



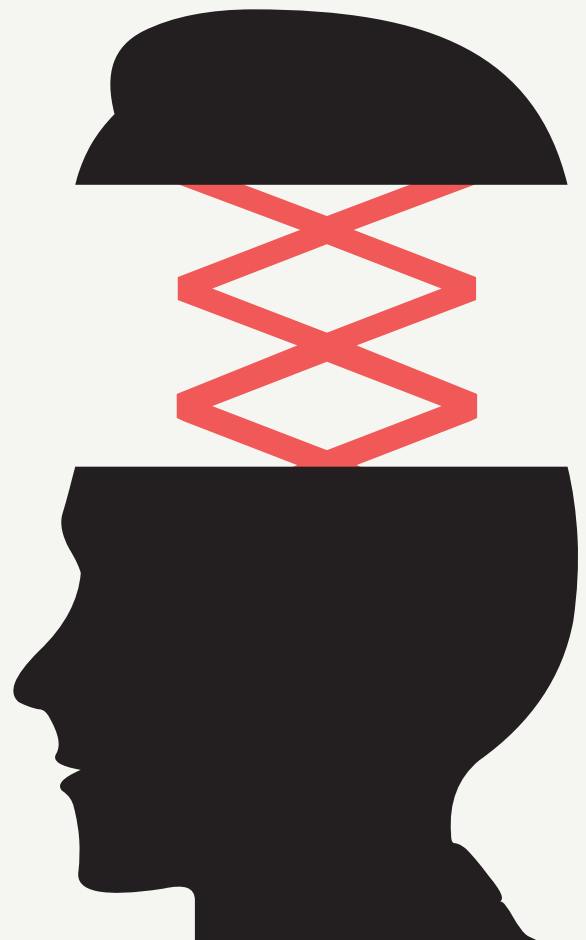
**ENGAGE  
EMPOWER  
EDUCATE**

**PAY **A**UTENTION**

**AUTISM AWARENESS MANUAL**

VISION:

PayAttention  
aims to facilitate  
an all-India network  
for neurodiversity  
support and inclusion  
in India.



# Pay Attention. Year One Milestones.



PayAttention Helpline  
and Resource Portal.



1200 Anganwadi workers  
trained as early identifiers.



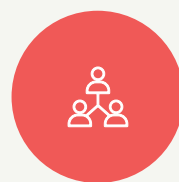
Inclusive Tech Expo  
promoting freedom from bias.



24 Awareness Street  
Plays in 5 States.



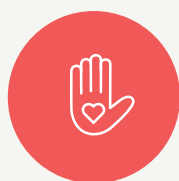
National Roundtable  
Conference on Neurodiversity.



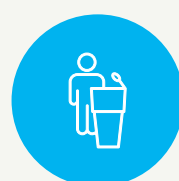
1000 Volunteer Program  
launched together with IHCL.



Over 10,000  
families reached.



Over 100 parent groups and  
corporates added to the network.



Maharashtra Neurodiversity  
Summit, 2023.



24 Home Learning Videos  
created for caregivers.



Webinar with Rehabilitation  
Council of India.

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Autism  
isn't a  
choice.  
Acceptance  
is.

Stuart Duncan



# Pay Attention, we are here for a big change.

PayAttention network is a one-of-its-kind phygital platform in India that provides support and guidance to volunteers, caregivers, community workers, and child-care ecosystems to enable early diagnosis and primary care for children with neurodiversity - with a special focus on Autism Spectrum Disorder. The program serves through a web portal with verified knowledge resources, learning videos, a helpline, expert webinars and workshops, events, and street plays to further this ecosystem.

Our outreach efforts have also touched the hearts and minds of over 5,000 community members through thought-provoking street plays in 6 different regions. The PayAttention support helpline (18002099488) has reached 17 states across India. Over 100 national and regional organisations have become part of the National Autism support network in India with PayAttention.

Over 1000 Anganwadi workers and Women SHGs have been trained to provide support for those with autism, resulting in an outreach of 5000+.

## **PAY ATTENTION AND TATA POWER ARPAN**

Tata Power's Arpan programme encourages our employees to volunteer, empowering them to engage in meaningful initiatives and make a positive impact in their communities. The Pay Attention 1000 champions for Autism Awareness aims to empower corporate volunteers, our ecosystem partners with tools to identify and support children with neurodiversity and their parents and caregivers.



# Our Aim

1 out of every 10 children below 10 years of age has autism in India. However, there is a lack of professionals and clinical services for identification and care of children with Autism Spectrum Disorder, especially in the remote areas of India.

Clinical services for intellectual disabilities and ASD like clinical evaluation, physical and psychological testing, parent counselling are inadequate and unevenly distributed. Hence, there is a substantial delay in identifying cases of ASD.

This training module for volunteers is an attempt to empower employee volunteers, parents/caregivers, Anganwadi workers and teachers to be the auxiliary support providers for early intervention to the children with Autism and improve all the core deficits of Autism Spectrum Disorder (ASD). This module aims to make volunteers 'Champions for Autism Awareness' and help them identify children with ASD in their own communities. Volunteers trained by this module can bring support to regions where awareness and professional services haven't reached. The training module is created keeping in mind three aspects: increasing awareness, providing auxiliary support and creation of local networks.

## What will Autism Awareness Champions do?

1

### PROPOGATE

They will become Autism awareness champions and spread awareness about Autism in their communities.

2

### IDENTIFY

They will help identify early signs of Autism in children and support parents by referring them to nearby support resources.

3

### PROMOTE

They will help in promoting Tata Power Pay Attention helpline for Autism support in the communities.

In a Nutshell



**18**  
million

1 in every  
**89th child**  
is autistic.



KNOWLEDGE  
**is key**  
to unlocking  
potential.



Indians are Autistic.



**AWARENESS CAN HELP US  
MANAGE AUTISM BETTER.**



**178% RISE**  
in the prevalence of Autism  
over the past 20 years.



In India, it is estimated that around 18 million people have Autism. There has been a 178 % rise in the prevalence of autism in the past 20 years. In India, every 1 in 89-100 children below the age of 10 has Autism. 1 in 125 children between the ages of 2 and 6 years and 1 in 80 between the ages of 6 to 9 years have been diagnosed with Autism.



