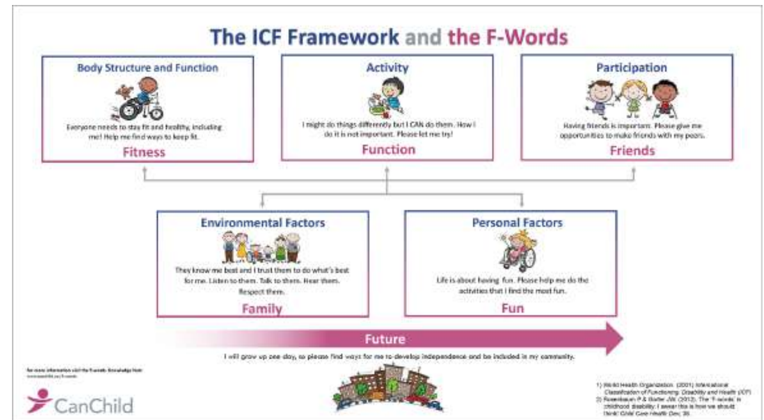
Poor nutrient intake can play a major role in behavioral and cognitive issues. Ensuring proper intake of nutrients is vital for overall development and functioning. So it is essential to try a GFCF diet only in Specific category of ASD children (with significant GI problems/celiac disease) with proper guidance from your Pediatrician & Nutritionist.

Compiled by :

Mrs A.S Lakshmi ,
Clinical dietician,
Certified Lactation professional , Maternal and child nutritionist.

SANGAMITRA- FRIEND OF THE SOCIETY

Sangamitra is derived from a Sanskrit word meaning "friend of the society". We are a family consisting of parents, children, doctors and therapists. The Centre Was established in November 2014, at Sahakarnagar, Bangalore, with 3 families. It caters to children with Autism Spectrum Disorder, ADHD, ADD, Down syndrome and other learning disabilities



To date, we have trained and guided more than 500 families to help themselves and their children to achieve and reach their potential.

The Sangamitra Model was developed from the parent based early intervention program for children with communication, socialization and behavioural difficulties. Parents (usually mothers) attend a 3 hour structured program along with their child, 5 days in a week in which they are trained by professional and qualified therapists, to teach their children specific skills and strategies to focus on their strength in various domains. It is ensured that Parental acceptance is created and parents are made to understand that their role is not to cure the disability, but to give their child the social and emotional tools they need to acquire and work through challenges. The mothers extend the program in their homes by practicing the similar activities for 2 hours every day.

During this pandemic, Sangamitra was able to switch over from offline to online, without much difficulty, as mothers were already an integral part of the program, and have been successfully able to conduct the sessions throughout.

Three hours program is based on the International Classification of Functioning, Disability and Health model of 5 F's.

FUNCTION, FUN, FITNESS, FAMILY AND FRIENDS

Foundation: Based on the SCOPE- (Social Communication Play and Emotional skills) profile assessment,every child is assessed for their current levels of functionality and hence a plan of action is designed to help them build their foundations in all the 8 domains of interventions ie. Receptive, Expressive, Imitation, Cognition Socialisation, Play, Fine Motor and Self help skills. Parents are trained using EDITT (Educating Parents on Interactive & Direct Teaching Techniques) modules to help them understand the teaching and training aspects for their child. Parents and children are trained under the able guidance of the therapists. The SCoPE Intervention Program was developed over three years in Sangamitra Early Intervention and Sensory Integration Centre, Bangalore. We are running a successful parent based intervention service for families who have children with developmental delays for the past 7 years.

Function: Mothers are trained to be interventionists themselves for their child and also help in advocating for other parents sailing on the same boat. Sangamitra follows the SCOPE (Social Communication Play and Emotional development) training module.

The SCoPE intervention program provides an individualized tailor made set of developmentally sequenced intervention activities in 6 developmental domains- receptive language, expressive language, play skills, social skills, imitation and cognition. Based on the functioning levels obtained for each domain from the SCoPE Assessment, the software generates appropriate activities that the interventionist can teach the child at a suitable pace. The SCoPE intervention program allows the interventionists to document the child's improvements in the activities and upon completing a level, will receive higher level activities. Thus we help in improving the functional ability of the children at their own pace with their mothers being their therapists. Apart from these domains, children are also trained with ADL's (Activities for Daily living skills) and other leisure activities like Art and craft, Music, Cooking and Baking so that they can be a part of the mainstream society and schooling.

