

# **Autism Guide**

Venu GVGK

2024-09-24

# Table of contents

<b>1</b>	<b>Autism Spectrum Disorder</b>	<b>7</b>
<b>2</b>	<b>An Overview of Autism</b>	<b>8</b>
2.1	The onset of Autism . . . . .	8
2.2	Why is this happening? How to deal with this? . . . . .	9
2.3	What does it mean for the parents, the child and family? . . . . .	9
2.4	What is the way forward? . . . . .	9
2.5	How does schooling and education work? . . . . .	10
2.6	Challenges people on the spectrum and families face as they grow up . . . . .	10
2.7	How is life as an adult on the autism spectrum? . . . . .	11
<b>3</b>	<b>Identification and Causes</b>	<b>12</b>
3.1	Identification . . . . .	12
3.1.1	Delay in developmental milestones . . . . .	12
3.1.2	Communication difficulties . . . . .	13
3.1.3	Restricted or repetitive behaviors and interests . . . . .	13
3.1.4	Other Characteristics . . . . .	14
3.2	How common is autism? . . . . .	14
3.3	What causes autism? . . . . .	15
3.3.1	Genetic Factors . . . . .	16
3.3.2	Environmental Factors . . . . .	16
3.4	Do vaccines cause autism? . . . . .	17
3.4.1	Origin of the vaccine connection . . . . .	17
3.4.2	Debunking the theory . . . . .	18
3.5	Timeline of Causes of Autism . . . . .	18
3.6	What does not cause autism? . . . . .	19
3.6.1	Bad parenting . . . . .	19
3.6.2	Vaccines . . . . .	20
3.6.3	Screen time . . . . .	20
3.6.4	Lack of social interaction . . . . .	20
3.6.5	Interaction with people on the spectrum . . . . .	20
<b>4</b>	<b>A short history of autism</b>	<b>22</b>
4.1	Autism – Initial definition and refrigerator mother hypothesis . . . . .	23
4.1.1	Leo Kanner – Psychogenic theories - 1941 . . . . .	23

4.2	Bernard Rimland – Autism as a neurological condition - 1964 . . . . .	24
4.3	Behavioral Approaches – Foundations of ABA . . . . .	24
4.4	Ivar Lovaas – Applied Behavior Analysis - 1965 . . . . .	24
4.5	Study of autism in twins – Investigating genetic origins - 1977 . . . . .	25
4.6	Autism Appears in DSM III - 1980 . . . . .	26
4.7	‘Discovery’ of Asperger’s Syndrome and Autism as a spectrum - 1981 . . . . .	26
4.8	Hans Asperger – the other end – 1944 . . . . .	27
4.9	The mystery of Asperger – Kanner Connection . . . . .	28
4.10	Lorna Wing – Bringing the ends together . . . . .	28
4.11	Autism in Adults – Temple Grandin – 1986 . . . . .	29
4.12	Emergence of neurodiversity paradigm-1990s . . . . .	29
4.13	Another step back – Autism Vaccine connection – 1998-2010 . . . . .	30
4.14	An old, yet modern take on autism 2013 . . . . .	31
4.15	Grunya Sukhareva – overlooked pioneer – 1925 . . . . .	32
4.16	Current understanding – 2024 . . . . .	32
<b>5</b>	<b>People’s Perspectives</b>	<b>34</b>
5.1	Parents of teenagers in a community learning space . . . . .	34
5.2	Profiles . . . . .	34
5.3	Early signs and diagnosis . . . . .	35
5.4	Just after diagnosis . . . . .	36
5.5	Initial steps and alternatives . . . . .	37
5.6	Initial sources of information . . . . .	39
5.7	Early intervention choices and impact . . . . .	39
5.8	Moving on from early intervention . . . . .	41
5.9	After early intervention . . . . .	41
5.10	Managing self and family . . . . .	42
5.11	Future - Hopes and apprehensions . . . . .	43
5.12	Advice for new parents . . . . .	44
<b>6</b>	<b>Getting a diagnosis</b>	<b>45</b>
6.1	The importance of diagnosis . . . . .	45
6.2	When should parents go for screening and diagnosis? . . . . .	45
6.3	Diagnostic Process . . . . .	46
6.3.1	Developmental Screening . . . . .	46
6.3.2	Screening Instruments . . . . .	46
6.3.3	Screening outcomes and diagnosis . . . . .	47
6.4	Next steps . . . . .	47
6.5	Screening and Diagnosis - A note for professionals . . . . .	47
6.5.1	General signs . . . . .	47
6.5.2	Communication . . . . .	48
6.5.3	Unusual interests or behaviours . . . . .	48
6.5.4	Other Characteristics . . . . .	49

6.6	Screening tools . . . . .	49
6.6.1	M-CHAT-R/F (Modified Checklist for Autism in Toddlers, Revised with Follow-Up) . . . . .	49
6.6.2	Occupational Therapy Evaluation . . . . .	50
6.6.3	Speech and Language Evaluation . . . . .	50
6.7	Diagnostic tools . . . . .	50
6.7.1	CARS - Childhood Rating Scale . . . . .	51
6.7.2	Autism Diagnostic Observation Schedule (ADOS) - (ADOS; Lord, Rutter, DiLavore, Risi, 1999) . . . . .	51
6.7.3	Autism Diagnostic Interview, Revised (ADI-R) - (ADI-R; Couteur, Lord, Rutter, 2003) . . . . .	52
6.8	Revealing the diagnosis to parents . . . . .	53
6.9	Diagnosis for adults . . . . .	54
6.9.1	Signs to look out for . . . . .	55
6.9.2	Diagnostic tools . . . . .	55
<b>7</b>	<b>Just Diagnosed - Next Steps for parents</b>	<b>57</b>
7.1	A few key questions . . . . .	58
7.1.1	Preschool versus therapies . . . . .	58
7.1.2	School readiness . . . . .	58
<b>8</b>	<b>Early Intervention</b>	<b>60</b>
8.1	Early Intervention Goals . . . . .	60
8.2	Communication Goals . . . . .	60
8.3	Social Goals . . . . .	61
8.4	Physical Goals . . . . .	61
8.5	Sensory Goals . . . . .	61
8.6	Behavioral and Emotional Goals . . . . .	62
8.7	Key Focus . . . . .	62
8.8	Choosing therapies . . . . .	63
8.8.1	A few guidelines . . . . .	63
8.9	Choosing a service provider . . . . .	64
8.9.1	Multifunctional Approach . . . . .	64
8.9.2	Family Centred . . . . .	65
8.9.3	Assessments and plans . . . . .	65
8.9.4	Clear communication . . . . .	65
8.9.5	Respect and dignity . . . . .	65
8.9.6	Training and qualifications . . . . .	66
8.9.7	References and history . . . . .	66
8.10	Autism, Speech and Communication . . . . .	66
8.10.1	Communication is not just speech . . . . .	66
8.10.2	Looking beyond speech - AAC . . . . .	67

8.11	Speech Therapy is not just about speech . . . . .	67
8.11.1	Functions of Speech Therapists . . . . .	68
8.11.2	Choosing an SLP . . . . .	69
8.12	Occupational Therapy . . . . .	69
8.12.1	Sensory Processing and Occupational Therapy . . . . .	70
8.12.2	Different sensory profiles . . . . .	71
8.12.3	Working with sensory processing . . . . .	71
8.12.4	Sensory Integration Therapy . . . . .	72
8.12.5	Sensory Circuits . . . . .	72
8.13	Beyond the five senses . . . . .	72
8.13.1	Proprioception . . . . .	73
8.13.2	Interoception . . . . .	73
8.13.3	Vestibular system . . . . .	73
<b>9</b>	<b>Caution: Cures and Remedies</b>	<b>75</b>
9.1	Why do people seek alternative treatments? . . . . .	75
9.1.1	Newly discovered conditions . . . . .	75
9.1.2	Seeking better results with less effort . . . . .	76
9.1.3	Inability to critically evaluate . . . . .	76
9.2	The case of autism . . . . .	76
9.3	Caution: Alternative approaches . . . . .	77
9.4	When to be critical . . . . .	77
9.5	A guide to decision making . . . . .	77
9.6	Chelation - A Dangerous approach . . . . .	78
9.6.1	What is chelation? . . . . .	78
9.6.2	History of chelation . . . . .	78
9.6.3	Why was Chelation tried for autism? . . . . .	79
9.6.4	Caution . . . . .	79
9.7	Miracle Mineral Solution (MMS) . . . . .	80
9.7.1	MMS and Autism . . . . .	80
9.7.2	History . . . . .	80
9.7.3	Caution: . . . . .	81
9.8	Stem Cell Therapy . . . . .	82
9.8.1	What are stem cells? . . . . .	82
9.8.2	What is stem cell therapy? . . . . .	83
9.8.3	History of stem cell therapy . . . . .	83
9.8.4	Why was it tried for autism? . . . . .	84
9.8.5	Caution . . . . .	84
9.8.6	Current status in India . . . . .	85
9.9	Hyperbaric Oxygen Therapy (HBOT) . . . . .	86
9.9.1	History of HBOT . . . . .	86
9.9.2	Why was HBOT used for autism? . . . . .	88
9.9.3	Caution . . . . .	88

9.10	Restrictive Diets . . . . .	89
9.10.1	Diet - Autism Connection . . . . .	90
9.10.2	History of diet as therapy . . . . .	90
9.10.3	Types of diets for autism . . . . .	92
9.10.4	Caution . . . . .	93
9.11	Homeopathy . . . . .	94
9.11.1	History of homeopathy . . . . .	95
9.11.2	Why homeopathy for autism? . . . . .	96
9.11.3	The Process of homeopathy for autism . . . . .	97
9.11.4	Caution . . . . .	97
9.12	Ayurveda . . . . .	98
9.12.1	Ayurveda and Autism . . . . .	99
9.12.2	History of Ayurveda . . . . .	100
9.12.3	Caution . . . . .	102
<b>10</b>	<b>Education &amp; Schooling</b>	<b>104</b>
10.1	Early Intervention vs Schooling . . . . .	105
10.2	Goals of Education . . . . .	105
10.3	Schooling issues . . . . .	105
10.4	A few options . . . . .	105
10.5	Pushing children through mainstream school . . . . .	105
10.6	Inclusive Schools . . . . .	105
10.7	Homeschooling . . . . .	105
10.8	A mix of approaches . . . . .	105
<b>11</b>	<b>Finding Work, Keeping It</b>	<b>106</b>
<b>12</b>	<b>Adulting on the Spectrum</b>	<b>107</b>
	<b>References</b>	<b>108</b>

# 1 Autism Spectrum Disorder

This guide deals with autism and various aspects of living with it.

We start with an overview of autism outlining the entire autism lifecycle as a precursor. Then we discuss how to identify autism, how common it is, what causes and what does not cause autism.

In the next section, we outline a history of autism, starting from early definitions and trace the path down to various developments in understanding and dealing with autism.

We then present perspectives of people living with autism, including people on the spectrum, families living with autism, medical professionals, and social workers. We attempt to cover the lifecycle of autism by including perspectives from different age groups.

In the next section, we address the diagnosis process starting from the need to diagnosis to the actual process of getting a diagnosis. We also include diagnosis for older people.

In the next two sections, we outline the immediate steps a family can take when they receive a diagnosis and proceed to explore various approaches to early intervention.

We then strike a cautionary note as we talk about alternative approaches to autism that are consider ineffective and sometimes, dangerous. This is done to ensure we provide all the necessary information.

We then proceed to education and schooling where we examine the goals and approaches to education and schooling in the Indian context.

The next section covers employment where we outline how people on the spectrum can train for work. We also provide some resources that can help them find and keep work.

The final section deals with being an adult on the spectrum.

## 2 An Overview of Autism

Autism spectrum disorder (ASD) is a way to talk about a group of complex brain-related conditions. These conditions can make it harder for people to communicate and behave in typical ways. In other words, it affects how they talk, interact with others, and act in various situations. Autism is called a “spectrum” since ASD can affect people differently, with some individuals experiencing milder challenges and others more significant ones. There are a range of possibilities, with each person’s experience being unique.

### 2.1 The onset of Autism

Autism in children usually becomes noticeable around the age of 2 to 3 years, all though with increasing awareness, early identification is becoming more common these days.

Parents initially start noticing differences in the way the child plays, communicates and responds to the environment. Many children do not respond to their name or make eye contact. They may not use any words or stop using the few words they have been using till then. They may not be interested in the usual things other children are interested in. They may seem to be obsessed with some unusual ways of occupying themselves like watching fans go round and round, flapping their hands, rocking themselves, singing to themselves constantly, lining up play things etc.

Children often show unusual amounts of distress when they are disturbed or they need to go from one activity to the other. They appear preoccupied and may not notice the presence of other children or adults around them. Parents typically struggle to understand why the child is in constant distress. The child appears adamant, uncommunicative and becomes unmanageable.

Usually this is the time when parents seek help from medical professionals. Pediatricians refer children to developmental pediatricians or developmental psychologists. The child may initially be identified to have a developmental delay and eventually handed a diagnosis of being on the Autism Spectrum.



## **2.2 Why is this happening? How to deal with this?**

Currently, we do not know the exact cause of autism, though the research points to a variety of factors – genetic, biological and environmental - contributing to it. Since autism is caused by a variety of factors working together, and currently we do not understand which specific factors are working together in which specific ways to cause autism, there is no medical way to “cure” autism. However, with the help of various therapies, many people on the spectrum can learn to manage autism to a large extent, and with the help of caregivers, lead fulfilling lives.

## **2.3 What does it mean for the parents, the child and family?**

The immediate implication of autism diagnosis for the parents is that they need to rethink their ideas of parenting and their expectations of the child. Children on the spectrum may have various neurological and physiological differences that cause them to experience the world very differently from other people. Parents need to be willing to learn about their child and how autism impacts them. They need to be open to learning about various therapies and educational approaches in order to learn to manage themselves and the child.

In the Indian context, where support from public institutions may be limited, a diagnosis of autism for the child may require the parents to radically rethink their lifestyle and goals. They may need to plan their lives such that one of the parents spends time with the child and coordinates with the doctors, therapists, school and other people who interact with the child.

## **2.4 What is the way forward?**

Once there is a diagnosis, the next thing to do is to think of various ways to start working with the child. This usually takes the form of therapies - behavior therapies to start learning to understand and manage the general behavior of the child; speech and language therapy to start a channel of communication; occupational therapy or physical activities to help the child with physical regulation. The specific things that are done in each of the therapies depend on the specific challenges and needs of the child.

Whichever of these therapies are chosen, one needs to ensure the therapies are aimed at making life easier for the child and the family. Over a period of time, the therapies are supposed to build the skills and competencies of the child, show the family how to work with the child, and over all, add to the quality of life of the family.

It also helps if parents continue to be involved in the therapies, understand the processes and learn the basic approaches, so that the child gets the same support whenever s/he needs it.

## **2.5 How does schooling and education work?**

Schooling and educational needs may vary according to the child's capabilities, difficulties, needs and interests. Thus, it is important to first develop an Individualised Education Plan (IEP) for the child based on his/her strengths and difficulties. The IEP generally takes into account the strengths and difficulties of the child, as seen by different people working with the child - parents, therapists, teachers etc. - and outlines a plan to equip the child with required competencies.

Depending on the specific needs of the child, a child may go on to a mainstream school with accommodations or go to a special school. Some children may need additional help. Homeschooling may also be an option in some cases.

## **2.6 Challenges people on the spectrum and families face as they grow up**

The challenge with autism is that it is a spectrum condition, meaning it shows up in different ways in different people. The symptoms of autism may occur together or separately, with varying degrees of severity. This makes it difficult to characterize autism in a single uniform way. As they say, everyone's autism is different and if you have seen one person with autism, you have only seen one person with autism.

For example, autism can cause severe coordination issues making a person unable to coordinate physical movements, leading to severe limitations in moving around, speaking and other motor planning activities. Autism may occur along with other neurological conditions like epilepsy. It can come along with conditions like anxiety, intellectual impairment, clinical depression, etc.

Each of these difficulties may need to be addressed in specific ways. Finding these therapies and educational approaches, paying for them and practicing them may become overwhelming for the family. There is also a social aspect to this - the family may not have much time and energy to socialize and may also face some social resistance.

One of the significant issues a family faces as the child grows up is to be able to continue to understand, relate to and work with the person he/she is becoming. Another difficulty is to find people and institutions that can provide help and support as the person grows up to be a young adult. In India, most therapy centers work with young children up to 8-10 years of age. Most schools - either mainstream or special - expect 16 year olds to graduate and go out. There are very few institutions that provide meaningful alternatives and support beyond the teenage years.

## **2.7 How is life as an adult on the autism spectrum?**

Children with autism grow up to be adults with autism. While they do learn to manage their autism and be able to deal with the world in their own different ways, they will continue to have autism and may also need to have continued support.

When one looks at the variety of difficulties, their varying levels and the different combinations they occur in, it stands to reason that there is a spectrum of outcomes as children grow up into adults. Some children grow up to be adults that need to depend on caregivers for basic health, hygiene and safety. Some children grow up to be adults that may be able to manage their own in controlled settings like homes and sheltered work spaces. Some children grow up to be able to physically manage themselves but may need continued emotional support to deal with the anxiety of being different from everyone else. A few children grow up to be able to manage like everyone else.

At present, the support and employment opportunities for autistic adults in India are still evolving and will need significant strengthening as we go forward.

## 3 Identification and Causes

Autism is a neurodevelopmental condition and the most effective way to work with autism is through a set of therapies. This makes early identification and intervention very important for autism.

However, autism is a spectrum condition, so the symptoms may vary in type and severity from child to child. In addition, since each child develops in his/her own way, some early signs of autism look like they are part of the natural development of the child. Also, Indian families often tend to think that speaking a little late, being a little unresponsive, is nothing to worry about. One often hears things like “oh, his father spoke at three, look he is all fine now!” and “boys start speaking late anyway”.

All of this makes early identification and action difficult for parents. Other family members and friends tend to keep their peace till the child is older. Most medical professionals may also advise a wait and watch approach.

While autism can look different in different children, the most common areas of difficulty are communication and interaction with others. Signs of autism can be noticed when the children are around 2-3 years of age or even earlier. Parents and caregivers may watch for these signs.

### 3.1 Identification

When you notice any of the following signs in the children around you, it is useful to consult a developmental psychologist or a developmental pediatrician at the earliest. It is possible that these signs do not mean autism, but if they do, then you would have identified the issues a little earlier and started the intervention, thereby helping the child enormously.

#### 3.1.1 Delay in developmental milestones

Children with Autism may show some early signs of being on the spectrum, such as missing certain developmental milestones / age-appropriate behavior (these vary for each child). For example, the child:

- Does not respond to name by 9 months of age
- Does not show facial expressions like happy, sad, angry, and surprised by 9 months of age

- Does not play simple interactive games like pat-a-cake by 12 months of age
- Uses few or no gestures by 12 months of age (for example, does not wave goodbye)
- Does not share interests with others by 15 months of age (for example, shows you an object that they like)
- Does not point to show you something interesting by 18 months of age
- Does not notice when others are hurt or upset by 24 months of age
- Does not notice other children and join them in play by 36 months of age
- Does not pretend to be something else, like a teacher or superhero, during play by 48 months of age
- Does not sing, dance, or act for you by 60 months of age

### **3.1.2 Communication difficulties**

About 40% of kids with autism spectrum disorders don't talk at all, and between 25% and 30% develop some language skills during infancy but then lose them later. Some children with ASD start talking later in life.

Most have some problems with communication, including:

- Does not give or sustain eye contact
- Delayed speech and language skills
- Flat, robotic speaking voice, or singsong voice
- Echolalia (repeating the same phrase over and over)
- Problems with pronouns (saying "you" instead of "I," for example)
- Not using or rarely using common gestures (pointing or waving), and not responding to them
- Inability to stay on topic when talking or answering questions
- Not recognizing sarcasm or joking
- Trouble expressing needs and emotions
- Not getting signals from body language, tone of voice, and expressions

### **3.1.3 Restricted or repetitive behaviors and interests**

People with ASD have behaviors or interests that can seem unusual. These behaviors or interests set ASD apart from conditions defined by problems with social communication and interaction only.

Examples of restricted or repetitive behaviors and interests related to ASD can include

- Lines up toys or other objects and gets upset when order is changed
- Plays with toys the same way every time
- Is focused on parts of objects (for example, wheels)
- Gets upset by minor changes

- Has obsessive interests
- Must follow certain routines
- Flaps hands, rocks body, or spins self in circles
- Has unusual reactions to the way things sound, smell, taste, look, or feel
- Fussy eating habits
- Lack of coordination, clumsiness
- Impulsiveness (acting without thinking)
- Aggressive behavior, both with self and others
- Short attention span

### **3.1.4 Other Characteristics**

Most people with ASD have other related characteristics. These might include

- Delayed movement skills
- Delayed cognitive or learning skills
- Hyperactive, impulsive, and/or inattentive behavior
- Epilepsy or seizure disorder
- Unusual eating and sleeping habits
- Gastrointestinal issues (for example, constipation)
- Unusual mood or emotional reactions
- Anxiety, stress, or excessive worry
- Lack of fear or more fear than expected

## **3.2 How common is autism?**

When parents are told that their child has or is at risk of autism, their first reaction is shock and then disbelief. They often think “how can this happen to us?” and then go on to “why is this happening to us?” Most people spend about six months to one year trying to make sense of it. They try to rationalize the symptoms; they hope the diagnosis is not correct and that the child will achieve the milestones in another year and things will then be alright.