## NEUROTYPICAL

# What is Neurotypical?

- Neurotypical refers to people who have typical neurological or general functioning, which means that their physical, motor, linguistic, and social milestones have advanced and been met at a specific and standard rate.
- Neurotypical people display commonly expected behaviors such as being able to establish friendships, modulate their volume and tone of speaking based on the situation and generally do not find maintaining eye contact distressing.
- They are also able to navigate complex social situations with ease, modulate their non-verbal behaviours, function in distracting or stimulating settings without becoming overloaded by stimuli or requiring consistent modifications to their environment.

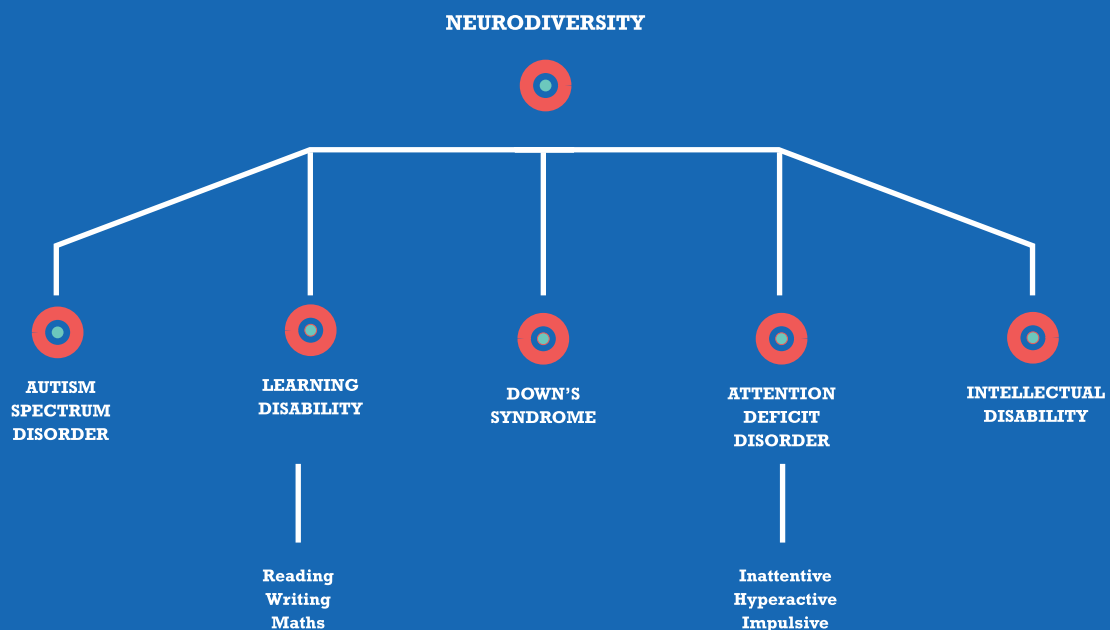


## NEURODIVERGENCE



# What is Neurodivergent?

- Being Neurodivergent means having a brain that works differently from the average or 'Neurotypical' person. It encompasses many conditions such as Autism, Specific Learning Conditions, Attention Deficit Hyperactivity Disorder and Obsessive Compulsive Disorders.
- Neurodiverse individuals often struggle with interpersonal, learning, sensory and communication (language) skills. They may find it hard to modulate their voice, understand social cues, form close relationships and may display repetitive and self-soothing movements like rocking, irregular hand or body movements.
- However, they may have exceptional memory for numbers, language, routes, tunes and lyrics as well as an ability to solve complex mathematical problems and recognition of patterns.



# Why use these terms?

Neurotypical and neurodivergent aren't terms used to medically differentiate people and neither is it to highlight the deficits in people. In fact, it is quite the opposite - it helps people understand their own set of unique strengths and challenges and helps them use that knowledge to adapt, implement modifications that they may require and succeed.



# Autism can manifest in different ways.



This means that neurodivergent individuals have a different set of strengths and challenges from neurotypicals. Neurodiverse individuals often struggle with interpersonal, learning, sensory and communication - language skills. They may find it hard to modulate their voice, understand social cues, form close relationships and may display repetitive and self-soothing movements like rocking, irregular hand or body movements. In order to understand and cope with these disparities, neuro-diversity is a concept that considers variations in the human brain's capacity for learning, emotion, attention, sociability, and other mental activities without pathologizing the situations. However, they may have exceptional memory for numbers, language, routes, tunes and lyrics; an ability to solve complex mathematical problems and recognition of pattern.

## AUTISM

# What is Autism?

Autism is one form of neurodiversity. It is a spectrum of symptoms, hence called Autism Spectrum Disorder (ASD). Since it develops before the age of 2 years, it is classified as a developmental disorder.

It is not an illness to be cured, hence does not require treatment, but interventions, especially early intervention, can help manage some challenges that Autism poses.