Fitness: Fitness Time is a regular part of our Intervention program. Children start their day with Brain gym exercises along with their mothers. Exercises incorporated here help kids to calm down and concentrate on their work. Fitness activities are also practised by staff and the mothers to keep themselves physically and mentally fit. Even during the pandemic children continued to practice the same. Every parent would record these sessions and update it on the common whatsapp group. This allowed the teachers to keep a track of the child and it also motivates the other parents to do the same.

Fun and Frolic : Fun and Sangamitra are synonymous. Every national and traditional festival irrespective of religion, Birthday celebrations for children, staff and parents, potlucks, yearly outings which include restaurant visits, movie shows, Air shows, short trips to nearby parks and lakes, visits to Decathlon and helping kids to play fun games etc are organised and celebrated with full enthusiasm.

It keeps the mothers, children and staff motivated. Fun filled atmosphere creates a beautiful bond between the whole family of parents, children and the staff. These activities also help parents to manage their stress levels.

Friends and Family: Each and every member of Sangamitra gradually becomes friends and connects more to support each other morally and emotionally. Children get an opportunity as a group to practise socialisation skills and learn to adapt well with each other. To help them provide these fun filled exposures we conduct yearly sports day celebrations, National festivals and other fancy dress functions where friends and relatives of families are invited so that awareness and inclusion is created among the extended family members and friends. With all these exposures staff, parents and children develop a beautiful bond and hence we are a big family. Being a family of known people not only helps to intervene in many learning and behaviour related issues that are common with children on the Spectrum, it also helps to counsel and support the mothers when needed. Mothers become confident, empowered and are able to accept, recognize, understand and guide the extended family and motivate them to be a part of the program.

QUIZ TIME

Here are a few questions on social developmental milestones of a child.
Let's try and answer the appropriate age at which these milestones are attained by a child.

1. Responds to name call

2. Child Follows what you are pointing at

3. Child uses pointing with index finger to indicate their needs

4. Sharing their enjoyment like showing their toy to you to share their happiness

5. Follows simple one step household instructions(bring glass/ pick up ball) without your gestural help (like pointing to the object)

Answers:

a) 7months b) 9-12 months c) 12- 15months d) 15-18months e) 15 -18 months

FEEDBACK

We are delighted to share the feedback we received for the March edition of the newsletter on DOWN SYNDROME. We received a lot of positive responses for this issue on covering Down Syndrome from a developmental perspective.
Here are some of the reviews from our dear colleagues, parents and caregivers.

- *Excellent newsletter. Wonderful effort by Dr Nandini and team. Especially liked the focus on sexuality and safety. Thanks for sharing these wonderful newsletters.*
- *It is amazing to see the team pull off so many newsletters in such a short span of time. Thanks for sharing. The parent perspective is a wonderful edition*
- *Very comprehensive coverage of complex topics in a simple manner*
- *Great compilation. Excellent well covered topics*
- *Kudos mam ! What and effort*
- *Wow! This is a parent manual ! Excellent compilation*
- *This is a great guide madam.*
- *It is an excellent issue. Thank you madam.*
- *Good job with the compilation.*
- *It has been an amazing issue. A new Developmental perspective added to DOWN syndrome. Appreciate the article on the relationship and circle concept.*

For any support or query kindly write to us at www.support@totsguide.com We would love to hear from you about this edition too!

Inclusion in the Workplace: Challenges and Opportunities in a Post-Pandemic World

PLEDGE

I Support Ensuring Routine Autism Screening For All Toddlers at 16-18 months

Dear Daddy/Mummy,

- You are so happy to see me grow up, walking, running…
- Please do monitor my early language & social development
- Rule out my risk for Autism

Is your healthy 18 mths old child able to do all these???

- Eye contact & reciprocal vocalizations
- Responding to name
- Following what you point towards
- Pointing (for needs/for sharing)
- Social Referencing to share interest/seek appreciation
- Imitating gestures

If not don't wait consult your pediatrician

Lets Pledge

I Support Autism Awareness