People seem to believe autism is a rare condition and most people haven’t heard of it before. However, the actual prevalence numbers tell a different story. The highest prevalence numbers come from the Autism and Developmental Disabilities Monitoring (ADDM) Network of the Center for Disease Control (CDC) in the US. According to their 2020 estimates, 1 in 36 children aged 8 were on the autism spectrum - that is about 3 children per hundred. In the same year, CDC estimated the prevalence of autism in adults at about 2.21% - that is about 2 persons per hundred. The World Health Organization has a lower estimate of about 1 in 100 worldwide, based on a review of about 71 studies across the world from 2012-21.

The prevalence numbers for India are not reliably available but the scientific community agrees that the biochemical pathways involved in core autism are unlikely to be different in different populations. This means that the prevalence of autism in India is likely to be closer to the worldwide estimates of about 1 to 3 people per hundred. This means about 1.3 - 1.5 crores of people on the autism spectrum, which is very significant.

What do these prevalence numbers mean? It means we need more awareness about autism because it is not as rare as people believe. We need more awareness in new parents and to-be parents so we are all better prepared. It means we need more facilities, resources and a coordinated action plan for autism in place of the current status where the responsibility is with individual parents.

There is another thing that comes to mind - World Health Organization estimates about 1 in 6 people across the world experience a 'significant disability' - that is about 16% of the population, numbering about 1.3 billion people. CDC also reports that about 1 in 6 (16%) children aged 3-17 years were diagnosed with a developmental disability in the study period of 2009-17. However, those of us who do not have any disability continue to believe that disabilities are rare, we ignore how common they are and continue to build a world that excludes those with disabilities. That way, people living with disabilities are one of the largest voiceless minorities in the world.

In such a world, it is no wonder that people go on without awareness of the incidence of disabilities, they are not educated about the possibility of a disability in their children, and are shocked and surprised when something like autism shows up at their doorstep.

These prevalence numbers should make us all aware of the size of the issue, jolt us out of the ignorance and get us started on the path of building more awareness, being more empathetic and inclusive in our daily lives.

### **3.3 What causes autism?**

Most families first respond emotionally when they are told that their child is on the autism spectrum. Some go through denial; others are sad or furious. Soon, emotions give way to questions and one of these questions is - "What caused my child's autism?" Parents often ask themselves what they could have done differently. Another thought is that if we know what causes autism, maybe we can "cure" it. Some parents also ask this question as they plan to have another child and wonder about the risk of the other child also having autism.

The truth is, we do not really know the specific causes of autism. Therefore, it follows that there is no way any parent could have done anything different so their child would not have had autism. Also, since we do not understand what exactly causes autism and how different factors work together, currently there is no way to "cure" it. However, the information we have from current studies indicates that if one child in a family has autism, there is a higher chance of having another child with autism.

What we know about causes of autism is that there are a variety of factors - “a spectrum of causes” - behind the occurrence of autism, including genetic and environmental factors.

### 3.3.1 Genetic Factors

Genetics plays a large role in the incidence of autism, as evidenced by a 2019 study of more than 2 million people across five countries, which estimated ASD’s heritability to be approximately 80%.

The role of genetics is also indicated by the concordance rate (both of two siblings having autism). In siblings, who share 50% of their genes, the occurrence of autism in both the siblings (the concordance rate) is 20%. Similarly, in fraternal twins, who share 50% of genes and grow in the same womb, the concordance rate is 31%. However, genetics are not the only causal factor - this is evidenced by the concordance rate of 77% even in identical twins, who share 100% of their genes, and grow in the same womb.

Here is a TED talk by Wendy Chung where she talks about genetic factors in autism.

<https://www.youtube.com/embed/wKlMcLTqRLs?si=FU5z2Jgf68XVavao>

Genetics play a large role does not mean autism runs in the family. Certain individuals have it brand new because of mutations in the sperm or egg at the time of conception which are not passed down. Also, while we know genetics play a large role, the current studies do not provide information on what genes are involved, or even if it is a combination of genes. Furthermore, A study by Simons Foundation found that the genetic changes/ alterations were different for different individuals even among a population of 2600 that had brand new autism - this means there is not 1 gene, but about 300-400 genes (that are not random, but fit together in a pathway/ network) causing autism - possibly why there is such a wide spectrum of autism.

### 3.3.2 Environmental Factors

A variety of environmental factors have been examined for their contribution to autism. While there are studies that have found correlation between some environmental factors and the incidence of autism, it is important to note that the research is in early stages. The evidence for some of these factors is strong and for some, it is confusing or weak. While we know some of these factors play a role, we do not know how exactly how that role works. In addition, some factors like air pollution are so generic and so widespread that there is little anyone can do about them. So, while we know in general that there are a variety of environmental factors, we do not have a single, actionable, point that can make a significant difference.

Some of the environmental factors that have a strong to moderate current evidence are:



- the use of certain medications during pregnancy - Valproic acid (given for epilepsy), Selective Serotonin Reuptake Inhibitors (Used to treat depression)
- extremely preterm birth and low birth weight
- Older parental age at the time of conception
- Bacterial and viral infections in the mother while pregnant
- Maternal autoimmunity

As of now, we do not exactly know what causes autism. There is much research being conducted on both genetic and environmental causes and the early results are promising. However, if a family has a child on the spectrum now, it might be more important to ask what can help the child rather than what causes autism, since the second question is unlikely to be answered in the near future in a definite way that can change the current ways of managing autism.

## 3.4 Do vaccines cause autism?

If you are remotely connected to autism, it is highly likely you have come across this question before. The answer is, no, vaccines do not cause autism. This theory was proposed in 1998, has been thoroughly investigated and conclusively proven to be false by 2010. What contributes to its widespread popularity and longevity?

### 3.4.1 Origin of the vaccine connection

In 1998, a physician by the name Andrew Wakefield made this claim in a paper published in the medical journal Lancet. During that time, the two most popular candidates for the cause of autism were refrigerator parenting and genetics/neurobiology. Wakefield looked at 12 children who were developing normally until the administration of the Measles, Mumps, and Rubella (MMR) vaccine and started exhibiting autistic symptoms shortly after. He believed that the vaccine affected the large intestine and assumed that neurotoxic proteins released through the intestine reached the bloodstream and brain, causing autism. His belief was strengthened when all the children he performed colonoscopies on exhibited the lesions.

The theory made sense as autism symptoms in children started to appear around the same time as the vaccine administration i.e. 12 to 15 months of age. “It was after the vaccine that my child stopped talking/ started behaving this way” is a common refrain one hears even today. The theory also gained popularity with parents as it took away the burden of blame from them. Autism cases were increasing rapidly, people were looking for a cause, and this plausible theory gained credence.

### 3.4.2 Debunking the theory

The vaccine link looked obvious and was convenient but other researchers were unable to replicate the findings. Also, considering the diversity of how autism presents itself, a common biological cause looked unlikely to the scientists. In 2005, an investigative reporter alerted the editors at Lancet that Wakefield's study had been flawed by severe research misconduct, conflict of interests, and falsehood.

After investigating the matter, Lancet retracted the article, and the British Medical Association took disciplinary actions against Wakefield. Since then, any direct connection between autism and the MMR vaccine has been discredited by dozens of studies investigating the roots of autism and the biological effects of MMR and the mumps virus. Also, even as more parents were opting out of MMR vaccination, the rates of autism had been rising.

Soon after, there was a suspicion about another autism-vaccine link. It was suspected that thimerosal, added to vaccines as a preservative, could cause autism. Thimerosal contains mercury, a poison, but there was no evidence that the small amount was harmful. To see if thimerosal was linked to autism, researchers studied children who received vaccines that contained it. They compared them to kids who received vaccines that did not contain thimerosal and did not find significant differences in the rates of autism. Even then, thimerosal was taken out of most vaccines.

Since 2003, there have been nine studies funded or conducted by CDC (Center for Disease Control) that have found no link between thimerosal-containing vaccines and ASD (autism spectrum disorder). These studies also found no link between the MMR vaccine and ASD in children.

Researchers have also looked to see if all the vaccines required before age 2 together somehow triggered autism. Children receive 25 shots in the first 15 months of life. Some people feared that getting all those shots so early in life could lead to the development of autism but there is no evidence that this is true. The CDC compared groups of children who received vaccines on the recommended schedule and those whose vaccines were delayed or did not get them at all. There was no difference in the autism rate between these groups.

Thus, through these several scientific studies, it has been concluded that there is no evident link between vaccines and autism.

## 3.5 Timeline of Causes of Autism

1949 - Kanner proclaims his theory that autism is caused by “refrigerator mother”, a term used to describe parents who are cold and detached.

1964 - Refrigerator mother theory challenged with possible neurological factors (Rimland)

1967 - Refrigerator mother theory reinforced through the “Empty Fortress” book

1977 - First study of twins and autism- Genetics as important risk factor

1998 - Andrew Wakefield claims MMR Vaccine triggers autism

2010 - Andrew Wakefield’s paper retracted, barred from practicing medicine, and loses medical license.

Autism research continues and so far, scientists have identified around 100 different genes and certain environmental factors that could contribute to the possibility of autism.

## **3.6 What does not cause autism?**

There are a lot of misconceptions around autism. Very often parents are blamed, or parents go ahead and blame themselves for the child’s autism. They may think that their parenting is responsible for the child’s autism or in the Indian context, they are likely to blame it on themselves and their bad ‘karma.’ This blame and guilt often push the parents into denial about the child’s autism or into depression believing there is something wrong with themselves. All of this is unnecessary and is only likely to waste precious time that can be better spent on working with children.

Similarly, some parents believe that the child’s autism is not really autism, but a set of mild symptoms caused either by too much screen time, or due to lack of social interaction in nuclear families, or because the child has spent time around other children who have autism. Under this belief and the fear of the burden of autism, parents again waste precious time trying to take temporary measures like sending the child to a school to increase social interaction, leaving the children with grandparents, sending them to preschool etc.

As we understand, autism research is still young, and we do not have a complete understanding of what exactly causes autism. As of now, what is clear is that a combination of several factors (genetics, parental age at the time of conception, other environmental factors- link to “what causes autism”) may cause autism and we have some clarity on what does not cause autism. The following are some factors that were identified as “causes of autism” earlier but have been ruled out through thorough research.

### **3.6.1 Bad parenting**

It was once believed that “refrigerator mothers” meaning cold, uncaring, and emotionally unavailable mothers caused autism in children. Later, by the early 1970s, this cause was studied further, and the theory of refrigerator mothers was disproved.

### **3.6.2 Vaccines**

One of the most prevalent myths among causes of autism is that vaccines, especially the Measle, Mumps, and Rubella (MMR) and the mercury containing vaccines cause autism. This claim has been investigated thoroughly and no link between vaccines and autism has been found. See Section [3.4](#) for more.

### **3.6.3 Screen time**

It has been noticed that some children develop autism-like symptoms due to increased screen exposure before 3 years of age. Some studies suggest that increased screen time is associated with melanopsin-expressing neurons and decreasing gamma-aminobutyric acid (GABA) neurotransmitter, and thus results in deviant behavior, decreased cognitive, and language development. This has been termed virtual autism.

While the symptoms are similar, and virtual autism may be diagnosed as autism, these are two different conditions. Autism spectrum disorder (ASD) is a neurodevelopmental condition with genetic links and is thus present lifelong. On the other hand, virtual autism has a definite cause, which is excessive screen exposure at an early age/ Intensive Early Screen Exposure and unlike ASD, can be reversed if intervened at the right time and with the right corrective measures.

There is no evidence that the autism spectrum disorder is caused by excessive screen time.

### **3.6.4 Lack of social interaction**

For children on the spectrum, social interaction is a difficulty. They do not intuitively know how to socialize appropriately and may not always have a pleasant experience socializing. However, this is a symptom of autism and not a cause. Children on the spectrum retain their autism, irrespective of the social exposure they get in childhood.

Social exposure may desensitize them to social situations but will not take away the autism from them. Thus, lack of social interaction may deprive the child from learning appropriate social skills but does not necessarily cause their autism.

### **3.6.5 Interaction with people on the spectrum**

Some of us believe that if a child is spending time with a child on the spectrum, they may catch autism. But autism does not work like the flu. As we have discussed before, autism is neurodevelopmental and has genetic links. If a child is getting a diagnosis, it is because the child has always had autism. It may be diagnosed late due to various other factors (denial

from parents, symptoms being masked etc.) Your child is not diagnosed with autism because he/she was spending time with another child who has autism.

In summary, some popular beliefs, or apprehensions about the cause of autism have been conclusively proved to be wrong and an awareness of these can help parents focus their time and energy on more useful approaches to dealing with their children's autism.

## 4 A short history of autism

*Why is the history of autism important? Why is the history of any scientific idea important, for that matter?*

The history of a scientific idea is important because science develops in the context of the challenges faced in a particular time and place. People who are doing science do not work in a vacuum, so what they notice and the way they interpret what they see, both depend on the context in which they are operating. However, when these interpretations become part of the science, they are sometimes seen to be somehow ‘objective’ by later day practitioners and students. This leads to a loss of context and inhibits the ability to critically examine older ideas, thereby giving them a longer life than they deserve.

Nowhere is this more visible than in the case of autism.

The acknowledged pioneer of autism research in the US was also the proponent of the claim that ‘refrigerator mothers’ caused autism. He focused on one specific end of the autism spectrum, ended up conveying the idea that it is a severely disabling, rare condition, and that led to a certain stigma around autism.

Another pioneer of autism, while he had a better understanding of the variety of autistic traits, had to focus on the ‘higher functioning’ end of the spectrum, as he worked in the Nazi regime that did not have a place for the ‘feeble minded’.

While both are Germanic, they wrote in two different languages making it difficult to reconcile these two ideas. Both failed to acknowledge the work of brilliant clinicians, who, incidentally, worked with one first and then with the other.

Both might also have known about but ignored the seminal contributions of a Soviet Jewish woman psychologist, possibly due to antisemitism, sexist attitudes, and anti-Soviet sentiments. These contributions, if accounted for properly, would have made autism what it is today, but much earlier and with much less misery all around.

Coming a little later, a parent of an autistic child, who worked tirelessly to disprove ‘refrigerator mother’ theory was also a supporter of controversial programs and alternative treatments like chelation, use of aversive and believed in the vaccine-autism link which was later discredited.

Then it took a British woman psychiatrist, also the mother of a severely autistic child, to bring these accounts together and help us see autism for the spectrum it is. It took the accounts of a few autistic adults like Temple Grandin and Judy Singer, movies like Rainman, the recent

tireless work of journalists like Steve Silberman, as well as countless others, to put the idea of neurodiversity as the basis of looking at and understanding autism, as we do today.

So, yes, the history of autism is interesting and informative. Here is a TED talk by Steve Silberman that touches upon some of the developments in the history of autism.

[https://www.youtube.com/embed/\\_MBiP3G2Pzc?si=fahLdja2XgMe4D9F](https://www.youtube.com/embed/_MBiP3G2Pzc?si=fahLdja2XgMe4D9F)

Let's dive in for more detail!

## 4.1 Autism – Initial definition and refrigerator mother hypothesis

*Kanner's perspective on autism, as an infrequent and narrowly defined condition, influenced perceptions for years, contributing to precise diagnosis but potentially hindering a broader understanding of the spectrum.*

Our understanding of autism has undergone significant evolution, shaped by both early observations and subsequent scientific advancements. Initially, the term “autism” was coined by Swiss psychiatrist Eugen Bleuler in 1908, describing symptoms observed in schizophrenia as a withdrawal into an inner world or self-absorption. Leo Kanner, born in Austria in 1894, later became a key figure in defining and shaping the early understanding of autism.

### 4.1.1 Leo Kanner – Psychogenic theories - 1941

Leo Kanner, who earned his MD degree in Berlin, moved to the United States, and embarked on a career in psychiatry. His influential work began in 1928 when he underwent psychiatric training and eventually joined John Hopkins University Hospital. Kanner's contributions included establishing a child psychiatric unit, transforming the doctor-patient relationship perspective. In 1935, he authored “Child Psychiatry,” the first English-language textbook on the subject. During this time, he helped clinicians Anne Weiss and George Frankl to escape the Nazi regime in Germany. Frankl later joined Kanner at John Hopkins University.

In 1941, Kanner presented a paper titled “Autistic Disturbances with Affective Contact,” which was eventually published in 1943. This seminal work outlined observations of 11 children with common signs, including social isolation, a desire for sameness, routine obsession, delayed echolalia, and splinter memory skills. Kanner's perspective on autism, as an infrequent and narrowly defined condition, influenced perceptions for years, contributing to precise diagnosis but potentially hindering a broader understanding of the spectrum.

Kanner proposed the concept of emotionally neglectful mothers (refrigerator mothers) in his observations of parents of children with autism. He suggested that cold and neglectful mothers might contribute to the development of autism in their children.

## **4.2 Bernard Rimland – Autism as a neurological condition - 1964**

It wasn't until Bernard Rimland challenged this hypothesis in 1964, advocating for a more biological and neurological understanding of autism in his book "Infantile Autism: The Syndrome and Its Implications for a Neural Theory of Behavior," that a shift occurred in the scientific community's perspective. Rimland's work played a significant role in steering away from psychogenic theories and toward a more comprehensive understanding of autism as a neurological condition.

## **4.3 Behavioral Approaches – Foundations of ABA**

*Grounded in empirical research, ABA is a data driven method relying on collection and analysis of objective data to analyze the effectiveness of behavior interventions. It has evolved into one of the evidence-based approaches to working with autism.*

As psychogenic theories were shifting with Bernard Rimland advocating for a more biological understanding, Dr. Ivar Lovaas played a pivotal role in developing Applied Behavior Analysis (ABA). Lovaas utilized behavior modification techniques to address language and communication challenges in young children with autism, employing principles of operant conditioning and reinforcement to encourage desired language behaviors.

## **4.4 Ivar Lovaas – Applied Behavior Analysis - 1965**

In 1965, Lovaas published a groundbreaking study, "A Stereotypic Language in Young Children," focusing on behavior modification techniques for language deficits in children with autism. Emphasizing individualized treatment plans, he recognized the diversity of autism and stressed tailored interventions based on each child's specific needs. Lovaas highlighted the importance of early intervention, acknowledging that addressing language deficits during early development could positively impact overall communication abilities in children with autism.

His study employed a data-driven approach, prioritizing the collection and analysis of objective data to evaluate the effectiveness of behavioral interventions. This commitment to empirical research became foundational to the scientific approach characteristic of Applied Behavior Analysis (ABA), which Lovaas and his colleagues further developed in the 1980s.

While the 1965 study focused on language development, it set the stage for Lovaas's comprehensive approach to autism treatment. Continuing his research and developing the Lovaas Method in the 1980s, he contributed to establishing ABA as a prominent, evidence-based intervention for individuals with autism.



ABA involves breaking down complex behaviors into smaller components and using reinforcement strategies to encourage desired behaviors while discouraging undesirable ones. The Lovaas Method features intensive one-on-one behavioral therapy, often exceeding 40 hours per week, with a focus on structured learning, positive reinforcement, and individualized goals. Grounded in empirical research, Lovaas's work, including the 1987 study "Behavioral treatment and normal educational and intellectual functioning in young autistic children," played a crucial role in establishing ABA as a leading intervention for autism.

## 4.5 Study of autism in twins – Investigating genetic origins - 1977

*The study's significance lies in shifting the perception of autism from an environmentally caused disorder to one of the most heritable psychiatric disorders.*

A few years down the line, despite Bernard Rimland's efforts to challenge the refrigerator mother theory, the concept resurfaced in 1967, perpetuated by Bruno Bettelheim, a psychoanalyst who echoed and popularized the theory in his book titled "The Empty Fortress."

A significant turning point came with the first-ever study of twins and autism in the history of autism research, providing an alternative perspective to blaming parents. Previous studies had noted a lack of resemblance for non-twin siblings, challenging the consideration of genetic influence on autism. The rarity of autism diagnoses at the time (2-4 children out of 10,000) contributed to the low rates observed in siblings, even if heritability were high.

The groundbreaking [study](#) conducted by Susan Folstein and Michael Rutter focused on 21 pairs of British twins, examining the concordance rates for autism. They studied identical twins (monozygotic), where a fertilized egg splits and develops into two babies with the same genetic information, as well as non-identical twins (fraternal or dizygotic) where two eggs are fertilized by two sperm and produce two genetically unique children.

Among the 10 pairs of fraternal (dizygotic, DZ) twins, where at least one twin was diagnosed with autism using strict criteria, not a single co-twin was diagnosed with autism, indicating zero concordance for fraternal twin pairs.

The most striking result emerged from the 11 pairs of identical (monozygotic, MZ) twins, genetically identical as clones. Among these pairs, 4 (36%) were concordant for strictly diagnosed autism. The researchers used case histories from interviews with parents and observations of the 42 children, maintaining blindness to whether the children were members of identical or fraternal twin pairs.

The study's significance lies in shifting the perception of autism from an environmentally caused disorder to one of the most heritable psychiatric disorders. As molecular genetic research advanced in the 1980s, autism became a prominent target. However, Folstein and Rutter anticipated that genetic influence on autism might result from multiple genes of small effect size, explaining the challenges in identifying specific genetic culprits.