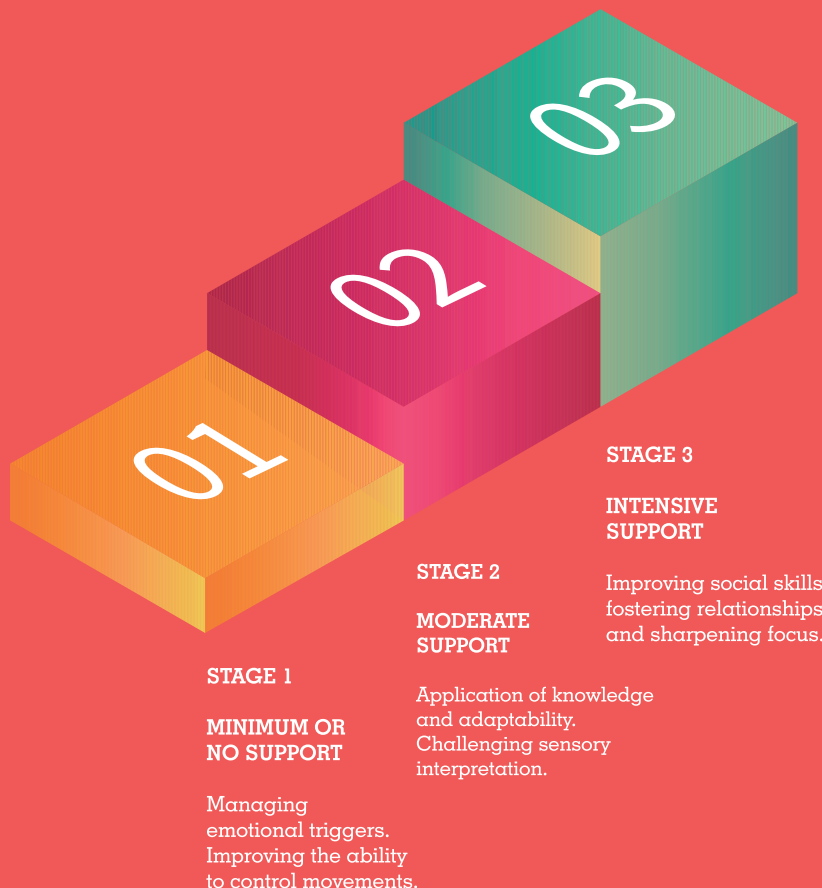
**AUTISM IS A NEURO-DEVELOPMENTAL CONDITION.**

**FIRST SIGNS ARE NOTICED IN EARLY CHILDHOOD (USUALLY BEFORE THE AGE OF TWO) AND HAVE A CONTINUED EFFECT INTO ADULTHOOD.**

**THESE IMPAIRMENTS CAN HAVE MILD TO SEVERE EFFECTS ON THE PERSON'S FUNCTIONING AND MAY IMPACT ONE OR SEVERAL AREAS OF FUNCTIONING, INCLUDING THEIR SCHOOLING, SOCIAL LIFE AND ACTIVITIES WE DO INDEPENDENTLY IN DAILY LIFE, E.G., BATHING, EATING, SLEEPING, DRESSING ETC.**

**IT IS NOT AN ILLNESS AND THEREFORE THERE IS NO MEDICINES TO CURE FOR IT, BUT INTERVENTIONS, ESPECIALLY EARLY INTERVENTION, CAN HELP TO MANAGE SOME CHALLENGES THAT AUTISM POSES.**

**IT IS A SPECTRUM CONDITION WHICH MEANS THAT IT PRESENTS ITSELF IN A WIDE VARIETY OF COMBINATIONS, RANGING FROM MILD TO SEVERE.**



# Difficulties in 3 key areas.



## DIFFICULTY IN COMMUNICATION

Avoids eye contact.

Finds it difficult to hold a conversation.

Repeats words or imitate other's words.

Slow to develop or lack of verbal communication skills.



## DIFFICULTY IN INTERACTION

Difficulty in making friends.

May not respond to their names.

Reduced sharing of interests.

Prefers to spend time alone.

Difficulty in recognising people.

May not be able to express emotions.



## DIFFICULTY IN PROCESSING

Avoiding or seeking of sensations: avoids certain textures in food/clothes, may find normal sounds painful, looks at colourful or bright lights more than usual, moves back and forth.

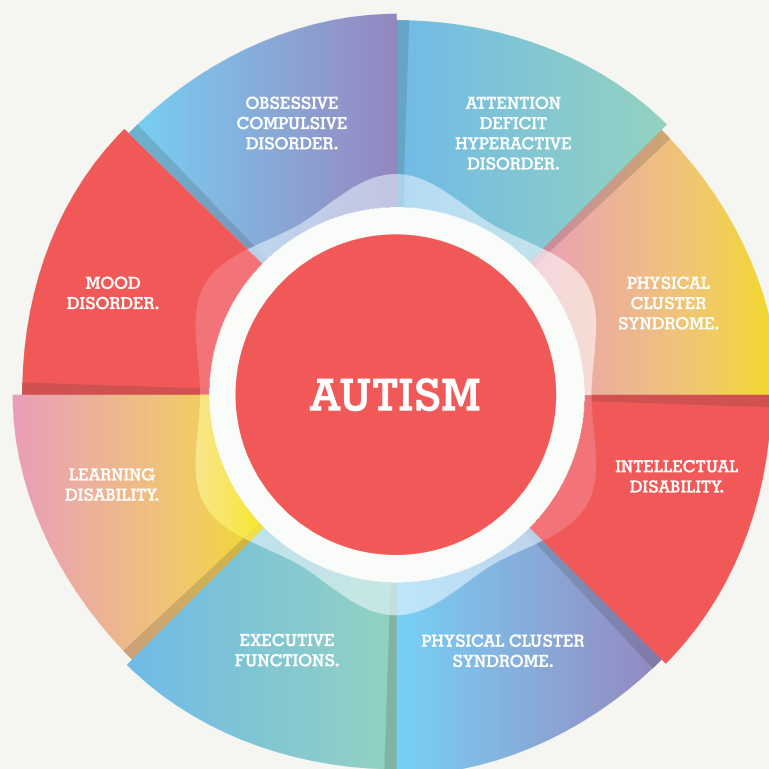
Restricted or repetitive behaviour. Repeated movements like flapping of hands, making postures in the body. Repeated lining up or stacking of toys.

Obsessive Compulsive Interest: Gets upset by minor changes or routine, plays with toys the same way every time.

While Autism is defined by a set of behaviours, children and adults with autism can exhibit any combination of the behaviours in any degree of severity. Therefore, two individuals with the same diagnosis will present very differently.

Thus, there is no set way to 'manage' or 'accommodate' a person with ASD. Persons working with individuals with ASD will need to develop a good understanding of ASD and will need to learn a generic set of strategies that can then be modified as per the needs of the individual that they are working with.