The 1977 paper not only contributed to understanding the heritability of autism but also made additional discoveries that continue to shape the research agenda for autism, particularly in refining the diagnosis of autism.

## **4.6 Autism Appears in DSM III - 1980**

Following the increased recognition and understanding of autism, Autism made its way to the DSM-III (Diagnostic and Statistical Manual of Mental Disorders, Third Edition) as an independent diagnosis. This marked a significant step in acknowledging and categorizing autism spectrum disorders within the psychiatric diagnostic framework.

## **4.7 ‘Discovery’ of Asperger’s Syndrome and Autism as a spectrum - 1981**

*Lorna Wing proposed the concept of the “autism spectrum.” She emphasized that autism is a spectrum of disorders with a wide range of presentations, including different degrees of severity and a diverse set of characteristics. Her work has had a lasting impact on autism research, diagnosis, and support systems.*

Dr. Lorna Wing (1928-2014) trained as a medical doctor specializing in psychiatry. She and her husband John Wing both specialized as psychiatrists. They had a daughter Susie in 1956. Susie was delayed in development and had a ‘detached, insular’ manner. Despite being specialists in psychiatry, it took them years to get a diagnosis of autism. Convinced of the need for more research in the space, Dr. Wing changed her focus to child psychiatry. Dr. Wing and her collaborator Dr. Judith Gold did pioneer work in the field of autism. They initiated Camberwell Case register to record all patients using psychiatric services in that area of London and relentlessly accumulated case data that formed the basis of the influential insight that autism formed a spectrum.

In 1981, she published a paper titled ‘Asperger syndrome: A clinical account’, popularizing the research of Hans Asperger. Asperger was an Austrian psychiatrist who, in 1940s, described a form of autism in a group of intelligent boys who were intensely interested in one or two subjects like dinosaurs or trains. They shared many of the usual problems associated with autism like the inability to make friends, repetitive behaviors, and distress at any change in routines.

Dr. Wing presented Asperger’s paper, along with her own research, as strong evidence for her larger argument that autism should be understood as a spectrum of disorders sharing common roots. At one end are some who, like Dr. Asperger’s patients, would go on to successful careers and untroubled lives, at the other end, may be patients like those studied by Dr. Kanner.

Who was Hans Asperger and how did his research not see the light of day till 1980s, while stigmatizing ideas of autism were around for about 40 years?

## 4.8 Hans Asperger – the other end – 1944

Hans Asperger (1906-1980), an Austrian pediatrician born in Vienna. He pursued medicine and received his medical degree in 1931 from the University of Vienna. He joined the University Children's Clinic in Vienna. His mentor and supervisor at the clinic for the most part was Franz Hamburger, a prominent Austrian pediatrician. Under Hamburger's guidance, Asperger had the opportunity to observe and work with a diverse range of pediatric cases.

Asperger's work on autism was influenced not only by his medical training but also by the clinical experiences and mentorship he received during his tenure at the University Children's Clinic. His colleagues had a unique way of treating children with special needs and they tried to adopt new ways of teaching and learning for those children. The collaboration between Asperger and Hamburger thus played a crucial role in shaping Asperger's understanding of child development and psychopathology, contributing to the pioneering observations that would later define his work on autism.

During his tenure at the Children's Clinic in Vienna, Asperger extensively studied over 200 children. These children displayed a range of symptoms, from prodigious abilities coupled with struggles in school to more severe disabilities that led to institutionalization. Despite the diversity, they all shared common features such as precocious talents, social awkwardness, and an intense focus on laws, rules, and schedules.

In 1944, Hans Asperger published a groundbreaking paper titled "Die 'Autistischen Psychopathen' im Kindesalter" ("The 'Autistic Psychopaths' in Childhood"). This seminal work detailed his observations and conceptualization of a distinctive set of behaviors displayed by certain children, which are now recognized as falling within the autism spectrum.

Asperger adopted a holistic understanding, viewing autism as a variation in neurodevelopment rather than a disorder. Crucially, Asperger recognized that these symptoms existed on a continuum, affecting both children and adults. He also keenly noted that the symptoms were noticeable in children only when they were 2 years old or older. Additionally, his work acknowledged the lifelong implications of autism but also expressed optimism about individuals leading fulfilling lives with appropriate support.

When Asperger eventually shared his research with the world, he chose to highlight his higher-functioning patients. This decision was influenced by the era he lived in, marked by the Nazis' pursuit of purifying the land of the "feble-minded," leading to the euthanization of many institutionalized children. Consequently, Asperger unintentionally conveyed the impression that autism was a rare condition affecting young geniuses, rather than the more common syndrome he had identified. However, despite its significance, the paper did not gain widespread recognition initially, due to the language barrier and the second world war.

## 4.9 The mystery of Asperger – Kanner Connection

Psychiatrist George Frankl was working at the Vienna clinic much before Asperger joined there. Psychologist Anne Weiss was also a part of the staff at the clinic. Both published papers in 1934-35, which included descriptions of children who had same characteristics as autism. They were working closely with Asperger. Both were jews, and they escaped the Nazi regime in 1935-37. Asperger was named the head of the clinic in 1935.

Frankl and Weiss, who later married each other went to work with Leo Kanner in 1938. Kanner's paper titled "Autistic Disturbances of Affective Contact" was published in August 1941. Asperger's paper, which Lorna Wing translated in 1981, was first submitted as a postdoctoral thesis in 1942 and was published in 1944.

It is difficult to imagine Kanner was unaware of Asperger's work, while definitive evidence is not available. One can only wonder what would have happened if they acknowledged each other's work and collaborated.

## 4.10 Lorna Wing – Bringing the ends together

Building on the work of Leo Kanner and Hans Asperger, Lorna Wing proposed the concept of the "autism spectrum." She emphasized that autism is a spectrum of disorders with a wide range of presentations, including different degrees of severity and a diverse set of characteristics. Adding on, Wing also introduced the concept of the "triad of impairments" to describe the core features of autism. This triad includes difficulties in social interaction, communication, and imagination (often manifested as repetitive and stereotyped behaviors). The triad of impairments became a foundational framework for understanding and diagnosing autism spectrum disorders. Along with Judith Gould, she also developed the Autism Diagnostic Interview (ADI), a structured interview for parents or caregivers of individuals with autism. The ADI became an essential tool for clinicians and researchers in diagnosing autism and gathering information about a person's behavior and development.

Wing, apart from actively being involved in advocating for individuals with autism and their families, contributed to better recognition and understanding of autism in girls and women by highlighting the underrepresentation of females on the autism spectrum. Her work drew attention to the fact that autism might present differently in females compared to males.

Her work has had a lasting impact on autism research, diagnosis, and support systems.

## 4.11 Autism in Adults – Temple Grandin – 1986

*As one of the first adults to break the stigma and publicly disclose her autism, Temple Grandin made enormous contributions to the field of autism by drawing attention to the lived experience of autistics.*

Temple Grandin (1947-) was born in Boston into a wealthy family. She was among the first adults to publicly disclose she was autistic, in her 1986 book ‘Emergence: labelled autistic.’ Born at a time when children like her were routinely institutionalized, Temple was supported by her mother and developed into the autistic savant as she is recognized today. Her book was based on experiences of an autistic, rooted in her personal experiences, observations, and advocacy. Grandin has provided invaluable insights into the lived experience of autism. Her book “Thinking in Pictures,” offers a first-person account of the sensory experiences, challenges, and strengths associated with autism.

Grandin’s unique cognitive style, characterized by visual thinking, has been a focal point of her contributions. She coined the term “thinking in pictures” to describe her thought processes, emphasizing the importance of visual cognition in understanding the world. This perspective has influenced how educators and researchers approach autism, and Grandin’s insights have extended to recommendations for creating sensory-friendly environments that support individuals with autism. Her suggestions for adapting educational settings and incorporating sensory considerations have played a role in shaping the design of spaces to meet the needs of individuals on the autism spectrum.

Beyond her literary contributions, Temple Grandin’s professional endeavors in animal science and her innovative designs for livestock handling facilities reflect her understanding of sensory sensitivities, a common trait in individuals with autism. Her work in enhancing animal welfare demonstrates her ability to apply a unique perspective to real-world challenges. In addition to her autobiographical writings, Grandin has authored numerous books and articles on autism, animal behavior, and related subjects, contributing to the widespread knowledge about autism in both academic and popular contexts.

Stories of Grandin and other adult autistics like her, and the 1988 movie Rainman, also gave rise to the idea that autistics are unusually good at arts or math – a condition called savant syndrome.

## 4.12 Emergence of neurodiversity paradigm-1990s

*Neurodiversity describes the idea that people experience and interact with the world around them in many different ways; there is no one “right” way of thinking, learning, and behaving, and differences are not viewed as deficits.*

Lorna Wing and Temple Grandin changed how people think about autism. They showed that autism is different for each person. Earlier, people thought of autism as the same for everyone. Wing created the idea of the “autism spectrum,” and Grandin talked about the strengths of people with autism. This changed how society saw disabilities. People started thinking about how society makes it hard for people with disabilities. This change made room for a more positive and inclusive view of neurological differences.

A movement for disability rights also started in the 1960s in the US. This movement said that people with disabilities have rights, and society should include them. The movement challenged old ideas that said having a disability is a problem. People with autism also spoke up for themselves. They said that autism is not just a problem but also a part of who they are. They wanted to show that they have strengths and unique ways of thinking.

Judy Singer, a key figure in the development of the concept of neurodiversity, learned about the idea of autism as a spectrum from the Autism Association of Australia. This understanding, influenced by British psychologist Lorna Wing’s work, recognized autism as a diverse condition that extends into the broader human experience. Singer’s daughter’s diagnosis with Asperger’s syndrome led her to recognize similar traits in herself, such as difficulty making eye contact and being disorganized.

Singer, who worked in the IT industry, later pursued studies in sociology and disability at the University of Technology in Sydney. With the advent of the internet, she engaged in online communities, including one called ILMV, where she collaborated with Harvey Blume. Through their discussions, Singer coined the term “neurodiversity,” in the mid 1990-s, emphasizing the value of diverse neurological conditions inspired by biodiversity in nature, which is about valuing different species.

Singer undertook a thesis titled “Odd People In,” exploring the emergence of a new social movement based on neurological diversity. The thesis focused on online communities and the need for autistic people’s voices to be heard and respected. Singer’s work contributed to the growing neurodiversity movement, advocating for the rights and inclusion of neurodivergent individuals. Neurodiversity is the idea that we should value and include people with different ways of thinking, like autism, ADHD, dyslexia, and more. It says that being different is not a bad thing; it adds to the richness of human experience.

Neurodiversity has become an important idea. It changed how we talk about and see neurological differences. The neurodiversity movement works for the rights and inclusion of people with different ways of thinking in all parts of life.

## **4.13 Another step back – Autism Vaccine connection – 1998-2010**

*In 1998, a paper in Lancet claimed that there is a connection between Autism and the MMR vaccine. While the study was later found to be fraudulent and was retracted, the questions about vaccine safety and impact on autism refuse to leave the public perception.*

Another detour in the journey of understanding autism was driven by Andrew Wakefield, a British gastroenterologist. Wakefield had been involved in researching gastrointestinal symptoms in children with developmental disorders, particularly those with autism. He had observed certain gastrointestinal issues in some of these children. Wakefield became increasingly concerned about the MMR vaccine, which is administered to protect against measles, mumps, and rubella. He questioned the safety of the vaccine and its potential association with developmental disorders, particularly autism.

In 1998, Wakefield and his colleagues published a study in the medical journal *The Lancet*, claiming to have found a link between the MMR vaccine, bowel disease, and autism in a small group of children. The study, based on a case series of 12 patients, suggested a temporal association between MMR vaccination, gastrointestinal symptoms, and the onset of developmental regression.

The study faced immediate criticism for its small and selective sample, lack of a control group, and methodological flaws. Moreover, ethical concerns were raised about undisclosed financial conflicts of interest. Wakefield had financial interests in pursuing research that could potentially link the MMR vaccine to developmental disorders. He was involved in a business venture to develop diagnostic tests for inflammatory bowel disease, and a vaccine scare could potentially benefit his business interests.

The study was eventually retracted by *The Lancet* in 2010 due to ethical concerns and the discovery of undisclosed financial conflicts of interest. Wakefield lost his medical license in the same year, facing disciplinary action for ethical violations.

The Wakefield study had a profound impact on public perception and contributed to vaccine hesitancy. However, it has been widely discredited by subsequent research, and Wakefield's actions have been condemned by the scientific community for their ethical and methodological shortcomings.

## **4.14 An old, yet modern take on autism 2013**

*In another twist, research notes from 1925, made by a Russian Jewish woman psychologist reveal a much more nuanced and modern understanding of autism.*

Irina Manouilenko, is psychiatrist based in Stockholm, Sweden. In 2013, Manouilenko translated Grunya Sukhareva's original descriptions of autism from Russian to English and compared them with the diagnostic criteria in the DSM-5.

Upon examination, Manouilenko found significant similarities between Sukhareva's early observations and the contemporary criteria for autism in the DSM-5. This discovery highlighted the noteworthy alignment between Sukhareva's work in the early 20th century and the current understanding of autism.

## 4.15 Grunya Sukhareva – overlooked pioneer – 1925

Sukhareva, a Soviet child psychiatrist, independently observed children displaying social withdrawal, language difficulties, and repetitive behaviors. Her detailed description of autistic features in the six boys she observed was published in 1925, nearly two decades before the more widely known work of Asperger and Kanner. Sukhareva recognized the unique cognitive profiles of the children she studied, emphasizing differences in information processing and engagement with the world. Her focus on early childhood and the importance of early identification and intervention aligns with later perspectives on autism.

Sukhareva held a positive view regarding children's ability to adapt successfully under favorable conditions. She emphasized the significance of the social environment, proper upbringing, and education in stimulating compensatory opportunities for children.

Sukhareva, as a child psychiatrist, observed and highlighted how crucial these factors were in aiding children's adaptation within their families and at school. This perspective aligned with her evolutionary-biological concept of mental illness. In her 1926 paper, Sukhareva balanced her descriptions by also noting unconventional behavior and challenges faced by the children she observed.

Sukhareva also documented motor coordination issues in some children, contributing to a more comprehensive understanding of autism that recognizes the diverse challenges individuals may face. Overall, Sukhareva's pioneering work laid a foundation for the evolving understanding of autism.

Sula Wolff, a psychiatrist based in Edinburgh, praised Sukhareva's 1926 publication, stating that Sukhareva summarized the children's characteristics "admirably" and described her work as "marvellous." According to Manouilenko and Bejerot, Sukhareva's descriptions were considered "structured, elegant, detailed," and "vivid." They also noted that Sukhareva's ideas on ways to help autistic children were remarkably "modern."

Manouilenko and Bejerot suggest that Sukhareva's gender, her Jewish identity, Russian nationality, and her publications in Russian and German were not an effective combination for gaining worldwide attention in the 1920s. One can only bemoan the loss to the autism community, clearly due to the established discrimination.

## 4.16 Current understanding – 2024

Today, "autism" refers to a spectrum of neurodevelopmental disorders characterized by challenges in social communication and interaction, as well as restricted and repetitive behaviors. The contemporary understanding emphasizes the multifactorial nature of autism, involving a complex interplay of genetic, neurological, and environmental factors.



“Working in different political, cultural and research settings might have influenced the way each of them perceived autism. Ultimately, it took a spectrum of these researchers to define autism’s full spectrum.”

## 5 People's Perspectives

In this section, we present perspectives of different people living with and working with autism. You will find perspectives of people on the spectrum and their parents at different stages of their autism journeys. We also include a few perspectives of professionals working with autism.

### 5.1 Parents of teenagers in a community learning space

The following are the perspectives gathered from four sets of parents whose children are in their pre-teens/early teens.

### 5.2 Profiles

S-I S is trained as a doctor and a dancer. Her 12 year old son I is interested in food and shows interest in doing academic work. He works at 3rd grade level now. He is verbal, and can ask for what he wants. He has a routine of dancing, exercise and regular physical and cognitive engagement. I was diagnosed at 3 and went through systematic early intervention till 9 before entering a community learning space.

H-M H is a microbiologist and a teacher. Her 13 year old son M is partially verbal and uses AVAZ to communicate. H trained as a therapist for 3 years along with M while he took his early intervention and continues to work as an expert mentor. M was diagnosed when he was 3 years old, went through systematic early intervention, and joined a community learning space. While he is independent with his daily living, he needs someone to be constantly with him to take care of his safety around the kitchen and on the roads. M enjoys nature.

S-S S is a housewife married to a doctor and are parents of 3 sons. The oldest being 14 years old, the second, S being 11 years old and on the spectrum and the youngest, 4 years old. S was 2 when he was diagnosed. They stayed in the US until the youngest son's birth and till they could find stable help for S back in India. S is verbal and can communicate his likes and dislikes. He often does so with Disney characters. S knows disney movie lines by heart.

S-G S is a nurse, lecturer and a teacher. Her son, G is close to 13 years old and is partially verbal. He was diagnosed when he was 1 year 7 months. He went through special education early intervention along with speech and occupational therapy. He started Applied Behavior Analysis (ABA) Therapy when he was 6 years old, has been using AVAZ since he was 6.5 years

old and can now communicate anything that he wants through the app. S has undergone parent training and also trained to be a Registered Behavior Technician (RBT) while G was taking ABA therapy. They are now a part of a homeschooling group where the parent and child participate in the teaching learning process under the guidance of experts. G loves listening to music.

All the four sets of parents and children are part of a community learning space, some full time and some part time, where they work together in groups of other mothers and children on the spectrum. They have help from experts in behavior intervention and teaching learning processes. The following are their responses to some of the questions that we asked:

### **5.3 Early signs and diagnosis**

What were some early signs or behaviors that made you think your child might be different? What prompted you to seek a diagnosis for your child?

SI - I always used to cry. I thought it was usual for babies to cry and always just tried to stop his crying. He didn't feel different at all. I left him under the care of my mother and went to continue my masters. My mother felt it was difficult to deal with him. He wouldn't communicate much but we assumed he could be a late speaker. Despite our medical background, we couldn't pick up on the signs until we went for a friend's get together and a pediatrician friend saw him and suggested we go for a diagnosis from a clinical psychologist. The appointment was 2 days away. So, I started reading up about Autism and realized that I was ticking off almost everything on the checklist. I could relate with all the symptoms. He was 2 years and 6 months old then. He was diagnosed with Pervasive Developmental Disorder, not otherwise specified (PDD, NOS) at that point.

HM - M had evident milestone delays by 5 months of age. He wasn't sucking, there was no neck control, no eye contact or any non-verbal communication. We were noticing the signs until he was 1 year old but could not understand what or why. He was 1.5 years old and there was no speech yet. Until then we were doubtful. We were also scared that if we go get it checked, there might be something wrong. We were convincing ourselves saying that he is a boy and so the developmental delays. But co-incidentally he also happened to swallow a plastic toy around that time and while visiting the pediatrician for that, I shared my concerns about his developmental delays. The pediatrician checked and referred to a developmental pediatrician. Through few assessments, they diagnosed him with Autism Spectrum Disorder and auditory intolerance.

SS - My mother-in-law visited us in the US when S was 2 years old. She, like any grandmother, tried interacting with my kids and noticed that S may have developmental delays. Until 2 years of age, it was like S was hitting off all the milestones. He would interact, respond to his name and even follow instructions. It was from 2 years onwards that he started walking on toes even when his shoes were on, and became a very picky eater, especially after he started daycare.

We then took him for diagnosis and they said he was on the borderline of the spectrum. We were not given a real picture at all.

SG - G was around 1 year old. He was a very happy, relaxed child. Social smile used to be there, but there was no responding to name or signs of imitation while interacting with my in-laws. Slowly, he started to spin anything and everything he could spin (plate, bicycle wheel). If there was nothing, he would sit and spin himself. He was meeting physical milestones with a 2-3 months delay, so we thought he would be a slow learner or maybe have some difficulty with hearing alone. My in-laws felt there was a delay in development and we also felt he was different from other kids we see around. We visited a pediatrician and he said there seems to be some issue and referred us (to NIMHANS) for diagnosis. There, within 5 minutes he was diagnosed with Autism Spectrum Disorder and we were just told that there is no cure, therapies are the only way to manage and that there are therapy centers where we can go and get more information. I had studied about Autism during my studies but in small detail. I knew it was a childhood disorder, but nothing more. My husband and I were not convinced with the way he was diagnosed and traveled to Mysore to get a detailed assessment done. There he was again assessed in detail, diagnosed and we were briefed about the disorder in good detail.

## **5.4 Just after diagnosis**

What were your feelings and thoughts before and immediately after the diagnosis? Was there a period of uncertainty? SI - I was in shock and denial. I knew vaguely about Autism from what we studied as part of our medical course, but nothing much. It was during the before and after diagnosis period when I gathered the information. I would cry almost everyday after the diagnosis. There was a period of uncertainty for about a month. But my sister and husband were very supportive through the process. My sister would send encouraging videos/resources. My husband believes that any problem will have a solution and he said we would be able to do something. So let's figure that out. There was now a shift in my career goals. My initial expectation was that my mother would take care of my son and I can complete my Postgraduate (PG) course. Now I had to take a break from my PG course and I decided to take care of the child full time. He became my first priority. I am very glad that I had and have my family's support. My father was slightly disappointed that I am unable to focus on my career and hoped that I would get back at it.