# Autism can co-exist with other conditons.



Autism can often coexist with other conditions such as difficulties with attention, hyperactivity, impulsiveness (ADHD), learning difficulties, difficulties with mood and anxiety, difficulties with general cognitive functioning, as shown below. Thus, it is very important to provide intervention for ASD and co-existing conditions. It helps greatly with the person achieving the maximum amount of self-resilience and independence that they can. It also helps them function at their best in every aspect of life.

# Impact of Autism on lifespan.

Autism is mostly considered as a childhood condition, with a majority of the focus of research and intervention being on early detection and intervention. However, the reality is that autism is a lifelong condition. As each of us go through different stages and phases in life and they are associated with different needs, so too individuals with autism progress through various stages. In order for the individual to thrive, live life to the fullest it is important that certain support and accommodations are made available. These could include educational, social, recreational, familial, medical, legal, employment, and assisted living needs. The provision of support in these areas will ensure a better quality of life for the individual and their family.

## TODDLER



- Lack of eye contact or limited eye contact.
- Lack of gesturing or pointing.
- Absence of joint attention.
- No response to hearing their name.
- Muted emotion in facial expression.
- Lack or loss of language.
- Can't stand when supported.
- Gut related issues.
- Sleep issues.
- May not have any single word utterances.

## AFTER 2 YEARS OF AGE



- Difficulties with understanding and using non-verbal communication.
- Delays in linguistic skill development.
- May repeat words that others say without using it meaningfully.
- May show a loss of previously acquired skills.
- Difficulties with understanding emotions.
- Limited or no response to their name.
- Few facial expressions.
- Shows a preference to play on their own; restricted interest in engaging with others.

## AGE 2 TO PRESCHOOL

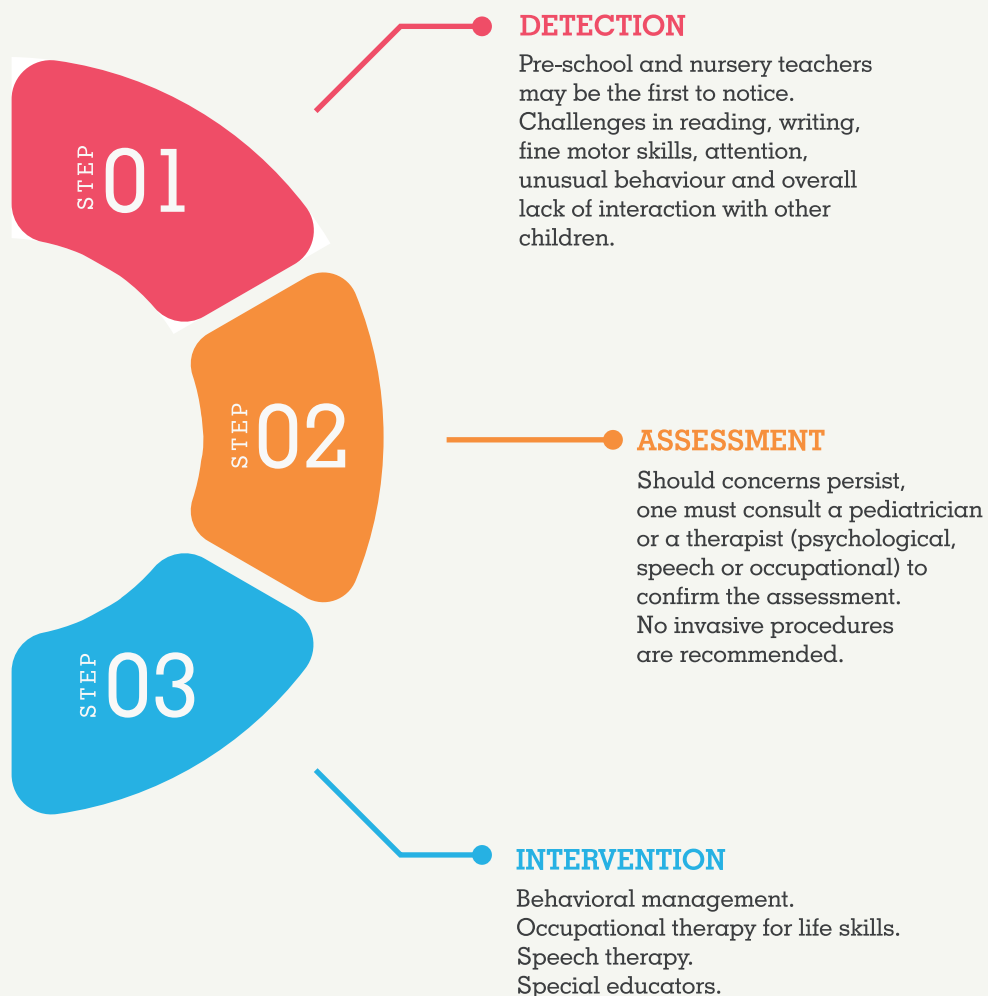


- Not smiling when seeing near and dear ones.
- Emerging sensory concerns like avoiding certain foods due to their texture or colour. Seeking or avoiding certain smells, sounds, tastes, movements and textures.
- Repetitive movements, such as hand flapping, spinning, flicking fingers, rocking back and forth
- Intense interest in a few special subjects or object.
- Parents might notice new concerns developing like hyperactivity, difficulties with paying attention for long periods of time, difficulty with learning new concepts, reading, writing and motor coordination.
- Low enthusiasm to explore new things.
- Preferring to play by themselves and finding it hard to understand group games and rules.
- Toilet training may pose a big concern for parents.



# Importance of early detection and diagnosis.

Neurodiverse conditions often have an unclear aetiology and no known direct cure or medications unlike other medical conditions. So, an accurate and timely diagnosis is very important for their transitions from early childhood to adolescence and so on. Research and evidence strongly recommend early diagnosis and intensive early intervention as it can significantly improve the quality of life of the individual as well as their carers and families. It not only helps both the child, and their parents or carers reframe their 'challenges' into 'differences', but it also means they will be able to access the neurodiversity support they need in a mainstream educational system, as well as find the best way to live a happy, balanced life that works for them. Most importantly, having a diagnosis helps us to identify the child's strengths and build a more accessible, safe environment for them to function.



# Early intervention therapies.

## ROLE OF A HEALTHCARE PROFESSIONAL IN THE MANAGEMENT OF AUTISM

### Developmental Paediatrician/ Neurologist

Identify autism.

Diagnose and treat co-existing medical disorders including sleep problems, seizures, potential genetic and metabolic disorders, behavioural co-morbidities such as hyperactivity, anxiety and depression.

May prescribe medicines to manage co-morbid conditions.

Follow-up plan in liaison with the therapy team.

### Child Psychologist

Developmental assessment.

Confirmation of ASD by standardised assessment.

Addressing problem behaviour:

Functional Behavioural Analysis.  
Structuring Routine.  
Behavioural Management.  
Parent Training.

Improvement in social skills, eye contact and joint attention.

### Speech Therapist

Assess communication skills and oro motor functions.

Work on improving pre-linguistic and language skills including socially appropriate expressive skills.

Augmentative and Alternative Communication (AAC) use in non-verbal children.

### Occupational Therapist

Assessing motor skills.

Training in self-care skills, help with co-ordination and fine motor tasks.

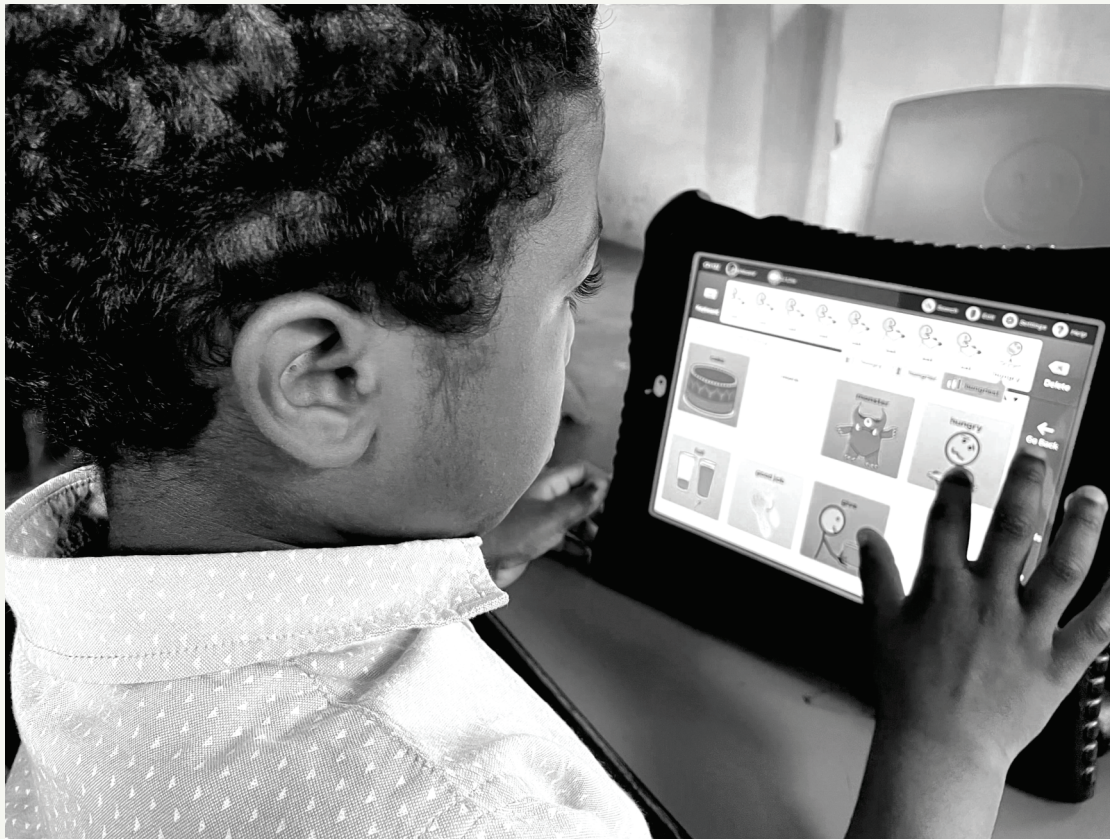
Sensory integration therapy for sensory processing problems.

### Special Educator

Formulating an Individualised Education Program (IEP) Work with teachers to help with the child's education based on individual strengths and challenges.

### Nutritionist

Customised Nutrition and Diet Plans for the child.



**SPEECH THERAPY: PICTURE EXCHANGE COMMUNICATION SYSTEM**



**SPEECH THERAPY: ORAL PROMPT THERAPY**



**SPEECH THERAPY: SIGN LANGUAGE**



**SPEECH THERAPY: AUGMENTATIVE AND ALTERNATIVE COMMUNICATION**



OCCUPATIONAL THERAPY





**SOCIAL SKILLS**





**SPECIAL EDUCATION**



**MUSIC THERAPY**

# What to expect when you meet an autistic person.

## IMPAIRED CONVERSATION SKILLS

The individual may appear to be quiet and introverted or may initiate a conversation with you. They may ask extremely personal questions (e.g., the food you eat, details of where you live, any illnesses that you may have) or might discuss at length issues that interest them like cars, insects, train stations, and bus schedules. They may appear to be disinterested in what you have to say or may reply with an answer that seems unrelated to the topic.

## DIFFICULTIES WITH EMOTIONAL REGULATION

The individual may find it hard to comprehend and subsequently express how they are feeling. They may also find it extremely difficult to understand how you are feeling, based on the context. They may make many errors in judgement when it comes to reading emotions and may not be able to change their behaviour based on the emotional reaction of others. They may also find it difficult to read subtle nonverbal cues or subtle hints given during conversations. If you need a change to be made, please state it directly and respectfully. You may draw out the situation, using simple line drawings and explain to them how you felt in a situation.

## EYE CONTACT AND PERSONAL SPACE

Individuals with ASD may find it hard to look at your face and maintain eye contact while engaged in an interaction. Alternatively, they might hold your gaze for longer than usual. They may also stand very close to you while talking to you or may brush by you as you walk past them. None of these behaviours are done intentionally and are related to their impairments in spatial perception and personal space. Preoccupation with a specific topic or interest will take precedence in all conversations. It may occupy an inordinate amount of their time engaging in these interests.