HM - Only M and I had gone for the assessment while my spouse was at his office. When they provided the diagnosis, I was in shock and sent an SMS to my husband. He also took off for the day and came immediately. M was 1 year and 8 months old then. I was scared, I cried and didn't eat properly for about a week. My husband also took a week's time to come to terms with this. We started therapy straightaway at the same center, but we were also trying to seek help from a neurologist, visited temples, made offerings and visited astrologers on the side. That was our period of uncertainty. We also blindly followed whatever was referred to

at the center. The professionals we encountered did not give extended support, but they did their work and did not give any false hope either. Other parents sailing in the same boat were my source of comfort at that point.

SS - Soon after he was diagnosed, we came to India thinking he would improve by being around the extended family. We also wanted to check out options available in India. But we couldn't get any help. Family was not supportive and we couldn't find the right therapists. It was so frustrating. We were clueless and returned to the US because it felt like there was at least something we could do there. Most people said that he would improve with age and my family members didn't believe in the idea of therapy. It took me 8 years to accept S's autism. Meanwhile I would question why this is happening only to me and had a blind hope that S would become normal.

SG - I would say that I didn't let the diagnosis affect me too much immediately. I thought this is something I know very little of. I need to know more and see what I can try. We were told that there is no cure. That was painful and uncomfortable for almost a year. I was expecting G to be a normal child or at least just a slow learner and what came to us was unexpected. But I did not go to the denial stage. I was aware and accepting of what has come to us. Questions of what next and the confusion were there. On that front, I wish during our first diagnosis itself, they spent a little more time with us to brief us about the condition. My family gave me all the emotional and moral support I required and I am thankful for that. The suggestions thrown at us from different directions to try homeopathy, ayurveda etc., lead us to a confused state and we didn't know what to do. However, we did not waste much time. We enrolled him for speech and occupational therapy right away. The special education center also provided us with parent training and also we could take counseling sessions. That was helpful. I stopped comparing G with other kids and feeling bad about it.

## **5.5 Initial steps and alternatives**

What initial steps did you take after diagnosis? What were the alternatives you considered? How did it work out? SI - We enrolled him in therapy for early intervention but things happening there scared me. I would just go into the center, cry and come back. In the occupational therapy assessments, they said he has mild to moderate autism. The occupational therapist suggested a few centers. Speech therapy was difficult to find. In none of the centers we were allowed inside and we didn't know much about what was happening inside. I would just see the materials used at the center and repeat them at home with my own knowledge. Those were out of my own will. There were no inputs from any of the centers. In one of the centers, they suggested a hands-on training course, but that's about it. Through different parents we met at different centers, and the therapists, we kept trying different centers for speech, Occupational Therapy and ABA. Most of the parents suggested alternative medicine treatments as well but we didn't want to go for it due to lack of empirical evidence.

HM - We continued therapy in the same center for 2 years. M was going to OT and special education. They would tell things we could try at home, but nothing regarding behavior management. We were still clueless about that. It was especially difficult with M, as he had a lot of behaviors. Eating was an issue with him, he would fall sick often, cry constantly and that would also affect me emotionally. He also went to a Montessori school briefly where he would just go, cry in class, jump on the trampoline and come back. We tried two Montessori schools in the hope that if he is in a group, he would pick up some skills. Nothing like that happened. We considered alternative medicine especially for his immunity. We tried homeopathy when he was 6 years old. We also tried a tapping therapy. By then my husband felt that M was not improving. He did the research and we joined a good therapy center.

SS - In India, we couldn't find anything suitable. We decided to go back to the US and once we were back, we tried HyperBaric Oxygen Treatment and the B12 shot. These were suggested by many people and we learnt from our research that it is safe and does not have side effects. We were told that S might have Attention Deficit Hyperactive Disorder (ADHD). We feel the B12 shot helped S with certain symptoms like hyperactiveness alone. In the US they use sign language with the kids in therapy, by default. There it is more like going with the flow of the child and not pushing them to do anything. We were not satisfied, but we didn't have many options either. S was also briefly going to daycare where I would drop and the father would pick him. I feel that may have affected our mother son relationship at that point because I would always drop. S also became a picky eater meanwhile. He would eat very selective foods - warm/ food that I cook/ it should be served in a bowl, strictly no milk etc. He went to school along with a shadow teacher while we were in the US, but it wasn't very effective. We also went through other challenges like having a non-supportive family, and ineffective therapy centers. I did not get any parent training anywhere. Much later, through a friend, we found out about a center in India providing Applied Behavior Analysis (ABA). We relocated and I would say the game changer was when we started writing down the instructions for S. S started following through so quickly. I realized how bothered he was with our verbal inputs. There was also a good set of therapists and structure in place for the kids. The schedule and transparency made me feel comfortable and felt I should have started here earlier.

SG- We started special education early intervention when he was 2 years old and speech and occupational therapy too. He was picking up skills, but we did give in to the influence of other parents of trying new things for 8 months in between. We tried Ayurveda when he was 5 years old. G was naturally a calm kid while we let him be. Through Ayurveda they again gave calming medicines only. So I didn't see any significant differences. Another major reason I dropped out of it was following the GFCF Diet. G is a foodie and I felt bad in restraining him from so many foods. It was also difficult for me to follow all the time. I then started believing in my efforts and myself for G.

## 5.6 Initial sources of information

Where did your knowledge of autism and how to work with it come from initially? Was it helpful? When and where did you find the most useful knowledge? SI- My knowledge of autism came from the readings I did online. I would watch youtube videos of ABA to work with him at home. What I found particularly helpful was videos made by Chrys Vawnik and Temple Grandin's Thousand ideas book. My sister would also send articles or videos of autistics doing well in society, to encourage me.

HM - Initially our knowledge of autism came from whatever the professionals were saying, whatever my husband was reading online and whatever I was hearing from fellow parents at the different therapy centers. After joining this therapy center and as I was training to be a therapist, I gained a lot of insight from the theories. ABA Goals gave me an understanding of what I can expect out of my child or any child I am working with. The Verbal Behavior Approach book by Barbara, was helpful for me.

SS - The doctor didn't give us any clear information. We did our own reading and we would hear from our friends or my husband's colleagues from the US. We also heard from the therapy centers. I would say nothing was helpful. We didn't gain any clarity. The readings were mostly from the US websites and it included the US way of looking at children, which didn't really suit our ideas of children. Colleagues and friends believed it would get better with age. The most useful knowledge I would say came from some readings that my husband did, like looking for alternatives. I would say most of my knowledge of autism came from this therapy center. That is where I got a real picture of my son.

SG - The first knowledge I got was from the center at Mysore where I took G for a detailed assessment. At AISHA, they gave us detailed information. Other sources of my knowledge also included friends who also have autistic kids, other parents I met anywhere in the public. They were helpful. I did not hide my kid. He would come with us everywhere. That opened new conversations and new ideas. That way I also was learning to handle G in different environments and that also let me know what I can expect out of my child. I think I can say that I relied more on the knowledge I gained from real experiences of people than textual or theoretical knowledge. Apart from that, I also gained more understanding when I did my RBT course and training and while I worked with other kids. The RBT theory really helped me understand things from the kid's perspective.

## 5.7 Early intervention choices and impact

What early intervention did you settle on and how did it impact you and your child? SI - I was always on the lookout as I was not completely satisfied with the therapies I was receiving. He was going for OT, Speech and other therapies where there used to be some schedule and goals. Everywhere it felt like we were paying a lot of money, I was going inside, crying and coming

back. At that point, I did not see crying behavior as a part of the learning process. We were a little unsettled because nowhere we were allowed inside and there was not much clarity. We also sent I to school. He attended LKG and UKG with a shadow teacher. My initial goals were that I should speak, should not cry and behave well, and that he should attend a mainstream school. These were the goals I had for him until he was 6 years old. After that, he started to communicate which I was happy about. By then he also acquired certain patterns and I had a shift in my goals. By then his OT was also going alright. The therapist gave home plans and some ABA tips. I was still seeking help with other therapies and asked for suggestions as I did not know how to manage at home. The therapist then referred me to this therapy center for ABA.. Since it was transparent and we were given a clear picture here, we felt more settled. At no point, I gave up working on him. Meeting parents who were confident gave hope that they must be doing something right. So I would seek their help. My family was very supportive through this process. My husband would say decide whatever is working for you and do that, we'll support you. My mom and sister were always available for me. Financially also we didn't have challenges. That was a big plus point for us. We also sent I to other classes like the Kumaon class where they teach the Japanese method of learning math and english. I stopped OT and started physical training instead when he was 7 years old.

HM - We started with special education, but since we did not see any improvement, we shifted to ABA. We knew about ABA before, but financially we were not sure if we could support it long term. While shifting we thought we'll see for 2 years and then we could homeschool. I wish we had started earlier. M underwent food intervention as he was not eating properly. Even to get him to drink water was a struggle. But once we cracked it, it opened up new skills and learnings for M. His sitting tolerance increased and hyperactivity went down. With the schedule in place, his anxiety also went down. We were very happy with the progress he was making.

SS - We settled on whatever was provided in the US. They were doing ABA, but quite different from what is being offered here. They used sign language for communication predominantly with kids who were not fluent. He was picking vocabulary from Disney movies and would then use that for communication. He started talking again by the time he was 8 years old. Until then his school provided speech therapy and Occupational therapy. I wish we found this therapy center earlier and started off here.

SG - Special education. It worked for G. He picked up a few skills. Even though it was slow, he was picking up things until I decided to put him in a preschool after 1 year of early intervention, going with the suggestion of his special education therapy center. I feel like he might have regressed there. He dropped even the few skills he had picked up. He was still continuing Occupational Therapy and Speech Therapy, so things were alright at that front. I removed him from the preschool and enrolled him in another special education therapy center itself for another year before going for ABA.



## 5.8 Moving on from early intervention

When did you feel early intervention had run its course and you needed to move on? Why? SI - He was 7 years old, getting educated and trained in different things, but we did not know what next for him. School was not working. What next in life, in academics, in leisure skills etc. were new questions that popped up. COVID hit and for 2 years he was taking online therapy. Simultaneously the learning community space opened and some parents I know were already a part of it. Since we were getting full time parent training there, we also decided to join the community learning space.

HM- We kept trying different things throughout but I realized that I am unable to be consistent at home. Managing household chores and M was becoming overwhelming. The consistency was limited only to the therapy center. COVID hit and that's when the realization hit as well. We realized that we can't homeschool him like we planned while joining ABA. There has to be something else. This learning community space opened and we thought that would be the next best option.

SS -Through the 8 years we were constantly in the lookout for something better as we were not satisfied with what was being offered in the US. That's when we got to know of this therapy center and we had our initial discussion with the founders of the center.

SG - He was 6 years old and I felt like he was still not picking any skills. He was still dependent on us for a lot of things. He wasn't even potty trained. So all of these were concerning and I started looking out for other options when I landed at this therapy center through a friend.

## 5.9 After early intervention

What were your next steps? What have you been doing over the last few years? How has your journey been? SI- It was not until I moved to the community learning space that I realized how prompt dependent I had been. Even with things I thought he was independent, I realized he is prompt dependent and not really independent. With being in such a space full time, came more awareness and knowledge. I had revised my goals for him by now. I wanted him to be able to express his feelings, have leisure skills where he is independent and that he should be able to manage himself even if I am not around. He should be able to work and be with other teachers/ therapists/ parents. I realized that each autistic kid is different and each of them are good at something of their own. We should provide the space to enhance those skills and encourage them. My journey has been full of learning that way and I feel like I am on my right path. When I look back, I feel hopeful. I have been able to achieve goals I had for myself and I see that I is also going there. An advice that has stuck with me is that we should have set goals for another 5 years and then we can work towards that. This advice has made me rethink the beliefs I had.

HM- We joined the community learning space and his food intervention continued in full swing. I figured that I am able to be much more consistent here and also bring in new ideas and goals as I interact with others and work with other kids. M also improved a great deal. He started to explore more food items. With that, he also became more open to other things. He started to pick up new skills like cycling, gardening etc. It has been a great learning journey for the both of us. We have new goals as he progresses. I also have the space to work on myself and set things in my own life.

SS - We booked our tickets to India after knowing about this therapy center. Unfortunately COVID hit and we had to wait for another 3 years before we moved to India. S was taking therapy at the early intervention center in order to be prepared to move into the community learning space. We were just waiting to know that he was ready. My youngest kid was also becoming a picky eater so I sought food intervention alone for him and now he is also here with us at the learning community. It is working well for us that way except that our oldest kid misses on the time he would get to spend with us. But he also sees the point of this now and he is okay. The siblings spend their time together during the weekends. I see a great deal of improvement in S and I am very happy I am here.

SG - We started ABA and there was no going back, It took 1 year for him to be potty trained by following schedules. The structured program in the center was very helpful. I could see a lot of changes in him within that 1 year. He already had some sitting tolerance and he used to follow instructions. But things improved with ABA and the introduction of AVAZ. The 3 mantras I would say that has worked wonderfully with G are structure, schedule and consistency. I also got the opportunity to be trained as an RBT and it has been a good experience for me. Getting to work with other children was rewarding and at the same time provided hope to work with my child. When you see the fruit for the work you put in, it is highly motivating. After ABA I tried group therapy for G for 1 year in between, but it wasn't very effective. Then COVID hit and we were working online and I was working with him at home. We are now a part of this homeschooling community where again I get to work with other kids and I am learning new things. G also gets to learn in a group and with new challenges, comes new learnings for the both of us.

## **5.10 Managing self and family**

How did you manage yourself and your family during this period? SI- Since my family has always been supportive, it didn't feel like a big deal. Everyone else adjusted according to our needs. My decision and my clarity was enough for all of them. My mother even moved closer to our house to help me out as I was juggling between different therapy centers. I wanted to get back to my career at some point but those thoughts came slowly as and when we were feeling slightly settled. I got to complete my PG course as well. Now I am able to leave I and go away for my work at least for a few hours and then come back. I feel like I have come a long way.

HM - My family was not very supportive. It was just my husband and I. I started attending to M full time. It was becoming overwhelming to manage household chores and M at home. I lacked the motivation to follow through M's interventions even though I knew what had to be done. Now I have come a long way and learnt so many things. I plan and organize my work better in order to balance my personal work and M's works. I also take or ask for help actively. I have learnt to do that and I am grateful.

SS - I dedicated myself to my family. I wish I had said no to other commitments now. I couldn't fully focus on S because of the other commitments. Right now, I am happy we are here. My youngest kid is also getting the right education and S is getting to be with him as well. So I am happy, going with the flow. Kids are my 1st priority for now and right now it is S. I have wasted a lot of time already and do not want to waste anymore.

SG - I made up my mind that now I will have to spend more time with my kid. I had to give up on my career as a lecturer, but I don't regret it. I feel I can get back to it anytime, right now G is my focus. And I don't feel whatever I'm doing currently is very different from what I wanted to do. I wanted to go to the hospital and work at some point, I would be serving the older population there, here I am serving the child population. My in-laws and husband were very supportive. I had difficulty managing time for the first 1 year then I learnt to prioritize. My family has supported me and my decisions consistently. They also learn the interventions and that helps in being consistent with G. They took time to accept AVAZ, but it wasn't very difficult to convince them when I stayed put.

## **5.11 Future - Hopes and apprehensions**

What are your hopes and apprehensions as you think of the future? SI - My journey is making me feel hopeful about the future as well. Now I is able to manage himself while I attend meetings and I am able to focus on my career as well while I am able to trust and leave him in the learning community. His learning is also not hindered. Goals are set and we are moving towards his goals as well while meeting our personal goals. I hope he will be in a position to manage our hospital reception at some point. Not much apprehension at this point in time. I used to be worried about him hitting or getting aggressive when he gets upset or angry. Now that we have been able to manage that, it all feels like it can be managed.

HM - M touches himself right now. That scares me, but at the same I am hopeful that we will figure out how to manage that as he is in a safe space now to learn that. I am slightly apprehensive of what he is going to be in the future, but at the same time in the mindset of whatever can be done in the present with him, let's do it and see where it is leading.

SS - As he is approaching adolescence, some fears and questions I have are about him managing his private space and understanding personal boundaries. He is still learning to close doors while he dresses up or to respect a closed door when others are dressing up. I hope he builds enough motor skills to protect himself and the question of what and who after me is lingering

in my mind. I do not want S to be dependent on his siblings nor do I want the siblings to feel obliged. Also the thought of “What if he gets physical when he is angry?” scares me now.

SG - I see people are more aware now and they provide support wherever and whenever they can. That makes me feel hopeful, but I would like for G to be independent with his life skills at least. My apprehensions are also on the same lines. Not all people will be the same. So that fear of how society would treat him, would they take advantage of his challenges are some questions I have in mind. Right now he is not completely independent, but I expect him to get to a stage where he can take care of himself. I also see new interests popping up as we expose him. So I am now open to exploring his interests with him and if he is able to pick on them, we as parents are ready to completely support him.

## **5.12 Advice for new parents**

What advice would you give parents of newly diagnosed children? SI - I feel parents have to go through their own journey in order to gain an understanding of their kid's autism and how the family has to work around it. But be involved with your kid. Put in the hard work, time and effort. If you have the chance to work with other autistic kids, it would enhance your understanding of autism. So take up such opportunities. Seek community support. It has been very helpful for us. I would also advise them to reach out to parents who are encouraging especially in the beginning stages as they give hope. Start as early as possible. Therapy is the best thing to do, but do some research as well as to what would work for the child and the family. According to me, the most important thing of all is to take support from wherever and whenever possible.

HM - Start with ABA. There is no cure to Autism, but it is manageable. So have hope in that and continue to work. Don't waste time and money on offerings/ astrology/ priests etc., while you are still figuring out Autism.

SS - Be strong and give all your attention to your kids while they are growing up. Don't wait for a miracle to happen, it is not going to happen. Instead, work with your kid.

SG - I know and understand that it will be very difficult to accept in the first because of the various expectations we formed as we were giving birth to the child, but eventually accept it with confidence. End of the day, this is still our kid. Be consistent with your effort and go ahead. Don't think like there is no life forward or nothing can be done. There will be positive sides, so try and look at them. With our kids, even little things make a lot of difference. Enjoy them! Also, do not just aim to put them in a normal school. Think through your decisions and think from the child's perspective as well. Do what would be best for the child. Our children's needs are different.

## 6 Getting a diagnosis

### 6.1 The importance of diagnosis

One of the questions that parents usually have is about the need for diagnosis. Many times parents do not want to get a diagnosis for a variety of reasons. Some parents argue that diagnosis just attaches a label and they are not comfortable with the label. Some parents feel that the child does not need a label as long as he/she is able to ‘cope’ with autism. Many parents are weary of the negative social implications of acknowledging their child’s autism.

So, why should one seek a diagnosis? The primary reason for either getting a diagnosis or not should be about the difference it makes to the child. When seen from that point of view, it seems to make more sense to get a diagnosis for the following reasons:

- A diagnosis provides parents with accurate information about the various difficulties the child may have. This will help them get appropriate help.
- A diagnosis helps get appropriate support for everyone, both the parents and the child
- Without a diagnosis, the child grows up without support and accommodations. However, many people on the spectrum are aware that they do not ‘fit in’. This could result in feelings of alienation. Also, the effort needed to ‘fit in’ and cope is hard work.
- In the absence of a diagnosis and an acknowledgement of their difficulties, children may be pushed to achieve goals that are set by the systems around them, instead of working on their specific difficulties. This may result in them growing up to be adolescents that have completed school and cleared exams but otherwise not functional for their age.
- As the child grows up to be an adult, and social and emotional demands on them increase, they may not be able to cope. In the absence of a diagnosis, it may lead to feelings of inadequacy and can lead to depression and other mental health issues.
- A diagnosis helps people make sense of who they are and their life experiences.

### 6.2 When should parents go for screening and diagnosis?

Naturally, parents routinely observe and assess their child’s progress during the early years, a practice known as developmental monitoring. In this process, parents, family members, or caregivers closely follow a child’s development in areas such as play, learning, speech, behavior, and physical movement. This vigilance allows them to gauge whether the child is reaching the typical developmental milestones and promptly detect any concerns that may arise. It’s

advisable to maintain regular communication with the child's primary physician regarding their developmental progress. Additionally, doctors routinely evaluate a child's development during their regular check-up visits.

When there are concerns about the development of the child, parents should consult their primary care physician and they may be referred for further screening.

## 6.3 Diagnostic Process

While there are no definite known causes of autism, the process of diagnosing it often requires the involvement of multiple professionals and various assessments. As a result, it may not be a straightforward procedure, but early diagnosis is crucial for both the child and their family to enhance their quality of life and meaningfully navigate the condition.

### 6.3.1 Developmental Screening

If any delays or concerns are observed, the next step is to undergo developmental screening, a more formal evaluation of a child's developmental progress. This screening process is conducted typically by a developmental pediatrician/ psychologist. It entails the use of structured questionnaires and checklists covering areas like language, physical abilities, cognitive skills, as well as behavioral and emotional aspects.