## TIME MANAGEMENT

My have difficulty organising their time and prioritising.

## MOTOR CONCERNS

Some individuals may appear to be a bit clumsy in their gait. They may swing their arms or take longer steps than others. May have issues climbing stairs or navigating doorways, escalators, and elevators.

## SELF-HELP SKILLS

Some individuals may be very careful with their own belongings and will ensure that a meticulous order is maintained. However, they may have challenges with doing the same with common resources. Please remember that the person is not doing this intentionally and just because they can organise their own possessions well that they are intentionally being disrespectful to common resources. Gentle and repetitive reminders can be very helpful to a person with ASD. showing anger or expecting the person to change in a short period of time will not be a reasonable expectation to keep. It will only result in a sense of frustration and defeat which would be counterproductive.

They may also have challenges with arranging their clothing neatly after using the restrooms. You may find that they are unable to completely tuck their shirt back in or buckle back their belt properly. They may need to be reminded politely to attend to these issues.



## SENSITIVITY TO ENVIRONMENT STIMULI

Some individuals might have increased sensitivity or aversion to certain tastes, smells, sounds or movement. They may avoid stepping into a room where the aversive object is present or may refuse to interact with a person they associate with a particular trait (strong cologne). Others might seek these stimuli and may repetitively smell a certain object, look at their hands or shadows, flick a pencil or small object between their fingers, eat the same food everyday, pace up and down, make sounds, self-talk. Please understand that engaging in these helps the person regulate themselves and brings a sense of calm and order around them. Making the person refrain from engaging in these behaviours will most likely result in an increase in anxiety or a meltdown/outburst.

## ANXIETY

This is a fairly commonly occurring condition in people with Autism. The presence of challenges in language and social comprehension, changes in the environment, loss of predictability, interaction with new people, and unfamiliar places and situations, can cause a lot of anxiety in the individual. They may be unable to identify or articulate the feelings and sensations that they are experiencing. When you notice an increase in somatic complaints like headaches, stomach aches, lack of sleep, digestion-related complaints and nausea it would be good to investigate if the individual is facing any challenges. Identifying any new changes in the work environment, changes in expectations and changes in the home environment would be pertinent and helpful in explaining the somatic symptoms. Refusal to go to school/work, increased/ decreased need for sleep, daytime drowsiness, forgetfulness, seemingly lost in his/her own thoughts. increased/decreased appetite, sweating, increase in self-talk, pacing, and withdrawal from family members may be signs that the person is feeling overwhelmed. Seeking professional help may be required if the challenges persist.

## COMMUNICATION AND SOCIAL RULES

Communication is so much more than spoken words. The ability to read body language, understand tone of voice, comprehending what is sometimes unsaid, understanding emotions and micro changes in facial expressions all constitute communication. Listening intently and responding accordingly can prove to be very challenging for an individual with ASD. People with ASD struggle with all these aspects of communication. You may notice that the communication style of individuals with ASD is mostly based around their areas of interest and needs. They struggle with incorporating these aspects into their own repertoire and so you may notice that they do not use gestures like shrugging shoulders, pointing using common gestures, to add meaning to their speech. They either avoid eye contact when listening/talking to someone or may stare for too long. They may also have difficulty judging personal space.

You may notice that a person with ASD also has difficulty determining essential information and filtering out less important information. They may seem like they are not listening to you or may appear overwhelmed if too much information is presented in one go or if the environment is fairly noisy and loud. This usually leads to an 'overload' of information, making it difficult for any information to be processed.

Noisy and crowded work environments can also affect how much information can be processed. All these factors make it very difficult for the individual with ASD to be understood. It can be incredibly isolating and upsetting when people around tend to misunderstand their behaviour.

Autism isn't  
a disability,  
it's a different  
ability.



# Autism in adulthood.

As individuals with ASD mature into adults, those of whom received consistent intervention and academic input may be able to gain employment when employed in a supportive environment. In order to determine which occupation would be best suited for the individual, an assessment of the individual's strengths and skills must be undertaken. Some strengths that many parents of young adults with ASD report are:

- Attention to detail
- Precision
- Good visual learners and grasp things that have a fixed consequence or a cause-and-effect response
- Goal-oriented
- Strong memory for information presented once or twice. Memory can be dates, routes, maps etc.
- Near zero errors for repetitive tasks
- Attendance and punctuality
- Ability to adhere to rules and follow instructions
- Do not get distracted
- Trustworthy
- Perseverance
- Motivation (for task of interest)
- Loyal
- Pattern recognition

Once there is clarity on what the young person's strengths are, it will be important to see what they naturally enjoy doing and how much support they need to get routine tasks done. This will help determine the kind of job that they are encouraged to seek, the accommodations needed and the level of mentor and support needed at the workplace. If the young person needs intensive support, caregivers may consider sheltered employment opportunities or look at starting businesses wherein they can provide the needed support for the young adults.

Listed below is a non exhaustive list of strengths and possible job opportunities that can be considered:

STRENGTHS	SUITABLE JOBS
High level of concentration Accurate information Attention to detail	Data Entry Operator Code Tester Quality Assurance Analyst
Prefers to work alone Requires a quiet environment	Filing Handcrafts including Wood Carving, Jewellery Making and Stitching
Prefers definite rules	Laboratory Technician Programmer
Does not require social interaction	Data Entry Operator Software Developer
Document/data comparison: cross-checking document versions or data sets to compare changes	Proof-reader Data analyst
Flexible work times	Animator Photographer
Visual thinkers	Graphic Designer Photo/Video Editor
Requires logical thinking	Computer Programmer Software Designer

# Living life to the fullest potential.

Receiving adequate training for the chosen job is as crucial as receiving support to help the individual with ASD understand how to work effectively in a work setting. Providing ongoing support at the workplace by mentors is also imperative. Each individual will have a unique set of accommodations and it is up to the individual, family and workplace to advocate for it. Working in an environment where the person feels valued and accepted can help tremendously with the person's experience of life. As far as possible, independence (or to the extent that is possible for the person) in every aspect of life must be encouraged.