In instances where there are concerns or if a child is at a higher risk for Autism Spectrum Disorder (ASD), such as having a family member with ASD, additional screening may be recommended. It's worth noting that developmental screening can be conducted as a standard part of a child's regular health checkup, even if there are no apparent concerns. The American Academy of Pediatrics (AAP) recommends developmental and behavioral screening for all children during regular visits at the ages of 9 months 18 months and 30 months.

In addition, AAP recommends that all children be screened specifically for ASD during regular visits at 18 months and 24 months.

### 6.3.2 Screening Instruments

Most often the Modified Checklist for Autism in Toddlers, Revised with Follow-Up (MCHAT - R/F) or the Childhood Autism Rating Scale (CARS) is used.

- [MCHAT](#) is a brief checklist of yes/no items for early detection among children 16 to 30 months of age.
- Childhood Autism Rating Scale (CARS) observes a child's behavior and uses a 15-point scale to evaluate a child's relationship to people, body use, adaptation to change, listening response, and verbal communication.

A well-executed screening will determine whether a more comprehensive assessment for autism is required. Additionally, it aids in the identification or exclusion of any other potential issues or conditions that may be present.

### **6.3.3 Screening outcomes and diagnosis**

Parental responses in the child's screening are highly significant. If all results are within normal parameters and parents have no concerns, that will conclude the process. However, if the child exhibits developmental challenges or if the doctor shares any concerns, they will direct the parents to a specialist for further evaluations, which may include tests to rule out other issues, such as speech-hearing impairment.

Once other conditions are ruled out, and the child meets the ICD (International Classification of Diseases)- 10 or DSM - 5 (The Diagnostic and Statistical Manual of Mental Disorders) criteria for Autism Spectrum Disorder, the child will be diagnosed with Autism Spectrum Disorder (ASD).

## **6.4 Next steps**

Based on the test results, the pediatrician may refer the parents for therapies (speech, behavioral, or occupational therapy). At this stage, it is vital that parents are taking informed decisions, understand the difficulties of their child and are aware and mindful of the choices they are making.

## **6.5 Screening and Diagnosis - A note for professionals**

A pediatrician typically serves as the initial point of contact for a child and their family within the medical field. Therefore, it is of utmost importance that pediatricians vigilantly monitor a child's natural development.

### **6.5.1 General signs**

- Does not respond to name by 9 months of age
- Does not show facial expressions like happy, sad, angry, and surprised by 9 months of age
- Does not play simple interactive games like pat-a-cake by 12 months of age
- Uses few or no gestures by 12 months of age (for example, does not wave goodbye)
- Does not share interests with others by 15 months of age (for example, shows you an object that they like)

- Does not point to show you something interesting by 18 months of age
- Does not notice when others are hurt or upset by 24 months of age
- Does not notice other children and join them in play by 36 months of age
- Does not pretend to be something else, like a teacher or superhero, during play by 48 months of age
- Does not sing, dance, or act for you by 60 months of age

### **6.5.2 Communication**

- Does not give or sustain eye contact
- Delayed speech and language skills
- Flat, robotic speaking voice, or singsong voice
- Echolalia (repeating the same phrase over and over)
- Problems with pronouns (saying “you” instead of “I,” for example)
- Not using or rarely using common gestures (pointing or waving), and not responding to them
- Inability to stay on topic when talking or answering questions
- Not recognizing sarcasm or joking
- Trouble expressing needs and emotions
- Not getting signals from body language, tone of voice, and expressions
- Restricted or repetitive behaviors and interests

### **6.5.3 Unusual interests or behaviours**

People with ASD have behaviors or interests that can seem unusual. These behaviors or interests set ASD apart from conditions defined by problems with social communication and interaction only. Examples of restricted or repetitive behaviors and interests related to ASD can include:

- Lines up toys or other objects and gets upset when order is changed
- Plays with toys the same way every time
- Is focused on parts of objects (for example, wheels)
- Gets upset by minor changes
- Has obsessive interests
- Must follow certain routines
- Flaps hands, rocks body, or spins self in circles
- Has unusual reactions to the way things sound, smell, taste, look, or feel
- Fussy eating habits
- Lack of coordination, clumsiness
- Impulsiveness (acting without thinking)
- Aggressive behavior, both with self and others
- Short attention span



### 6.5.4 Other Characteristics

Most people with ASD have other related characteristics. These might include

- Delayed movement skills
- Delayed cognitive or learning skills
- Hyperactive, impulsive, and/or inattentive behavior
- Epilepsy or seizure disorder
- Unusual eating and sleeping habits
- Gastrointestinal issues (for example, constipation)
- Unusual mood or emotional reactions
- Anxiety, stress, or excessive worry
- Lack of fear or more fear than expected

When any of these signs are observed, it is advisable to recommend that the family consult with a developmental pediatrician who can conduct more extensive screening and assessments.

## 6.6 Screening tools

Screening tools are assessments that identify at risk children. Children who are found to be at risk with the screening tool, should go for further assessments. Screening tool commonly used by clinical/ developmental psychologists and psychiatrists in India is

### 6.6.1 M-CHAT-R/F (Modified Checklist for Autism in Toddlers, Revised with Follow-Up)

The Modified Checklist for Autism in Toddlers, Revised with Follow-Up (M-CHAT-R/F; Robins, Fein, & Barton, 2009) is a two-stage parent-report screening tool designed to assess the risk of Autism Spectrum Disorder (ASD). The M-CHAT-R/F is freely available for download for clinical, research, and educational purposes. Here are the usage instructions:

- The M-CHAT-R can be utilized and scored during routine well-child care visits, and it is also suitable for specialists and other professionals to evaluate the risk of ASD.
- The primary objective of the M-CHAT-R is to maximize sensitivity, meaning it aims to identify as many cases of ASD as possible. Consequently, there is a relatively high rate of false positives, indicating that not all children who score as at risk will be diagnosed with ASD.
- To address this, the Follow-Up questions (M-CHAT-R/F) have been developed. Users should be aware that even with the Follow-Up questions, a significant number of children who screen positive on the M-CHAT-R will not receive an ASD diagnosis. However, it's

important to recognize that these children are at a heightened risk for other developmental disorders or delays, making it crucial to consider further evaluation for any child who screens positive.

### **6.6.2 Occupational Therapy Evaluation**

As an occupational therapist (OT), the evaluation of a child with autism involves a comprehensive assessment of various domains, including social, communication, cognitive, sensory, and motor skills. It is valuable to incorporate a sensory profile of the child and consider the results of assessments conducted by other professionals. The Autism Spectrum Disorder (ASD) assessment conducted by an occupational therapist can take place in diverse settings, such as at home, in school, or at one of our clinics.

During the ASD assessment, the occupational therapist, using their clinical expertise and specialized training, employs a combination of a sensory profile, autism checklist and clinical observation. The checklist and sensory profile is designed to gather information on how the child perceives and interacts with the world. For example, it includes questions related to the child's comfort level in social situations, their preference for solitary play versus engaging with others, and other factors that provide insights into their sensory experiences and responses. This multidimensional assessment approach helps tailor intervention strategies to meet the child's specific needs and challenges.

### **6.6.3 Speech and Language Evaluation**

As a Speech Language pathologist (SLP), one can conduct initial screenings to identify any communication and language delays or atypical behaviors that may be indicative of autism. SLPs can conduct comprehensive assessments to evaluate a child's communication and language skills. This assessment may involve evaluating speech and language development, as well as social communication abilities.

## **6.7 Diagnostic tools**

It's important to emphasize that while SLPs and OTs are experts in the area of communication and functional skills respectively, they do not have the authority to diagnose autism. The formal diagnosis of autism is typically made by a medical professional, clinical psychologist, or developmental pediatrician based on a comprehensive evaluation that considers various factors, including communication and language development, social interactions, and repetitive behaviors.

### **6.7.1 CARS - Childhood Rating Scale**

The Childhood Autism Rating Scale (CARS) has been updated as the CARS-2. The original CARS was a widely-used rating scale for autism, primarily designed for individuals with co-occurring intellectual functioning. However, it faced criticism for not accurately identifying higher-functioning individuals on the autism spectrum. The CARS-2 preserves the original CARS format for use with younger or lower-functioning individuals (now known as the CARS2-ST or “Standard Form”). Simultaneously, it introduces a distinct rating scale designed for higher-functioning individuals (referred to as the CARS2-HF or “High Functioning”).

Clinically, the original CARS was sometimes misused as a parent questionnaire, but it was originally intended as a clinician rating scale to be completed following direct observation of the child by a professional knowledgeable about autism, who had also received some brief training on how to assess the CARS items. The CARS-2 maintains this format. Parent input can be gathered using the CARS2-QPC (Questionnaire of Parent Concerns), a form that parents use to document their observations (although it is not scored).

Specific guidelines for usage include: + CARS2-ST can be employed with children under the age of 6, or over the age of 6 but with an estimated IQ of 79 or lower, or if there is a significant communication impairment. + CARS-HF is administered to children aged 6 or older, with an estimated IQ of 80 or higher, and who possess fluent communication skills.

### **6.7.2 Autism Diagnostic Observation Schedule (ADOS) - (ADOS; Lord, Rutter, DiLavore, Risi, 1999)**

The Autism Diagnostic Observation Schedule (ADOS) is considered the ‘gold standard’ for assessing and diagnosing autism and pervasive developmental disorder (PDD) in individuals of all ages, developmental stages, and language abilities. This semi-structured assessment is versatile and can be applied to evaluate individuals suspected of having autism, ranging from toddlers to adults, and encompassing those with a wide spectrum of language skills.

The ADOS comprises four distinct modules, each of which can be administered in a relatively short timeframe of 35 to 40 minutes. The module selected for assessment depends on the individual’s expressive language level and chronological age. Guided by the instructions in the manual, the appropriate module is chosen for each person. Module 1 is designed for children who do not consistently use phrase speech, Module 2 for those using phrase speech but not verbally fluent, Module 3 for fluent children, and Module 4 for fluent adolescents and adults. It’s worth noting that the ADOS does not specifically address nonverbal adolescents and adults within the autism spectrum. During the ADOS assessment, there’s a 30- to 45-minute observation period that offers ample opportunities for a trained administrator to observe social and communication behaviors relevant to the diagnosis of pervasive developmental disorders. As the ADOS is conducted, observations are recorded and later coded to formulate a diagnosis. Cut-off scores are provided for both the broader diagnosis of PDD/atypical autism/autism

spectrum and the more traditional, narrower concept of autism. By offering standardized materials and ratings, the ADOS provides an evaluation of autism spectrum disorders that remains independent of language capabilities.

### **6.7.3 Autism Diagnostic Interview, Revised (ADI-R) - (ADI-R; Couteur, Lord, Rutter, 2003)**

The Autism Diagnostic Interview, Revised (ADI-R) is a structured interview employed for the purpose of diagnosing autism, planning treatment strategies, and distinguishing autism from other developmental disorders. Having been used in research studies for many years, this comprehensive interview is an invaluable tool for conducting a thorough assessment of individuals suspected of having autism or related autism spectrum disorders. The administration and scoring of the ADI-R typically take between 1 1/2 to 2 1/2 hours.

To administer the ADI-R, a skilled clinical interviewer engages in a structured dialogue with a parent or caretaker who possesses in-depth knowledge of the developmental history and current behaviors of the individual being assessed. This interview can be utilized for assessing both children and adults, provided their mental age is above 2 years and 0 months.

The ADI-R consists of 93 items and focuses on three key functional domains: Language/Communication Reciprocal Social Interactions Restricted, Repetitive, and Stereotyped Behaviors and Interests

Following highly standardized procedures, the interviewer records and codes the responses provided by the informant. The interview questions cover eight distinct content areas:

- The subject's background, including family, educational history, previous diagnoses, and medication use.
- An overview of the subject's behavior.
- Early development and achievement of developmental milestones.
- Language acquisition and potential loss of language or other skills.
- Current functioning related to language and communication.
- Social development and play.
- Interests and behaviors.
- Clinically relevant behaviors, such as aggression, self-injury, and possible epileptic features.

Unlike tests, the ADI-R is an interview process that focuses on behaviors that are uncommon in individuals not affected by autism. As a result, it yields specific results rather than relying on scales or norms. These results can be used to support a diagnosis of autism or to determine the clinical needs of various groups in which a high prevalence of autism spectrum disorders might be expected. This includes individuals with severe language impairments, certain medical conditions, congenital blindness, or those who have experienced institutional deprivation.

Here is a comprehensive [note](#) on autism assessment, screening tools and communicating with parents.

## 6.8 Revealing the diagnosis to parents

Absolutely, revealing an autism diagnosis to parents is a crucial and sensitive step in the process. It's essential for professionals to approach this conversation with empathy and provide guidance on the next steps. Here are some suggestions for professionals on how to convey the diagnosis and offer support to parents:

- **Choose the Right Setting:** Find a quiet and private space to discuss the diagnosis, ensuring that you have enough time for the conversation without interruptions.
- **Empathetic Communication:** Start by expressing empathy and understanding. Acknowledge the emotions they may be experiencing, which can include relief, shock, denial, or a range of other feelings.
- **Provide Information:** Explain the diagnosis clearly and in simple terms. Offer educational materials or resources that parents can take home and review at their own pace. This might include brochures, websites, or books.
- **Answer Questions:** Encourage parents to ask questions and address any concerns they may have. Be patient and provide honest, accurate information to the best of your knowledge.
- **Offer Emotional Support:** Let parents know that their feelings are valid and that they are not alone. Mention local or online support groups or organizations where they can connect with other parents in similar situations.
- **Discuss Treatment and Intervention Options:** Depending on the child's needs, provide information about available treatment and intervention options. This might include therapies like Applied Behavior Analysis (ABA), speech therapy, occupational therapy, and more. Discuss the benefits and potential next steps.
- **Referrals:** If necessary, provide referrals to specialists or service providers who can further assess and assist the child. Explain the roles of these professionals and the importance of early intervention.
- **Develop a Care Plan:** Work together with the parents to create a care plan tailored to their child's specific needs and strengths. This plan may involve therapies, educational programs, and other services.
- **Legal and Financial Guidance:** Discuss any legal and financial matters, such as eligibility for government programs, insurance coverage, and educational rights, to ensure parents are aware of available resources.
- **Encourage Advocacy:** Encourage parents to become advocates for their child's needs and rights. Provide information about special education services, Individualized Education Programs (IEPs), and the importance of being involved in their child's educational journey.

- **Recommend Reading Materials:** Suggest books, articles, or online resources that can help parents better understand autism and learn strategies for supporting their child.
- **Follow-Up:** Schedule a follow-up appointment to check on the family's progress, address any new questions, and assess how the child is responding to interventions.

Remember that every family's situation is unique, and the way they react to the diagnosis can vary greatly. Your support, understanding, and guidance can make a significant difference in helping parents navigate this challenging but important phase in their child's life.

## 6.9 Diagnosis for adults

Autism Spectrum Disorder is a neurological condition typically identified in childhood, which may raise questions among adults about the possibility of developing autism later in life, particularly if they've observed symptoms resembling autism.

Due to the basic nature of the disorder, it is not possible for adults to acquire autism. Autism arises from atypical brain development, and by adulthood, the foundational neurodevelopmental processes are already complete. Thus, it is impossible to develop autism later in life. However, autism symptoms can start to show up/ affect later in life and the diagnosis of Autism can happen late for some individuals due to a variety of reasons:

- **Masking and Camouflaging:** Many individuals, especially those with higher-functioning forms of autism, may develop coping strategies to mask their autism traits and fit in socially. This masking can make it challenging for professionals to recognize the signs of autism.
- **Gender Differences:** Autism is often underdiagnosed in girls and women, as the diagnostic criteria were historically based on male presentations. Girls with autism may exhibit different social and behavioral traits that are less recognizable as typical autism symptoms.
- **Mild or Subtle Symptoms:** Some individuals with autism have milder or subtler symptoms that may not be as noticeable in childhood but become more apparent as social demands increase in adolescence or adulthood.
- **Co-occurring Conditions:** Individuals with autism may have co-occurring conditions, such as anxiety, depression, or attention deficit hyperactivity disorder (ADHD), which can complicate the diagnostic process and delay recognition of autism. They are often secondary conditions that occur when the autism is left untreated. It takes a keen eye and specialist who is well-versed in the nuances of autism to identify autism symptoms in adults.
- **Late Recognition of Differences:** Some families and individuals may not recognize autism traits until later in life, especially if they have limited exposure to autism or were unaware of the spectrum's diversity.

- **Change in Life Circumstances:** Life transitions, such as moving to a new environment, starting a new job, or entering college, can highlight social and communication challenges, prompting individuals to seek assessment and diagnosis.
- **Access to Services:** Limited access to healthcare or diagnostic services can delay the identification of autism. In some regions, diagnostic resources may be limited, leading to later diagnoses.
- **Stigma and Misunderstanding:** Social stigma or misunderstanding of autism can deter individuals and families from seeking diagnosis or support until later in life. “He/she will start talking when she is 5 or 6 years old. Their uncle/dad also started talking late only. Let’s wait.”

In most cases, it could be a combination of these reasons. The family is not aware of Autism and its symptoms, the child is bright academically and somehow manages to mask the symptoms.

As Samriddhi Malhotra, an individual on the autism spectrum, diagnosed in her 30s, shares: “My family couldn’t understand this because I was considered academically bright. Because of these ‘odd’ behaviours, people would say things like ‘she’s so careless and haphazard’ or ‘she’s lazy’. As an adult, I wouldn’t always understand social cues, the dynamics in a friend circle and the subtext and subtleties of what people say. But, over the years, I learnt to master them almost like a science. Piecing it together logically, like, oh, this is what people mean when they say this or that, and I learnt to adapt.”

### **6.9.1 Signs to look out for**

Symptoms of autism in adults closely resemble those in children, such as difficulties in social situations, obsessive interests, and strict adherence to routines. Key symptoms that are often observed in adults with autism include:

- Difficulty understanding other people’s feelings or reactions
- Social anxiety
- Trouble making and keeping friends
- Coming off as brutally honest and not realizing they’re offending others
- Not being interested in others’ points of view or feelings
- Difficulty expressing how they feel
- Interpreting things very literally or in black and white
- Stuck in having the same routine every day and being uncomfortable if it is interrupted or threatened to be changed

### **6.9.2 Diagnostic tools**

Since symptoms are not very different from what we observe in a child, the diagnostic process would be more or less similar. In most cases of adolescents, it would be the school that first

reports concerns and then with the help of a psychologist one may undergo the diagnostic process. In adults, it could pose some challenges because symptoms of other disorders could be overlapping with autism symptoms. Either ways, a combination of assessments and clinical judgements could be used to diagnose older people. Some tools are:

- Autism Diagnostic Observation Schedule (ADOS) - (ADOS; Lord, Rutter, DiLavore, Risi, 1999) The Autism Diagnostic Observation Schedule (ADOS) is considered the ‘gold standard’ for assessing and diagnosing autism and pervasive developmental disorder (PDD) in individuals of all ages, developmental stages, and language abilities.
- Autism Diagnostic Interview, Revised (ADI-R) - (ADI-R; Couteur, Lord, Rutter, 2003) The Autism Diagnostic Interview, Revised (ADI-R) is a structured interview employed for the purpose of diagnosing autism, planning treatment strategies, and distinguishing autism from other developmental disorders.

Receiving an autism diagnosis according to a recent study with 9 adults over the age of 50, was seen as a positive development that enabled them to redefine their sense of self and gain a deeper understanding of their unique requirements. Before the diagnosis of autism, they had undergone treatment for anxiety and depression. They also reported experiencing behaviors associated with Autism Spectrum Conditions (ASC) during their childhood and often feeling isolated and aloof from others, growing up.

Although most people feel relief, it may also be accompanied with a feeling of guilt or grief over their life thus far, for they have to redefine themselves and their lifestyle. Therefore, it could be helpful to continue receiving psychological support while processing the diagnosis for themselves.



## 7 Just Diagnosed - Next Steps for parents

So your child is just diagnosed with autism.

First, convince yourself of the diagnosis. Take a second opinion or third opinion as necessary. Meet other parents. This is because if you are unsure of the diagnosis, you will be unsure of what to do and that will waste time. Try and understand the rationale for the diagnosis and the recommendations.

Second, recognise that you need help both in terms of expertise about autism and your own emotional health. You are most likely to be someone who does not know about autism. This diagnosis has come as a shock to you. You need help to make sense of it. Find support groups. Seek the help of experts, other parents, counsellors or family members. Remember that your child needs you in good shape.

Then, recognise that the child needs help. A child with autism has a different neurology than you. She may have sensory experiences that are very overwhelming. She might be struggling with social situations, and may have communication problems. While it might be difficult for neurotypical people to imagine these problems and their severity, these difficulties are real. Traditional parenting approaches may actually make it more difficult for the child. Also, every person on the spectrum has slightly different difficulties and experiences life differently. It is important for you as a parent to learn more autism, how it is impacting your child and then help her.

As you go ahead and make further decisions, remember that the objective is to help the child. The child needs help with sensory experiences, social issues and communication, at the very minimum. Every decision you make should be examined in the light of this question - how is this likely to help the child?

Look for more information to make sense of autism and what your child is going through - If you are already on this resource page, you have made a start!

Usually, the recommendation from developmental psychologists is to start therapies. Check the therapy centres around you. Examine their credentials and choose a good therapist. Here is a note on how to choose therapists. Once again, think about their recommendations and how they are going to help your child.