Shared below are examples of young adults with Autism who have overcome their challenges and are working to their best potential. Liya and Rohit are two young adults who enrolled in CADRRE's Employability Training Program for young adults with Autism and received intensive training in life skills, social skills, communication skills and IT skills, to equip them for workplace employment, and after nearly a year of training were placed as paid interns in a renowned IT company.



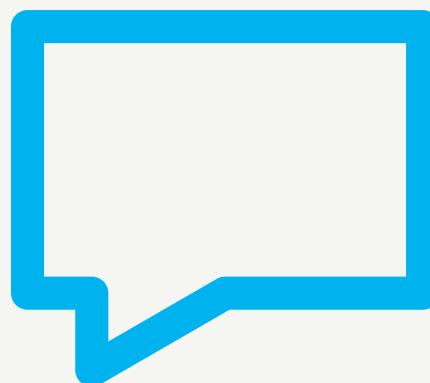
Despite the intensive training that they received, some workplace accommodations were needed for them to be productive and to be able to complete their work efficiently. These are shared with you with the intention that as an autism champion you become aware of the ongoing support that is required throughout a person's lifetime.

**1. Rohit has issues with motor planning and could sometimes barge into other employees' personal space. He was shown many videos demonstrating how to maintain personal space. However, he often found this hard to follow due to his sensory needs. The company that he was employed with provided a separate space for him to be seated. Other individuals with neurodiversity were also encouraged to use the space if it benefited them. Sensitization workshops for all employees including the support staff, security guards, and cafeteria staff were also provided to better educate the workforce about the needs of people on the spectrum.**

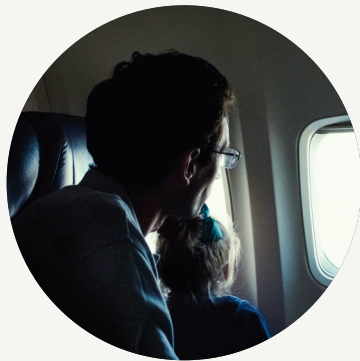
**2. Companies usually expect their employees to do certain tasks on a weekly or monthly basis. For example, filling timesheets for billing purposes every week, booking food coupons prior to the day that they visit the office, etc. Individuals with ASD can find it hard to plan and execute this by themselves. To bring more independence in their functioning, alarms with clear labels were introduced to remind them of the tasks. Initially, verbal prompts from their mentors like "Why is the alarm ringing now?" were asked. Over time, these prompts were reduced and they could independently do this by themselves.**

# Do's and Don'ts while interacting with an autistic child or the family.

Do's	Don'ts
<p>Do talk about their interests. Some children with autism can become fascinated by the endless knowledge from numbers, maps, cars or more.</p>	<p>Don't force or expect the child to pay attention to your area of interest.</p>
<p>Do give the child time to respond. They might need more time to process and understand, especially when someone talks loudly or in a crowded place.</p>	<p>Don't take things too personally. They may have a meltdown or not be able to understand what you are trying to convey.</p>
<p>Do be supportive and encourage to build friendships. Invite them to interact with others without forcing them.</p>	<p>Don't be critical; if you can't say anything nice, just don't say anything at all.</p>
<p>Do make use of kind, socially acceptable language and be as direct as possible. They might process language literally and may not understand jokes.</p>	<p>Don't use creative language such as sarcasm, idioms or exaggeration as it might confuse them.</p>
<p>Do accept their behaviour before staring at them or judging them. Making noises, and flapping hands is not a parenting fault.</p>	<p>Don't document or try to correct their behaviour, instead you can help them to adapt the environment for them to be more functional.</p>
<p>As a parent, Do make sure that you acknowledge the stress and strain that you and your family may be undergoing and do not feel guilty if you need to take some time out to spend by yourself. Looking after your physical and emotional health is equally important.</p>	



# Scenarios to understand persons with Autism.



- A dad is taking a flight with his 6-year autistic daughter. The little girl does not like being buckled down to her seat and throws a tantrum; the dad knows that nothing can soothe his daughter and waits patiently for her to tire herself out before she calms down. Seeing the dad do nothing to quieten his daughter infuriates the passenger sitting in the next seat and he asks him "why don't you discipline your daughter, gag her or something?" The dad almost gets into a physical fight with him. Autism is a hidden disability and to the co-passenger the girl just appeared to be a badly brought up child.



- Raju is a 7-year old autistic boy who loves to play in water. His father decided that they would join swimming lessons. Inside the pool complex, Raju is only comfortable using one particular bathroom that is strategically placed near the entrance and closer to a window. When that specific bathroom is in use or is unavailable, Raju refuses to use any other bathroom. He cries and starts screaming to use the bathroom of his choice which makes on-lookers uncomfortable, especially since his father doesn't rebuke him for his behaviour. His father is embarrassed and other people who come to the pool purposefully avoid them. The child was not 'visibly autistic' and so everyone around them misunderstood the child's behaviour and his father's reaction to it.



- Isha is a 7-year old autistic girl. One day her mother takes her to her office as part of family day celebrations at work. Isha goes to the function where she is initially comfortable. However, Isha is a hyperactive child who requires frequent physical stimulation activities to keep her regulated and to keep her hyperactivity in check. So in some time, she starts running around the room incessantly while laughing loudly. Everyone in the auditorium is visibly disturbed by her behaviour and consider her behaviour awkward and disrespectful. The event coordinator asks her mother to escort her out of the room because of her daughter's unruly behaviour. The mother and the event coordinator get into a huge argument. To a lay person, Isha's behaviour is unruly and disrespectful. However, her autism diagnosis comes with a range of sensory issues which require acceptance from the larger