While the therapies and the amount of help your child needs may look overwhelming at first, a lot can be done using common sense. Think of how you can skill yourself up. What can you do at your end? In the Indian context, most institutions that deal with children - preschools,

schools, activity centres etc. - do not have much understanding of the needs of children on the spectrum. Remember that you cannot help other people working with the child unless you have a good sense of your child, her difficulties and how to respond to them.

All of this is going to require your time. Plan such that you are able to spend time with the child, interface with therapists and gradually develop an understanding of how to help her manage her daily life.

In summary, take care of yourself, understand your child and continue working. You can do this.

## **7.1 A few key questions**

Here is a short note on a few key questions parents tend to have when their child is diagnosed.

First is a set of questions like what caused my child's autism, is it my fault etc. This [note] (<https://disability.farmhill.in/disability-guides/autism/identification-causes.html#what-causes-autism>) talks about causes of autism. Hopefully, it will answer some of your questions and set you on the path of action.

### **7.1.1 Preschool versus therapies**

Another question is about preschool versus therapies. Parents usually think that the child needs to go to preschool. There is a belief that going to school and mingling with other children will help the child learn social and other skills. There is merit to this thought provided the child has the necessary skills and temperament. However, most of the children tend to need therapy help with basic social and communication aspects like greeting others, being around others, pointing to what they want, saying yes or no etc. Many children also tend to have sensory issues around sound, touch, smell, space etc. In such cases, it is a good idea to get help for the child and ensure she is comfortable in the preschool environment. Otherwise, just sending the child to school and bringing her back may not be helpful. Also, going to an environment which she does not feel comfortable in but is compelled to perform one way or the other can have long term negative consequences.

### **7.1.2 School readiness**

Another area where parents tend to be anxious is the school readiness of the child. Most parents believe that going to school is a necessary part of a child's life. So, when their three year old is diagnosed with autism, one of their goals is to equip the child with basic skills needed to go to a preschool or school. Some of these skills include basic rule following, sitting in one place, playing nicely, being social with other children, etc. Some parents also believe it

is important for their children to learn academic skills like reciting the alphabet, a few rhymes etc.

While going to school may help a child acquire a set of necessary skills, children on the spectrum often do not learn by imitating others. They need help with navigating day to day environments due to their sensory and communication challenges. Many children tend to engage in what we think of as inappropriate behaviours - screaming, biting, scratching, just following someone around, watching things go round and round, flapping, constantly humming, zoning out etc. These are all their responses to the difficulties they are facing.

In such a scenario, it is more important to address the child's primary difficulties and equip her with some basic skills before sending her to an environment like a preschool.

In summary, once again, the answer to whether a child should go to preschool or learn to be school ready depends on the same question - is it good for this child? If the child is able to navigate the environment, then the answer is yes. Else, no.

## 8 Early Intervention

Once a child is diagnosed with autism and the parents have made some sort of peace with the diagnosis, the next question is, what do we do to help the child?

This is when we talk about a variety of approaches called ‘early interventions.’ Early interventions like occupational therapy, speech therapy, and in some cases behavioral therapy are routinely recommended for children on the autism spectrum. A variety of other supplemental approaches like play therapy, music therapy, art therapy and in some cases horse therapy, water therapy and horticulture therapy are also offered.

### 8.1 Early Intervention Goals

However, before we go further into what these therapies are and how to choose them, it may help to stop and ask what our goals are while we put the child through these early interventions. Yes, the child is on the spectrum, yes, she has certain challenges but then, what should early intervention help the child with? Once we are clear about the goals of for the child, we can go ahead and talk about choosing interventions accordingly.

To start with, early childhood development goals for children on the spectrum are not different from the same goals for children in general. In both cases, one is looking for development along physical, social, cognitive, and emotional dimensions. However, children on the spectrum are likely to have a variety of specific challenges in these areas, and therefore, the goals are likely to be more specific. They may also find it difficult to learn these behaviors from the environment by observing and copying adults and other children, and so, may need suitably designed interventions and therapies.

### 8.2 Communication Goals

Children on the spectrum tend to face challenges related to speech, language, and communication. Some children may not be able to speak at all, due to poor motor coordination and other physical and neurological difficulties. Some children may be able to produce all sounds but limit their verbal interaction to a few words and not sentences. In some cases, children may be able to produce language fluently, as in be able to speak full sentences, recite poems etc. but may not be able to use language to communicate by asking questions, making observations

etc. Many children may not understand verbal inputs and instructions. Some may be able to understand but may not be able to respond. Even in cases where children are unable to speak, they may show a willingness to communicate if the speech barrier is removed. In most cases, parents manage by trying to guess what the child means or wants. As the child grows up, this does not work and the inability to communicate leads to anxiety and other difficulties. So, an important goal is to help children develop a channel for two-way communication either using speech or using other alternative forms of communication.

### **8.3 Social Goals**

Children on the spectrum also have a variety of social difficulties, starting with not responding when parents call their name, not being able to interact with parents. Children may not want to interact with peers or may not know how to take part in interactive games. They may behave inappropriately as they do not understand the rules of social behavior. For example, when in a play area, they may just follow other children around, copy their actions or snatch toys from others. So, teaching appropriate social behaviors and helping children cope with the demands of everyday social interactions at home, play areas and public places is another goal.

### **8.4 Physical Goals**

Children on the spectrum may have physical challenges, with movement and balance. For example, many children walk on their toes, or find it difficult to hold erect posture while walking. Some are not able to balance naturally and so might find it difficult to walk up and down stairs, step over small obstacles like doorsteps etc. A few children may experience significant difficulties in coordinating their movements, to the extent of not being able to move around or use their hands without assistance. Many children also present with low muscle tone and overall poor motor coordination. One of the goals of early intervention is to help children develop better motor coordination and be able to navigate their world comfortably.

### **8.5 Sensory Goals**

Children also present a variety of sensory challenges. Due to their neurological uniqueness, some children may have a different sensory experience than others. For example, some children are overly sensitive to the sound of a pressure cooker whistling. They may close their ears, run away, or show other unusual forms of distress around the noise. Some children find it difficult to handle different textures either to touch or to mouth. They may refuse to eat certain kinds of foods and may prefer to stick to one or two items of food. This preference might pose significant challenges when children end up eating only chicken nuggets or fruits and milk for

years together. The interventions we choose need to address the sensory challenges of the child.

## **8.6 Behavioral and Emotional Goals**

They may also experience a variety of behavioral and emotional challenges. Many children do not like to be disturbed when they are engaged in an activity and may find it difficult to transition from one activity or physical space to another. For example, a child might go to the play area and might resist coming back home. Or she might be playing with toys and may resist moving to the dining area for lunch. Children may also appear to not understand emotions – they find it challenging to read the emotion from facial expression and body language. Young children may not have enough linguistic and cognitive ability to understand emotions in the abstract. Guiding and helping children manage these variety of challenges needs to be among the goals of early intervention.

## **8.7 Key Focus**

It is important to understand that the way a child experiences autism and the way it shows up through her behavior in the environment, comes from a combination of multiple factors. A child may not like the texture of food presented to her, may have a severe sensory response to it and may start feeling distressed. Now, she does not have language or other tools to communicate the same, does not understand the social behavior expected of her, and may start experiencing a serious emotional response. When a helpful adult tries to touch her, feed her, or talk to her, the added physical and verbal inputs further aggravate her distress. If she does not get help at this stage, she may resort to what is seen as ‘inappropriate behavior’ to communicate her distress. For the others around her, it looks like the child was offered tasty food, was encouraged to try out and taste it, but instead of doing what is expected, she has started closing her ears, shouting, kicking, and throwing the food around. However, the way she experiences the entire interaction is hugely different.

As we have seen above, these difficulties sometimes work together to produce profoundly difficult outcomes, and it is important to take all these areas into account while planning the goals for early intervention. The focus is to understand the variety of ways the child is distressed by the environment, trace the distress back to various difficulties the child has, and try address these difficulties, while building her skills and competencies.

## 8.8 Choosing therapies

As discussed above, early intervention approaches need to address language and communication, social, physical, sensory, behavioral, and emotional goals. One therapy or approach is unlikely to address all these goals. Usually, a combination of behavior therapy like ABA (Applied Behavior Analysis), Speech and Language Therapy and Occupational Therapy are recommended. In addition, there are many other options like art therapy, music therapy, play therapy, animal therapy and so on. In the Indian context, there are alternatives like homeopathy, ayurveda and other traditional medicines. In addition, there are approaches like supplementary diets, medicines etc.

In this era of internet, news media and social media, each of these proven or unproven treatments are promoted through stories of success. Also, since every person's autism is unique, there is no one-size-fits-all solution to address the needs of every person on the spectrum. There is an overwhelming amount of information available, and making an informed decision becomes a challenge.

### 8.8.1 A few guidelines

You should learn to critically evaluate the information you receive. Get information from objective sources.

- People promoting various treatments may really want to help your child but may also have additional business motives.
- Anyone making claims about “complete recovery” from autism or “curing” autism should be viewed with suspicion. There are no cures for autism.
- The therapy approaches you choose should be evidence based. This means there should be enough scientific evidence that the approach works. Please remember that anecdotes are not evidence. Evidence-based practices include behavior approaches, developmental approaches like speech language therapy and occupational therapy.
- The therapy approach or the combination of approaches you choose should be able to address all the goals mentioned above for the child. The therapy approach should enable you to get an assessment of your child's specific needs in each of these areas and provide a comprehensive plan to progress on each of them.
- The demands of the therapy approach should be aligned with your family's capacity. For example, if a therapy approach needs you to spend more time with the child, you need to think of whether you can do this or not. It should also suit your financial ability.
- Complimentary approaches involving working with art, music, movement, animals, swimming, play should be treated as complimentary therapies. These can be practiced in addition to the evidence-based early intervention approaches above.

- Most methods of working with autism work slowly compared to the quick results one expects from medical treatments. That is the way it is. Anyone making time bound promises like “making your child school ready in six months” needs to be evaluated with caution.
- Since there are no medicines for the core symptoms of autism, one needs to be cautious about medication as a solution. Please evaluate the medication carefully. With young children, it may be best to avoid medication except in case of severe medical conditions like seizures.
- Extra caution is advised in using medication from ayurveda and other traditional medical systems. Most of these medications may be untested and unproven. Homeopathy may also be approached with caution – there are many controversies about whether it works at all. One of the problems with relying on unproven alternatives and medications is that these practices distract the family, divert attention from what needs to be done and may even interfere with the therapies.
- Similarly, the efficacy of diets and supplements is at best questionable. An additional problem with restrictive diets is that children end up being deprived of many commonly consumed food items and may be nutritionally impacted. This feeling of deprivation may result in behaviors like grabbing food from others. Additionally, in the Indian culture where most social occasions revolve around food, children may also be socially impacted. While putting a child on a diet may look like an easy option, it may end up having profound consequences.

**In summary, the key to choosing a good approach is to go with one that is evidence based, addresses the development needs of the child, and suits the family circumstances.**

## **8.9 Choosing a service provider**

After understanding the goals of early intervention and how to choose a therapy approach comes the question of how to choose a service provider for the therapy delivery and what to expect as you start working with them. Here are some thoughts that can help.

### **8.9.1 Multifunctional Approach**

As we saw earlier, all the goals and needs of a child cannot be addressed by one therapy or approach. When working with multiple therapy providers, the parents end up having to coordinate between different therapists. In such cases, it is important to ensure the therapists are willing to work with you for this purpose. A better case would be when therapists are



willing to talk to each other. The best is when a single service provider brings together the multifunctional team needed to meet all the therapy needs of your child.

### **8.9.2 Family Centred**

While it is the individual with autism that receives the therapy, it is the entire family that is dealing with autism. A service provider willing to take a family centric approach should be preferred. The service provider should understand the importance of co-opting the family, keeping them involved, and support and train them, as necessary. Parental involvement and training become especially important when young children are involved as the children may benefit more when therapists and parents understand each other and work together.

### **8.9.3 Assessments and plans**

When the therapy providers start working with your child, they should assess your child's needs and develop an Individual Education Plan. Please ask the service providers what kinds of assessments they conduct to ensure they identify the specific needs and goals of your child. These assessments are necessary, so an individually designed therapy plan is developed for your child. This plan should also include details of how they plan to track and communicate the progress to you. Please insist that this plan be made and shared with you in a reasonable time. It is also important that the providers explain this plan to you in a way you can understand. Ideally, this plan should include your input and requirements as well.

### **8.9.4 Clear communication**

At all points of time, the service providers should provide clear and transparent communication regarding the goals, the program, and the progress. Service providers should be willing to include parents and other caregivers in the therapy program.

### **8.9.5 Respect and dignity**

Any practice that does not respect the individual with autism and the caregivers needs to be questioned. Individuals need to be treated with dignity and respect, irrespective of the goals and efficacy of the therapy. Parents and caregivers must be treated with respect and recommendations delivered respectfully. Most importantly individuals and parents should never feel pressurized or bullied by professionals.

### **8.9.6 Training and qualifications**

Whether the therapy is provided by a single provider or by different providers, it is important for the parents to ensure that the therapists are well trained and qualified to deliver the therapy. Please do not hesitate to ask for details of certification and training.

### **8.9.7 References and history**

When choosing a service provider, please ask for references and learn about the experience of other parents who have worked with them before. Please learn about how the providers deal with children, parental questions, and concerns and what the outcomes of the therapy were.

**In summary, the therapy provider you choose should take a multifunctional approach, involve the family, provide comprehensive therapy plans and progress tracking and be respectful to the individual with autism and the family.**

## **8.10 Autism, Speech and Communication**

One of the key features of autism is communication challenges. These include not understanding the importance of communication, not being able or willing to communicate, not being able to communicate appropriately in social situations, etc.

In addition, an estimated 25 to 35 percent of people on the autism spectrum have little or no functional speech. Speech in autism is also along a wide spectrum, including those that speak fluently to those that do not speak at all. The usual words used in this regard are – minimally verbal for someone who uses little speech, nonverbal for someone with no speech and preverbal for young children.

Like in many areas related to autism, the current research on non-speaking autism is limited, and we do not really know what causes functional speech difficulties. A variety of causes for limited speech in autism are possible: auditory processing, the system in brain that interprets words, might be poor; there could be motor planning issues like speech apraxia that impacts peoples' ability to plan and coordinate mouth and tongue movements; differences in brain anatomy in the speech production network can also be involved.

### **8.10.1 Communication is not just speech**

However, there is a difference between speech and communication – speech is the ability to produce words, whereas communication is the ability to convey and receive meaning. It is a misconception that children who do not speak cannot understand or communicate. It is also not true that those that can speak can automatically communicate and understand others.

Also, people who do not or cannot speak do not have less intelligence scores than those who speak. They need communication as much as anyone else.

Living in a world that revolves around language, speech and communication can be particularly challenging for people on the spectrum and more so for those that do not use much speech. The current assumption is that people who cannot communicate become frustrated and that becomes a trigger for various other unhelpful behaviors. Whether it is completely true or not, there is broad agreement among experts that having a two-way communication channel is important for everyone.

### **8.10.2 Looking beyond speech - AAC**

Speech is particularly difficult for some people on the spectrum. We do not understand the reasons for these difficulties, but recognize that effective communication is important for everyone, and that speech is not the only way to communicate. It therefore makes sense to look beyond speech and enable everyone to find a channel of communication, using augmented and alternative communication (AAC) as necessary. AAC is a broad category that includes sign language, gestures, pictures, written words, and electronic devices.

This is not to say that speech is not necessary or important. Speaking and understanding spoken language can make life significantly easier for people on the spectrum and their families. However, considering the difficulties they have with communication and speech, limiting oneself to speech-only approaches can be counterproductive. It is advisable to explore the use of AAC for communication, as early as possible.

AAC can provide a communication channel for people on the spectrum who have difficulties with speech and communication. It has been shown that even with people who speak, the use of AAC can make communication more effective, by providing a necessary scaffold. Also, the common apprehension that use of AAC stops children from acquiring speech is not true, as shown by a 2021 study, among others.

**In summary, communication is a key element of working with autism and needs to be highly prioritized. People who find it difficult to speak should be supported with augmented and alternative communication as needed.**

## **8.11 Speech Therapy is not just about speech**

Yes, speech therapy and speech therapists are not all about “speech.” A speech therapist is really a speech language pathologist (SLP), but they are not just about language either. The overall goal of SLPs is to help a person communicate in functional ways.

Communicating in functional ways certainly includes learning to use speech and language for communication but may also include learning to read nonverbal communication like facial

expressions and gestures, learning to communicate in social situations etc. When working with people on the spectrum, the focus of SLPs is to holistically improve the ability to communicate and that may include using augmented and alternative communication (AAC).

Communication and speech related challenges vary widely from person to person on the autism spectrum. Some individuals may not be able to produce any sounds, some may be able to produce speech but may not be able to use it to communicate, and at the other end, some may be able to speak fluently yet may have difficulty sticking to a topic or communicating appropriately. Accordingly, SLPs perform a variety of functions.

### **8.11.1 Functions of Speech Therapists**

- Prelinguistic skills – help children learn skills like eye contact, gestures, vocalizations
- Nonverbal communication – help people learn to notice nonverbal signs in a conversation
- Feeding interventions – some individuals tend to have difficulties with chewing, swallowing etc. Some SLPs are trained to help in these areas.
- Assisted and Augmented Communication (AAC) - SLPs can also train people in using AACs to communicate. These may include Picture Exchange Communication System (PECS), sign language or electronic devices.
- Speech fluency – SLPs can help people on the spectrum with speech clarity, and fluency.
- Articulation – Speech requires coordination of different structures. SLPs can help improve the muscle strength, coordination and manipulation needed to produce speech.
- Grammar – many children on the spectrum struggle with grammar and sentence structure. SLPs can help them understand language
- Functional Speech – echolalia, repetition of sounds, words and phrases is a common coping mechanism. SLPs can help in building functional speech.
- Social skills – SLPs can help coach people on the spectrum to communicate in different settings, either in one-to-one sessions or group sessions.
- Social communication – SLPs can help children use language for different purposes like demanding, informing, commenting.
- Transition to work – SLPs can also continue to help as the individual transitions to a work environment by coaching how to communicate in written and spoken forms.

When working with an individual on the autism spectrum, SLPs assess strengths and challenges and develop a program with goals for the person and the approaches to achieve them. This program then becomes the basis for working together and assessing the effectiveness of the therapy.

Parents of children on the spectrum should understand that the goal of the SLP is to facilitate communication and be willing to prioritize functional communication. **A two-way channel of communication is the most important need of a child on the spectrum.**

### **8.11.2 Choosing an SLP**

- SLP is an important member of the team of experts working with your child. Choose someone whose program matches your priorities and goals.
- Remember that functional communication is the priority, over speech or being able to repeat rhymes or learning alphabet.
- Ensure the SLP is willing to work with other experts either directly or through you.
- Work towards building transparency in your relationship with the SLP. You should know what is happening in the session and be trained to carry out some interventions at home, as needed.
- Choose someone who can help with AAC as needed, training you, the child and others who interact with the child.

**In summary, speech therapy is not just about speech or language but about holistic communication. A speech therapist is an important member of the team working with your child and should be chosen carefully to align with the child's goals and requirements.**

## **8.12 Occupational Therapy**

Many people on the autism spectrum face motor difficulties. They may have gross motor difficulties, such as a clumsy way of walking or difficulty with large motor movements or difficulties with fine motor skills like writing, coloring in the line or using scissors. Some may have trouble coordinating movements between the right and left sides of the body making it difficult to skip, jump, hop or get down the stairs. Some others may have trouble with hand-eye coordination making it difficult to catch a ball, hit a ball with a bat etc.

In addition to these motor difficulties, children on the spectrum may also struggle with low muscle tone, sensory processing issues (too much or too little response to sensory inputs such as sound, touch, smell etc.), as well as difficulties with proprioception and interoception.

It has been estimated in a 2020 study conducted in the US that as many as 87% of children between 5 and 15 years of age on the spectrum face motor difficulties. Yet, only about 30% of the children were receiving any therapy for the same.

Motor issues may appear in infancy where 1-month old infants who are later diagnosed with autism move their arms less, they may struggle to keep their head in line with shoulders when pulled up to sit at 4 months and may struggle to stand at 14 months.

Poor motor skills may contribute to and accentuate autism traits as motor issues can delay babbling, gesturing, and acquisition of new vocabulary. Lack of motor skills may also elicit less interaction from caregivers and provide children less prompts for learning. Poor motor skills later in childhood may make children on the spectrum reluctant to participate in physical activities, limiting opportunities for social interaction. Bad handwriting can impact academic performance. Since visual-motor integration skills are important for imitation and learning from others, lack of these skills can hamper social development. Thus, motor difficulties might have cascading effects on cognitive, social, and emotional development.

That is why occupational Therapy is among the top therapies recommended for autism. The general focus of occupational therapy is to improve the client's ability to participate in activities of daily living, which may include things like schoolwork to dressing and brushing teeth.

When an occupational therapist starts working with a child, they usually assess their support needs. They may use some tests like the school function assessment test (SFA), Children's Assessment of Participation and Enjoyment/Preference for Activities of Children (CAPE/PAC), Assessment of Life Habits (Life-H), Children Movement Assessment Battery for Children Second Edition (Movement ABC2), Sensory Integration and Praxis Test (SIPT) etc. In addition, the therapist may observe the child in a range of settings to see if they are able to complete tasks of daily living. For example, they may watch to see if a child can button a jacket, cut with scissors, play appropriately in the playground, etc.

Once the tests and observations are complete, they develop an individual plan for the child. The plan is personal and may include academic goals like using scissors, printing letters, using a paint brush; daily living skills like brushing teeth, zipping jacket, tying shoes; social functioning goals like catching a ball, jumping on trampoline etc.

Occupational therapists usually work with the children in occupational therapy rooms or sensory rooms equipped with exercise balls, swings, jump ropes and other equipment. Therapists use techniques to strengthen the child's hands, legs, and core, provide tools like weighted vests or large pencils to make some tasks easier etc.

The role of occupational therapists is not limited to working with children. They may work with adults to build living skills like cooking, cleaning etc. They may help with designing more comfortable workstations and equipment for adults working in offices. They can help in various areas of self-care, productivity, and leisure.

### **8.12.1 Sensory Processing and Occupational Therapy**

We rely on the information coming from our senses (sight, sound, smell, touch, taste) to make sense of the environment around us. People on the autism spectrum may have difficulties

dealing with the information coming in from different senses. A child may be distracted by the noise of a drill that you can barely hear. Another child may be feeling uncomfortable with the shirt label scratching on their neck. Yet another child might be getting overwhelmed with the perfume in the air. Too much sensory information can cause stress, anxiety, and physical pain. This can result in withdrawal, distressed behavior, or meltdowns.

### **8.12.2 Different sensory profiles**

People on the autism spectrum can be under sensitive, oversensitive or both (at separate times) to any of their senses. For example, people who are under sensitive to sight may not have a good depth perception and may not be able to catch or throw. Those who are oversensitive may find it difficult to sleep even with a little light around. People who are under sensitive to sound may prefer crowded, noisy places or bang doors and objects. Those that are oversensitive to sound may not be able to filter out background noises, leading to difficulties in concentrating. People under sensitive to smell may sometimes lick things to get a better sense. Those that are oversensitive may have difficulties using toilets or may dislike people with distinctive, strong perfumes. People under sensitive to taste may like very spicy food. They may also eat or mouth non-edible items such as stones, dirt, soil, feces etc. This is known as pica. People with sensitivities to taste may end up with a restrictive diet. People under sensitive to touch may hold others tightly, enjoy heavy objects like weighted blankets on top of them. They may have a high pain tolerance and may self-harm. Those oversensitive to touch may not like to be touched and may have difficulties brushing and washing hair. They may also tolerate only certain types of clothing or textures.

### **8.12.3 Working with sensory processing**

In general, people who are under sensitive to a sense seek out more of that sensory input to calm themselves, to relieve anxiety and sometime just for pleasure and relaxation. Those that are oversensitive try to avoid that sensory input for the fear of being overwhelmed. People on the spectrum may need help in handling these sensitivities. The general approach is to provide manageable alternatives to the under sensitive system and to slowly desensitize the oversensitive system through gradual exposure. For example, if a child is easily overwhelmed by sounds, she may close her ears every time someone speaks to her, losing out on useful information and learning opportunities. The therapy approach in this case would be to offer her earmuffs that can decrease the intensity of the noise, couple the sound input with a visual and gradually help the child be comfortable with the sound of spoken voice. A child who is under sensitive to touch may keep scratching walls or rough surfaces for stimulation, causing injury to fingers and nails in the process. In this case, the therapist may offer a manageable alternative by giving her a polystyrene sheet to scratch and get the sensory input.

#### **8.12.4 Sensory Integration Therapy**

Occupational therapists trained in dealing with sensory processing difficulties can help by providing interventions to target each sense, helping the child's nervous system become more organized and regulated. Sensory integration therapy is one of the names given to such an approach. One of the options is to put a child on a sensory diet, a specially designed daily activity plan that provides the child with a variety of sensory activities. The focus is to help the child be regulated and improve attention and focus. When the child's arousal level is too low, they can be given stimulating activities like dancing, singing, light exercise etc. When the arousal level is high, they can be given calming activities like going for a walk, reading, listening to music etc. It is important to choose activities that suit each child and provide the appropriate level of arousal or relaxation.

#### **8.12.5 Sensory Circuits**

Sensory circuits are another tool used by therapists to help children achieve a ready-to-learn state. Each session includes three elements.

- Alerting activities to stimulate the body's central nervous system in preparation for learning. For example, spinning, bouncing on a gym ball, skipping, star jumps
- Organizing activities which demand brain and body to work together. For example, balancing on a wobble board, log rolling, juggling
- Calming activities give an awareness of their body in space and increase the ability to self-regulate sensory input. For example, heavy muscle work and deep pressure like wall pushes, pushups, using weights.

**In summary, some people on the spectrum may have sensory processing difficulties that make it difficult for them to process sensory information. Occupational therapists trained in sensory integration can help by designing sensory diets and other programs that can help children be more regulated, calmer, and focused, thereby reducing anxiety and increasing opportunities to thrive and achieve in the overwhelming environment in which we now live.**

### **8.13 Beyond the five senses**

We are all familiar with the five senses – sight, sound, touch, smell, and taste. However, there are three other senses that are not as well known. In the context of autism, it is important to know about these senses as people on the spectrum tend to experience processing difficulties related to these senses as well.



The three other senses are – Proprioception, Interoception and Vestibular system. Proprioception is our body's intrinsic ability to sense and position itself in space. We have a set of sensory receptors in our muscles, joints, and tendons, that help us with full-body awareness. Interoception is our ability to sense our internal body states and emotional states, using the information we receive from receptors on our internal organs. The vestibular system is in our inner ear and helps us with our sense of balance and body control.

### **8.13.1 Proprioception**

People on the spectrum can have proprioceptive difficulties that make it difficult for them to apply the right amount of pressure for a task. They also bump into things often and may have difficulties walking up and down stairs. They may struggle while feeding themselves, and frequently miss the mouth. They may also struggle with posture and movement fluidity when faced with a new motor task. They may underperform in sports and may struggle to remember the body posture associated with a new skill.

Proprioception difficulties can be addressed by occupational therapists using sensory integration techniques and practicing gross and fine motor movements with visual assistance like looking into a mirror while performing a task.

### **8.13.2 Interoception**

Regarding interoception, people on the spectrum may be less aware of what is happening inside their bodies. The interoception center in our brains is called the insular cortex, which also plays a vital role in the perception of pain, primary emotions like joy, anger, awareness of bodily states like feeling of cold, and in the perception of being a self. Therefore, interoception difficulties may be responsible for emotional processing issues, problems in identifying and describing emotions, and difficulty with empathy and perspective taking. At an extremely basic level, people on the spectrum may not be able to recognize when they are thirsty, or hungry. They may not realize when they are full and may tend to overeat. They may find it difficult to self-regulate their emotions, attention, and behaviors. They may not be able to point to the source of their discomfort like where the pain is.

Interoception can be improved by practicing interoception awareness activities like guided self-body scans, deep breathing, guided progressive relaxation. Young children may need support with the help of timers for eating, drinking and toileting, portion control to help eat for balanced nutrition etc.

### **8.13.3 Vestibular system**

The vestibular system refers to the structures in the inner ear that detect movement and change in the position of the head. This is the system that tells us if our head is upright or

tilted, even with our eyes closed. Children who are oversensitive to this system can have fearful responses to ordinary movement activities like swings, slides, ramps etc. They may appear clumsy and fearful of moving in space. However, some children may actively seek intense sensory experiences such as excessive whirling, jumping, climbing heights, etc. Vestibular dysfunction can cause postural instability, gait dysfunction and impaired gaze. This can lead to delayed milestones such as sitting and walking and poor motor coordination. Vestibular dysfunction may be accompanied by auditory sensitivity and dysfunction.

Repetitive actions like mild rocking can help calm down an over stimulated vestibular system. Providing structured activities that satisfy an under sensitive system seeking stimulation can also help.

In summary, the sensory processing disorder, and related difficulties in autism go beyond the five better known senses and may impact proprioception, interoception and vestibular system. The impact of these dysfunctions is still being researched and understood. An occupational therapist can provide sensory integration therapy to help with these difficulties.

## 9 Caution: Cures and Remedies

In this section we examine some of the alternative treatments to autism.

### Caution

Please note that the alternative treatments for autism discussed here are considered ineffective and some can be outright dangerous. These are included to provide a cautionary note and are NOT recommended.

### 9.1 Why do people seek alternative treatments?

There are many alternative treatments or protocols advised for conditions like diabetes, skin allergies or even cancer. Similarly, there have been many alternative treatments that have been and continue to be practiced for autism, despite no evidence of effectiveness. In some cases, people believe in and are willing to try alternative approaches, even when there is evidence of harm.

What prompts people to try these approaches, against all reason?

#### 9.1.1 Newly discovered conditions

When a condition is newly discovered or becomes widespread, and an effective treatment is yet to be determined, it is typical for people to explore a range of potential causes, treatments and “cures”. An approach that might have been effective for a different condition that appears to be related may be tried. For example, in the case of COVID, when the infection hit, there was no cure. Healthcare workers primarily focused on providing symptomatic treatment and tried approaches that worked for other infections and respiratory conditions like flu. A variety of treatments ranging from allopathy, ayurveda to homeopathy were tried before a vaccine was developed and a protocol that works was devised.

### **9.1.2 Seeking better results with less effort**

Even when some understanding and evidence-based interventions are available, there might be a desire to seek alternative solutions in the hope of achieving better or anticipated results, and with lesser effort. For example, it is understood that diabetes cannot be cured but can be managed with lifestyle changes. Many people find these lifestyle changes difficult to make and maintain. They seek alternative approaches instead.

### **9.1.3 Inability to critically evaluate**

It is also possible that people may not have the mental capacity to critically evaluate the feasibility of promised cures versus the potential harm as they deal with the stress placed by the condition they are dealing with. Sometimes they also believe that they have tried everything there is to try and there is no harm in trying one more thing. You see this approach in people dealing with cancer and such life threatening conditions.

## **9.2 The case of autism**

Many of these factors seem to be working in the case of people who are willing to try alternative treatments for autism. Autism has been a poorly understood condition whose cause is not clearly known. It impacts children and it is no secret that many of us do not understand parenting, education and child development well enough. When a child is diagnosed with autism, parents do not immediately understand all the implications and its lifelong impact. Many see it as improper behavior on the child's part or a set of symptoms that are preventing the child from going to school and seek to address them quickly, in time for the child to join a school. They also hear from healthcare professionals that there is no medical cure for autism. The evidence based interventions are behavioral, requiring significant time, energy and resource commitment from everyone involved. Most people are stressed out with the effort of bringing up the child and an autism diagnosis just makes things worse.

It is in such an environment that alternative approaches, promising cures or at least significant improvements quickly, with little or no effort, become popular. Some of these are approaches that work for another condition, e.g. chelation, which is a treatment for heavy metal toxicity. Chelation was tried for autism initially because symptoms of autism resembled mercury poisoning and later because people believed autism was caused by mercury from vaccines. Similarly, hyperbaric oxygen therapy works for traumatic brain injury and was tried for autism because people believed increasing oxygen supply to the brain can help autism. There is homeopathy, which has been tried for everything that is not well understood in current medical science. In the Indian context, there is ayurveda, siddha and other alternative systems offering everything from remedies to cures for autism. Many others like restrictive diets are approaches that claim to cure a wide variety of conditions.

### 9.3 Caution: Alternative approaches

Currently, we understand Autism as a brain wired differently. Symptoms of autism may pose some social challenges for individuals in the spectrum, for which one can seek symptomatic treatment to enable a functional and meaningful life within the society. The cause of autism is unclear and so is the cure for autism. Scientifically, no evidence supports the existence of a “cure” for autism. Evidence-based interventions aim to manage specific symptoms, yet other interventions driven by speculative theories of “curing” autism not only lack efficacy but can also result in severe side effects. Consequently, interventions that demand careful attention and caution include:

- Chelation
- Miracle Mineral Solution (MMS)
- Stem cell therapy
- Hyperbaric oxygen therapy (HBOT)
- Restrictive diets
- Homeopathy
- Ayurveda

### 9.4 When to be critical

Some treatments might appear appealing due to their success in addressing a different condition with similar symptoms, success stories from certain individuals, or alignment with personal beliefs or expectations of a cure. However, it is important to exercise serious caution when the intervention is promoted in the following ways:

- The treatment lacks substantial scientific evidence or is based on unverified claims.
- There is pressure or persuasion to adopt the intervention without clear and transparent information about its potential risks.
- The treatment is presented as a “miracle cure” or a one-size-fits-all solution for a complex condition like autism.
- Claims of success are primarily anecdotal and not supported by reliable research or clinical evidence.
- The intervention involves risks or potentially harmful side effects that are not adequately addressed or disclosed.

### 9.5 A guide to decision making

Distinguishing between legitimate therapies and questionable ones can be challenging, particularly when conventional approaches seem ineffective for parents of autistic children. While

alternative treatments may, in some cases, offer assistance, it's crucial to recognize that no single method is universally effective for treating autism. If you are contemplating a non-traditional option, the following questions can guide your decision-making process:

- Who is recommending this option and what do they have to gain if you accept?
- What do reliable sources such as the CDC (Centers for Disease Control and Prevention) or NIMH (National Institute of Mental Health) or The Central Drugs Standard Control Organisation (CDSCO) have to say about this particular method?
- What do established organizations led by people living with autism, such as the Autistic Self Advocacy Network (ASAN), Action for Autism (AFA) and the Autistic Women and Nonbinary Network (AWN) have to say about this therapy?
- Is this method aimed at “curing” autism?
- What are the potential risks related to using this treatment?
- What methods are in place to ensure the person's safety?
- How will you measure changes or improvements?

## 9.6 Chelation - A Dangerous approach

### Caution

Chelation is not recommended for autism. It can have dangerous side effects.

### 9.6.1 What is chelation?

In chelation, the aim is to administer medications (chelators) that bind with metals in the body and remove it from the system via urine when the medicine itself is excreted. This has been useful to treat heavy metal toxicity. Most commonly used medications are dimercapto-succinic acid (DMSA) or ethylenediaminetetraacetic acid (EDTA). This treatment is typically administered intravenously or orally under medical supervision following a detailed baseline assessment of metal content in the system, usually with a urine test.

### 9.6.2 History of chelation

Chelation process dates back to 1935 when it was used as binding and extracting agent of calcium in the dyeing industry. The use of Chelation therapy in humans started between the 1950s and 1960s when it was used in patients with hypercalcemia and lead poisoning, consequently showing improvements in their cardiovascular condition. Since then it has been established as an effective treatment for lead poisoning or any heavy metal toxicity for that

matter and as anticoagulants. Between 2002 and 2007, despite several warnings and prohibitions by the FDA (Food and Drug Administration), chelation gained popularity in the U.S. for treating heart conditions and other health issues.

However, due to its intensity and potential harmful side effects, it is strictly administered under medical supervision. In 1989, a “Protocol for the Safe and Effective Administration of EDTA” was established and later updated. This comprehensive protocol establishes strict criteria for patient selection and urges clinicians to conduct an initial assessment of renal function using the Cockcroft-Gault equation. It further emphasizes the continuous monitoring of renal function throughout a series of chelation treatments. Additionally, emergency procedures are outlined in case of adverse reactions during the process.

### **9.6.3 Why was Chelation tried for autism?**

It gained attention in the context of autism due to concerns about heavy metal toxicity in the systems of individuals in the spectrum, but scientific research hasn’t supported the theory that autism is caused by heavy metal toxicity. Some studies have suggested that children with autism may have higher levels of certain heavy metals in their systems, but the direct cause between heavy metal exposure and autism has not been established. One hypothesis that autism is caused due to exposure to heavy metals (mercury) through vaccines has been studied thoroughly and research suggests no causal link between vaccines and autism. Other theories of autism being caused due to intrauterine or environmental exposure to heavy metals is still under study and there is no established link as of now.

On the other hand, scientific research investigating the effectiveness of chelation therapy for autism remains limited and inconclusive. Clinical trials investigating the impact of chelation on autism symptoms have shown mixed or inconclusive results, and many of these studies have methodological limitations.

### **9.6.4 Caution**

Chelation therapy can be risky and has the potential for serious side effects such as hypocalcaemia (level of calcium in blood is too low), renal impairment and reported deaths. The presence of certain metals like calcium, copper, iron, magnesium, manganese, molybdenum, chromium, potassium, sodium, and zinc is essential to facilitate normal biological functioning of the human body. It is a cause for concern if there are lower or higher levels of these metals than what is required. It necessitates meticulous and supervised administration of medications to avoid excessive removal of metals. Medical organizations do not recommend chelation therapy for autism due to safety concerns.

Some researchers also suggest that due to the greater risks associated with chelation compared to its efficacy as a treatment for autism, it is advisable to first establish a definitive causal link between heavy metals and autism. This approach emphasizes the need to first validate the

relationship between heavy metal exposure and autism before further studying on chelation as a treatment.

Therefore, it is crucial for anyone, whether medical professionals or families, considering chelation therapy to conduct a thorough baseline assessment and cost-benefit analysis of the treatment before proceeding with it. There is no medical organization that is in favor of using chelation therapy for autism.

## 9.7 Miracle Mineral Solution (MMS)

### Caution

MMS is not recommended for autism. It can have dangerous side effects.

Miracle Mineral Solution (MMS) is a controversial substance promoted in alternative health circles. Marketed as a cure for various ailments, MMS is a combination of sodium chlorite and citric acid, creating chlorine dioxide. Advocates claim it can treat conditions like malaria, cancer, and even autism. However, its use is highly controversial and poses serious health risks.

### 9.7.1 MMS and Autism

MMS has been suggested as a remedy for autism, asserting its ability to alleviate symptoms and enhance well-being in individuals on the autism spectrum. It's essential to note that there is no scientific evidence supporting MMS for autism, and major health organizations strongly advise against its use.

### 9.7.2 History

Miracle Mineral Solution (MMS), found in 2006 by Jim Humble, has a controversial history, marked by its promotion as a supposed cure for various illnesses despite serious health risks associated with its use. Here's a brief overview of the history of MMS:

- **Origins in Water Purification:** MMS is derived from sodium chlorite, a chemical used in some industrial applications, including water purification. It was first promoted by Jim Humble, a former Scientologist, who claimed to have discovered its health benefits during a mining expedition in South America.



- **Promotion as a Health Supplement:** Jim Humble initially marketed MMS as a health supplement with the claim that it could cure numerous diseases, including malaria, cancer, HIV/AIDS, and more. He founded the Genesis II Church of Health and Healing to promote MMS as a sacrament.
- **Claims for Autism and Other Conditions:** Over time, MMS gained attention as a purported treatment for autism spectrum disorder (ASD) and other developmental conditions. Despite lacking scientific evidence, some individuals and groups advocated for its use in the autism community, claiming improvements in symptoms.
- **Legal Actions and Warnings:** Regulatory authorities, including the U.S. Food and Drug Administration (FDA) and other health agencies worldwide, raised concerns about the safety and efficacy of MMS. The FDA issued warnings about the potential dangers of consuming MMS, emphasizing its corrosive nature and adverse health effects.
- **Legal Challenges:** Legal actions were taken against individuals and organizations promoting MMS as a cure for various illnesses. Authorities cracked down on the sale and distribution of MMS, emphasizing its lack of approval for medical use and the risks it posed to public health.
- **Global Controversy:** MMS gained international attention and sparked controversy, with health agencies in multiple countries issuing advisories against its use. The substance became a focal point in debates about pseudoscience, unproven treatments, and the potential exploitation of vulnerable populations.
- **Continued Advocacy Despite Warnings:** Despite widespread condemnation and legal actions, there are continued reports of individuals advocating for and using MMS. Online platforms have been used to disseminate information about MMS, leading to ongoing concerns about its accessibility and use.
- **Ethical Considerations:** The promotion of MMS for serious medical conditions, including autism, raises ethical concerns within the medical and scientific communities. Advocates for evidence-based medicine emphasize the importance of protecting individuals from potentially harmful and unproven treatments.

The controversy surrounding MMS underscores the importance of relying on evidence-based medical practices and the need for public awareness regarding potential health risks associated with unproven treatments. In addition, the popularity of MMS at one time as a remedy for autism should make us all weary of the power of zealous beliefs supported with religious fervor and no evidence.

### **9.7.3 Caution:**

- **Lack of Scientific Support:** The endorsement of MMS as an autism treatment lacks scientific credibility. Rigorous clinical trials with proper controls and methodologies are absent, rendering any claims about its benefits for autism unproven.
- **Health Risks and Side Effects:** MMS contains chlorine dioxide, an industrial chemical. Ingesting it can lead to severe health risks, including nausea, vomiting, diarrhea, and

potentially life-threatening complications. The Food and Drug Administration has issued warnings about the dangers of MMS consumption.

- **Ethical Concerns:** Using MMS for autism raises ethical concerns, especially when targeting vulnerable populations like children with autism. Advocates for evidence-based medicine and ethical healthcare practices strongly caution against the use of unproven and potentially harmful substances.
- **Legal Implications:** Due to health risks, the sale and distribution of MMS as a medical treatment face legal challenges. Regulatory authorities take actions to prevent its promotion for therapeutic purposes, highlighting the potential harm to public health.