# FAQs by parents to volunteers.

- **How is ASD diagnosed?** There are no laboratory blood tests, scans, prenatal tests or genetic tests that can be done to confirm a diagnosis of ASD. At present, diagnosis is a result of two general steps: Developmental Screening and a Comprehensive Diagnostic Evaluation.
- **What does a comprehensive diagnostic evaluation entail?** Comprehensive Diagnostic Evaluation is a thorough review of your child's behaviour and overall development. It will look at language skills, regression in skills, cognitive or learning problems, challenging behaviours, and attention span. It may also include a hearing and vision screening, genetic testing, neurological testing, and other medical testing (Centers for Disease and Control, 2015). After fully considering all possible factors, the medical doctor may or may not conclude with a diagnosis of ASD.
- **What kind of professional can help me determine if my child has ASD?** A neurologist, developmental behavioural paediatrician, psychiatrist, developmental psychologist can help you with determining if your child has ASD. Often, the first point of contact may be a speech and language pathologist as many children may show delays in the development of speech and language. A speech and language pathologist may also be able to identify the red flags of ASD and direct you, the parent, to the appropriate professional.
- **What kind of therapists will be involved in the care of my child?** A speech language pathologist, occupational therapists, psychologist/ behaviour therapist, paediatrician/ neurologist, special educators and occasionally nutritionists will be involved in the care of the child.
- **Will my child have autism throughout their life?** Autism does affect a person for the entire duration of their life. The severity of symptoms may vary with age. If a child receives consistent and individually tailored intervention it will significantly help with reducing the severity of the symptoms.
- **Is there a cure for ASD?** No, there is no cure for ASD; however it is extremely important to support the child with therapies for each of their concerns.
- **Is it my fault? Did I do something during pregnancy that caused autism?** Not at all. No causal factors have been identified with the expression of autism. While it is natural to have these thoughts, it is more important to focus on educating yourself about autism and ensure that your child receives help at the earliest.
- **If I have another child, will the child have autism too?** The chances of having a second child with autism are higher when you already have one child with autism, however it is not necessary.
- **Can my child attend regular school?** It depends on the severity of symptoms and the presence of co-morbid conditions like seizures, learning difficulties, self harm that may make learning in a school difficult. the child may need additional support and be able to attend a school. Alternatively you can look for a school with a special needs unit attached to it or a special needs school that also caters to the therapeutic needs of the child.
- **I have heard there are medicines to help induce speech in my child. Is there any credibility in this information?** Medical intervention can help manage symptoms of comorbid conditions like difficulties with attention, hyperactivity, self harm but specific medicines that claim to induce speech must be looked into carefully. It may also be beneficial to get a second or third opinion from a trusted and licensed medical practitioner.
- **Will my child be able to lead a 'normal' life, i.e get a job, live on their own?** It depends on the severity of symptoms that the individual experiences, the level of ongoing support they have, and the skills they have acquired. An individual may be able to gain employment, launch a business with assistance, and live independently. If their strengths are identified early and they are taught to manage the challenges they experience. Independence in all facets of life must be encouraged from a young age.

- **Are alternative medicines (homoeopathy, ayurveda) helpful for Autism?** There is no cure for Autism in any form of medicine. Anecdotal evidence for the efficacy and limited gains exist. However, parents must exercise extreme caution while giving their child any medicines. If any side effects or exacerbation of symptoms are noticed, do meet your child's paediatrician at the earliest. Also, remember to consult only licensed practitioners.
- **What skill should I focus on the most?** Observe your child and when you notice that your child has a special interest or aptitude, try and encourage it. Be careful not to overdo it as the child may feel pressured and give it up entirely. It is important to remember that children may show an aptitude in a certain area (e.g. drawing) but after a while may give it up completely. This is very normal- try and encourage your child to take up some other hand work like craft, sewing, crochet that taps into their artistic abilities but gives them an avenue to express themselves through another medium. Giving the child opportunities to try new things and working on it consistently for a while is the key in being able to identify a strength.
- **Should I stop my child from flapping/ jumping/ pacing/ making repetitive finger movements/rocking back and forth?** These unusual physical mannerisms are their responses or methods of coping with their stress, anxiety or sensory difficulties. So these behaviours help them relax or feel calm in their mind. You do not have to stop them from these behaviours, instead you can give them a lot of physical activities in a stress free environment and time to relax after that. You can redirect the child to show a more appropriate way of coping with stress as they grow older.
- **My child doesn't like writing. What can I do to help?** Children with Autism often have difficulties in fine motor skills and coordinated movement. This is because the area in the brain that helps in coordinating the movement is affected among most of the children with ASD. It is not because they have some issues in their hands or they don't like writing. There are many activities to improve the way of holding a pencil and practising writing. These activities focus on improving the muscle strength, eye-hand coordination, bilateral coordination, dexterity and isolated finger movements which are necessary for writing. An occupational therapist can guide you in detail about the exercises and activities.
- **My child doesn't speak. How can I help him/her?** It is important to get your child evaluated by a speech language pathologist. They will be able to help you ascertain the areas that need attention. With regular sessions and home training your child will make gains in language/ communication.
- **I had similar concerns as a child (spoke late, preferred to be on my own) but I outgrew it as I grew older. I never went for therapy, so why should I take my child for therapy? Will he catch up as he grows older?** Speech delay or no speech is just one of the characteristics of autism. Apart from speech delay there are other symptoms to be diagnosed as ASD. Some children may speak at the right age, but they may have a monotonous, or robotic voice, with a tendency to keep saying things repeatedly in the same manner. In some cases, there will be a loss of speech. So it is difficult to predict that the child may speak later in life and it is important to identify it early by a professional and provide necessary intervention at the right time.

In case you suspect  
a child has Autism,  
talk to their  
caregivers and call  
**18002099488**  
for support.



## INFORMATION WHICH CAN HELP PARENTS

Parents should be encouraged to:

- Connect with other families whose children have been diagnosed with Autism. It helps create a community, share resources and address concerns that a newly diagnosed family may have.
- Inform themselves about Autism and the various therapies available.
- Find out about local ASD resources that are accessible, reliable and are licensed to practice.
- Take care of themselves and learn to identify early signs of stress. Seeking help and managing ongoing stress is extremely important in this journey.



Scan to join the  
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and  
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Maya Angelou





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