In conclusion, Miracle Mineral Solution (MMS) lacks scientifically proven benefits for treating autism or any health condition. Its use is associated with significant health risks, and regulatory authorities strongly discourage its consumption. Individuals and families seeking interventions for autism are urged to prioritize evidence-based treatments and consult healthcare professionals for the well-being and safety of those with autism spectrum disorder.

## 9.8 Stem Cell Therapy

### Caution

As of 2022, the use of stem cell therapy as a treatment or cure for autism is prohibited in India. This restriction has been implemented due to misleading promotions and false claims. The only way to legally and ethically access stem cell therapy is to participate in an approved clinical trial.

### 9.8.1 What are stem cells?

Stem cells are a group of cells that are present in our bodies through all stages of life. In fact, they are one of the first cells developed during the embryo stage. These cells, under the right environment, have the ability to generate new stem cells and also other cells with specialized functions (blood cells, brain cells, bone cells etc.) Because of this unique feature, stem cells play a key role in the development of newborn children and also in the restorative processes after a disease or an injury. Their ability to self-renew and multiply, ensures an ongoing source of new cells to replace old or injured ones. During the developmental years, this growth is vital for maturing into an adult. Once development is complete, this ongoing growth aids in healing and repairing damaged tissues or organs at a cellular level. These special characteristics make stem cells highly important in regenerative medicine, as they can create entire tissues and organs from just a small group of precursor cells. This characteristic of stem cells has kindled research interest in trying this as a treatment for various diseases.

### 9.8.2 What is stem cell therapy?

Stem cell therapy, also known as regenerative medicine, aids in fixing damaged, malfunctioning, or injured tissues using stem cells or their byproducts. It marks a new phase in organ transplantation, utilizing cells rather than donor organs that are limited.

In laboratories, scientists cultivate stem cells under favorable conditions. These cells are modified to become specific cell types, like heart muscle, blood, or nerve cells. These specialized cells can be placed into a person's body. For instance, if someone has a heart condition, these cells might be inserted into the heart muscle. The transplanted healthy heart muscle cells may assist in repairing the damaged heart muscle.

### 9.8.3 History of stem cell therapy

Zoologists Theodor Heinrich Boveri and Valentin Häcker used the term stem cell to describe cells committed to give rise to the germline.

- 1950s - scientists studied the potential of stem cells majorly through bone marrow and its role in generating various blood cells
- 1956 - first successful bone marrow transplant was done. This procedure laid the foundation for using stem cells in medical treatments, especially in treating diseases like leukemia and other blood-related disorders.
- 1981 - mouse embryonic stem cells was first cultured in the laboratory
- 1988 - first umbilical cord blood stem cell transplant took place in a child with Fanconi's anemia.
- 1998 - scientists isolated and cultured human embryonic stem cells. This breakthrough enabled researchers to work with cells that had the potential to develop into almost any cell type in the human body. This discovery opened up new possibilities for regenerative medicine and treatment of a wide array of diseases and injuries.
- 2006 - Discovered the technique of human-induced pluripotent stem cells (iPS), which involves transforming adult skin cells into cells that closely mimic human embryonic stem cells
- Presently, stem cell therapy is applied in various areas of medicine. For example, bone marrow transplants are used in the treatment of leukemia and other blood disorders. Stem cells are being researched and utilized for regenerative medicine to potentially treat conditions such as heart disease, spinal cord injuries, Parkinson's disease, diabetes, and more. Clinical trials and research studies continue to explore the safety and efficacy of stem cell therapies for various health conditions.

#### 9.8.4 Why was it tried for autism?

Stem cell therapy has been considered as a potential treatment for autism due to the belief that it might target certain biological mechanisms or symptoms (immune system regulation and inflammation, neural connectivity, etc.) associated with the condition.

Reasons why stem cell therapy is being explored for autism include:

- **Regenerative Potential:** Stem cells possess the capability to transform into various cell types. The idea is that they might aid in repairing or regenerating damaged or dysfunctional cells in the brain or nervous system, potentially impacting autism-related symptoms.
- **Inflammation and Immune Modulation:** Studies suggest that immune system dysregulation or inflammation might contribute to certain cases of autism. Some types of stem cells, particularly mesenchymal stem cells, have shown potential in regulating immune responses and reducing inflammation. Researchers hope that this immune-modulating ability might alleviate certain autism-related symptoms.
- **Neuroprotective and Neurotrophic Effects:** Stem cells produce substances that support the growth and survival of neurons. Researchers explore whether stem cells could protect existing neurons, encourage neuronal growth, and potentially enhance neural connections in individuals with autism.
- **Experimental Nature of Treatment:** While conventional treatments for autism primarily focus on behavioral and therapeutic interventions, stem cell therapy is considered experimental. It aims to address potential underlying biological factors that traditional therapies might not directly target.

However, it's essential to understand that while stem cell therapy has shown promise in various medical areas, its effectiveness and safety in treating autism are still being investigated. Clinical trials exploring the safety and potential efficacy of stem cell therapy for autism began in the early 2010s. These trials aimed to investigate the safety, feasibility, and any potential improvements in behavior, communication, and other symptoms associated with autism. It remains an experimental and unproven treatment for autism.

The scientific and medical community stress the necessity for further comprehensive research, including well-designed clinical trials, to determine its safety, efficacy, and long-term impact on individuals with autism.

#### 9.8.5 Caution

Stem cell therapy for Autism is still under investigation and there is no established finding of cure in using the treatment for autism. There are limited studies and no definitive results yet.

Among the limited studies, the results cannot be generalized as all of the studies have a small sample size. Like any medical intervention, stem cell therapy also carries potential risks.

- Unintended side effects or complications could arise from the procedure, such as infection, immune rejection, or the formation of tumors.
- The outcomes of stem cell therapy for autism can vary widely from person to person. It's difficult to predict how an individual will respond to the treatment or if it will have any positive effects on their symptoms.
- It involves invasive medical procedures and requires the individual to be admitted for at least 5 days. Furthermore, the treatment is hard on the pocket when done commercially.
- Some facilities offering stem cell treatments might not adhere to strict regulatory standards or might lack sufficient scientific evidence supporting their procedures. If any medical center is experimenting and an individual is part of a clinical trial, they should be treated free of cost.
- There have been reports of adverse short-term effects associated with stem cell therapy, including aggressive behavior, nausea, vomiting, and seizures. Research on the long-term effects of stem cell therapy is still in its early stages, and a comprehensive understanding of its lasting impact is yet to be established.

#### **9.8.6 Current status in India**

Starting around 2010, stem cell therapy has been advertised as a potential cure for autism by many practitioners in India, despite no evidence for the same. Many parents have fallen victim to the unethical medical and business practice associated with stem cell treatment.

As of 2022, the use of stem cell therapy as a treatment or cure for autism is prohibited in India. This restriction has been implemented due to misleading promotions and false claims. Currently, stem cell therapy for conditions outlined in the National Guideline for Stem Cell Research (NGSCR) 2017, excluding Bone Marrow Transplant (BMT)/ hematopoietic stem cell transplant (HSCT), is neither accessible nor permitted. Individuals can only participate in stem cell treatment through a clinical trial if they meet the specified criteria for the trial.

In this context, it's important to highlight that there is currently no clinical evidence validating the effectiveness of stem cell therapy for treating autism. Therefore, any facility claiming otherwise should be approached with caution and careful consideration. The National Medical Council (NMC) calls it professional misconduct when anybody practices, advertises, or promotes stem cell therapy as a treatment or cure for autism.

Given these factors, families considering stem cell therapy believing it will lead to significant improvements or a cure for autism need to seriously reconsider and make an informed decision. The only ethical and scientific way to get stem cell therapy is to participate in a well designed

clinical trial or study. The path ahead demands a cautious approach to verify the safety, efficacy and long term impacts of the therapy.

Here is a video created in 2023 by Yash Charitable Trust (YCT), and Forum for Autism, against the use of stem cell therapy as a treatment.

<https://www.youtube.com/embed/aXXbkDzKtqE?si=RrY3-wkt4Eh68bru>

## 9.9 Hyperbaric Oxygen Therapy (HBOT)

In hyperbaric oxygen therapy (HBOT), the individual enters a pressurized chamber where they inhale pure oxygen. Inside this chamber, the air pressure is double compared to the normal air we breathe outside. This treatment increases the amount of oxygen dissolved in the blood, allowing it to reach the brain and other parts of the body.

HBOT is based on the principle of delivering increased levels of oxygen to the body's tissues by exposing individuals to pure oxygen in a pressurized chamber. The primary components are increased atmospheric pressure and elevated oxygen concentration. It enables increased oxygen supply to organs that lack sufficient oxygen. The oxygen is dissolved in the blood, plasma, and cerebrospinal fluids. The increased oxygen levels stimulate and accelerate bodily functions that rely on oxygen, from essential processes like heartbeats to cognitive functions and movements. Due to this, HBOT has shown promising potential in addressing or lessening symptoms related to cognitive and mobility decline. Studies have indicated that the combination of high oxygen levels (hyperoxia) and pressure in a hyperbaric environment can boost tissue oxygenation. It is believed that this manipulation affects oxygen and pressure-sensitive genes, ultimately leading to improved tissue metabolism.

### 9.9.1 History of HBOT

The use of oxygen therapy goes back to 1662 when British physician Nathaniel Henshaw built the first pressurized room to treat pulmonary and digestive conditions. The basic principle behind Henshaw's work was the notion that breathing in a pressurized environment could have positive effects on health. However, the understanding of the physiological effects of increased pressure and the therapeutic applications of hyperbaric environments was in its infancy then.

- 1662: The concept of increased atmospheric pressure influencing the human body was first proposed by British clergyman and scientist Henshaw. He built a "Domicilium," a sealed chamber, and suggested that it could be used to treat various medical conditions.
- 1834: French surgeon Junod constructed a portable hyperbaric chamber and reported beneficial effects on patients with various conditions. The Bulletin of the Academy of Medicine reported Dr. Junod's success with a complete recovery from a variety of medical conditions.

- 1861: Paul Bert, a French physiologist, conducted comprehensive studies on the effects of increased atmospheric pressure and discovered the toxic effects of high-pressure oxygen that were manifested as seizures. He is known as the “father of hyperbaric physiology”
- 1900s- Interest in oxygen therapy resurged when French doctors observed that patients undergoing hyperbaric-assisted surgery experienced fewer complications. Dr. John S. Haldane played an important role in advancing this field by studying the effects of compressed oxygen and subsequently developing dive tables for the Royal Navy. He came to be known as “Father of Oxygen Therapy.”
- 1928- Dr. Cunningham discovered that there is a difference in mortality rate between flu patients living in higher elevations compared to patients living at lower elevations. In higher elevations, one breathes in less oxygen. He built a 5 storey chamber that offered more than 60 rooms designed to treat flu patients. In addition, Harvard Medical School built its first hyperbaric chamber,
- 1937-1942: The U.S. military used hyperbaric oxygen to treat deep-sea divers with decompression sickness, also known as the bends.
- 1955- Churchill-Davidson applied HBO to potentiate the effects of radiation therapy in cancer patients, while at the same time Boerema developed HBO as an adjunct to cardiac surgery, thus prolonging the time for circulatory arrest
- 1956: The U.S. Navy established the first hyperbaric research program to explore various therapeutic applications.
- 1960s: Hyperbaric oxygen therapy gained recognition for treating conditions such as carbon monoxide poisoning, crush injuries, and non-healing wounds.
- 1970s: Hyperbaric chambers became more widely available, and research expanded to explore the therapy’s potential in treating other conditions, including chronic non-healing wounds and certain infections.
- 1980s: The Undersea and Hyperbaric Medical Society (UHMS) was founded to promote research, education, and standards of practice in the field of hyperbaric medicine.
- 1990s: Hyperbaric oxygen therapy gained popularity in treating chronic wounds, radiation injuries, and other conditions. However, there was controversy and debate about its efficacy in some applications.
- 2000s: Research continued to explore the use of hyperbaric oxygen therapy for various neurological conditions, including traumatic brain injuries and certain neurodevelopmental disorders.
- Present: Hyperbaric oxygen therapy is used as a standard treatment for conditions such as decompression sickness, chronic non-healing wounds, and certain infections. Ongoing research is exploring its potential applications in areas such as neurology, sports medicine, and chronic diseases.

### 9.9.2 Why was HBOT used for autism?

HBOT, given its principles, was believed to address the biological symptoms of autism such as immune system dysregulation and inflammation. It is still experimental and no regulatory body approves using HBOT as a treatment for autism. It was seen as a potential treatment for autism due to:

- **Anti-Inflammatory Effects:** Some studies have proposed that inflammation might play a role in the development of certain cases of autism causing communication issues and behaviors. HBOT, having its anti-inflammatory properties, is believed by some to potentially reduce inflammation in the brain, contributing to improvements in symptoms.
- **Oxygenation and Neural Function:** The therapy involves exposing individuals to increased levels of oxygen, which may enhance oxygenation of tissues, including the brain. This increased oxygen availability is thought to support neural function and promote overall brain health.
- **Neuroprotection and Tissue Repair:** HBOT is known for its role in promoting tissue repair and regeneration. Proponents of HBOT for autism suggest that the therapy might have neuroprotective effects and contribute to the repair of neural circuits, potentially improving certain aspects of neurological function in individuals with autism.
- **Blood Flow and Oxygen Delivery:** The increased atmospheric pressure in the hyperbaric chamber enhances the solubility of oxygen in the blood, leading to higher oxygen concentrations in tissues. This is believed to improve blood flow and oxygen delivery to areas of the brain that may be affected in individuals with autism.
- **Mitigation of Oxidative Stress:** Oxidative stress, resulting from an imbalance between free radicals and antioxidants, has been implicated in some cases of autism. HBOT proponents believe that HBOT may have antioxidant effects, potentially mitigating oxidative stress and its impact on the brain.

Similar to other alternative treatments, hyperbaric oxygen therapy (HBOT) is categorized as an alternative treatment due to insufficient data, lack of conclusive evidence regarding its efficacy and impact. Comprehensive and definitive research is required before considering HBOT as a treatment for autism. Presently, studies suggesting its efficacy in treating autism are still experimental, and no definitive claims have been established. Therefore, like any alternative treatment, caution is advised when considering HBOT for autism.

### 9.9.3 Caution

While hyperbaric oxygen therapy (HBOT) has demonstrated effectiveness for certain conditions like the flu and decompression sickness, its impact on individuals with autism remains unclear. Like any treatment, HBOT has associated side effects. Combined with the absence



of conclusive evidence regarding its positive effects for autism, it is crucial to approach such treatments with caution and make informed decisions. Some reasons to exercise caution include:

- **Lack of Definitive Evidence:** Scientific evidence supporting the efficacy of HBOT for autism is limited and inconclusive. The absence of well-designed, large-scale clinical trials makes it challenging to firmly establish the safety and effectiveness of HBOT for autism.
- **Heterogeneity of Autism Spectrum Disorder (ASD):** Autism is a heterogeneous condition with a wide range of symptoms and underlying factors. Responses to HBOT can vary among individuals with ASD, making it difficult to predict outcomes or adopt a one-size-fits-all approach.
- **Risk of Adverse Effects:** While generally considered safe, HBOT is not without risks. Adverse effects, such as ear barotrauma and sinus discomfort, can occur. The potential long-term effects of prolonged or repeated HBOT sessions for individuals with autism are not well understood.
- **Medical procedure and Financial Costs:** HBOT requires a lot of sessions and can be expensive. It may also not be covered by health insurance for the treatment of autism due to its experimental nature. Families should carefully assess the financial implications and weigh potential benefits against costs.
- **Ethical Considerations:** Offering HBOT for autism without conclusive evidence of efficacy raises ethical concerns. Families should be cautious about therapies making bold claims without robust scientific support.
- **Unregulated Clinics and Non-Medical Settings:** Some facilities offer HBOT for autism outside rigorous clinical trials, and standards of care may vary. Treatment in reputable healthcare institutions with experienced professionals ensures safety and monitoring.

In summary, caution is advised when considering HBOT for autism. Thoroughly understanding the current scientific evidence, potential risks, and the experimental nature of the treatment is essential. Consulting with healthcare professionals and participating in well-designed clinical trials, when available, can offer more guidance on the appropriateness of HBOT for individual cases.

## 9.10 Restrictive Diets

A diet is the combination and quantity of foods that an individual consumes. A healthy diet is one that provides all the necessary nutrients required for optimal well-being. Nutritional needs can vary based on factors such as geography, lifestyle, and health conditions. Therefore, individuals may benefit from diverse diets tailored to their specific requirements.

One common symptom of autism is restricted eating patterns, making individuals with autism more susceptible to certain dietary challenges. Some individuals with autism may experience heightened sensitivity to taste and food textures, similar to their sensitivity to light and touch. This sensitivity can influence the types and quantities of food they consume. However, it's essential to note that the nutritional needs of individuals with autism are generally not significantly different from those of others in their age group. Therefore, exposing them to a healthy and varied diet is crucial for their overall development, unless there are specific allergies or intolerances to certain foods as some autistic individuals suffer from Gastrointestinal disturbances.

### **9.10.1 Diet - Autism Connection**

The concept of diets impacting various autistic symptoms is rooted in the understanding of the gut-brain connection. The physical and biochemical connection between these two organs involves several mechanisms:

- **Vagus Nerve:** The vagus nerve, one of the largest nerves in the body, establishes a strong connection between the gut and the brain. It facilitates the bidirectional transmission of signals.
- **Neurotransmitters:** Chemical messengers known as neurotransmitters play a crucial role in connecting the gut and the brain. These neurotransmitters, which regulate emotions and feelings, are produced in the brain. For instance, serotonin, a neurotransmitter associated with happiness and circadian rhythm control, is produced in both the brain and the gut. Additionally, gut microbes contribute to the production of gamma-aminobutyric acid (GABA), a neurotransmitter that helps manage feelings of fear and anxiety.
- **Gut Microbes:** The trillions of microbes residing in the gut are integral to this connection. They produce various chemicals, including short-chain fatty acids that can reduce appetite and contribute to the formation of the blood-brain barrier. Moreover, these microbes play a role in immune system functioning, impacting inflammation. An overactive immune system can lead to inflammation, which, in turn, affects brain health.

In summary, the physical and biochemical interactions between the gut and brain involve the vagus nerve, neurotransmitters, and the activities of gut microbes. These connections influence emotional well-being, immune responses, and inflammation, contributing to the overall health of both the gut and the brain.

### **9.10.2 History of diet as therapy**

The use of diets as a treatment for various medical conditions has a long and diverse history, and different diets have been proposed and implemented for therapeutic purposes.

- **Ancient Civilizations:** Ancient cultures recognized the influence of diet on health. Hippocrates, often referred to as the “Father of Medicine” in ancient Greece, emphasized the significance of diet in maintaining health and preventing disease.
- **Fasting in Ancient Religions:** Fasting has been a practice in many ancient religions for spiritual and health-related reasons. It is believed to purify the body and mind.
- **Diet in Traditional Chinese Medicine (TCM) and Ayurveda:** Traditional Chinese Medicine and the traditional system of medicine in India, Ayurveda, incorporate dietary principles as essential components of holistic healthcare. These systems emphasize balancing energies within the body through proper nutrition.
- **Diet in the Middle Ages:** In medieval Europe, dietary practices were often influenced by religious beliefs. Fasting and abstaining from certain foods were common practices in the belief of purifying the body from toxins.
- **Vitamin Deficiency Diseases:** In the 18th and 19th centuries, the recognition of deficiency diseases, such as scurvy (vitamin C deficiency) and rickets (vitamin D deficiency), led to the understanding of the role of specific nutrients in preventing and treating illnesses.
- **Diets for Epilepsy:** The ketogenic diet, a high-fat, low-carbohydrate diet, was introduced in the 1920s as a treatment for epilepsy. It fell out of favor with the advent of antiepileptic drugs but experienced a resurgence in the late 20th century.
- **Dietary Approaches for Specific Conditions:** Over the years, various diets have been proposed and explored for specific health conditions. For example, the low-sodium DASH (Dietary Approaches to Stop Hypertension) diet for managing hypertension and the Mediterranean diet for heart health gained recognition.
- **Development of Therapeutic Diets:** Therapeutic diets, designed to manage specific health conditions, have been developed. These include the gluten-free diet for celiac disease, the low-FODMAP diet for irritable bowel syndrome (IBS), and the low-phenylalanine diet for phenylketonuria (PKU).
- **Emergence of Dietary Therapies for Neurodevelopmental Disorders:** In recent years, specific dietary interventions, like the gluten-free, casein-free (GFCF) diet, have been investigated for conditions such as autism spectrum disorder (ASD). Dr. Karl Reichelt proposed a hypothesis in 1991, suggesting that the consumption of gluten and casein by individuals with celiac disease might contribute to autism, particularly in those predisposed to the condition. According to this theory, these proteins, in the presence of a “leaky gut,” could be absorbed, leading to the creation of peptides with opioid-like effects. These peptides, in turn, were theorized to mimic or induce autism. This hypothesis led to the development of the Gluten-Free and Casein-Free diet (GFCF), sparking considerable controversy.

- **Current Trends:** Today, there is growing interest in the role of diet in overall health and disease prevention. Diets like the ketogenic diet, paleolithic diet, and plant-based diets are popular, and research continues to explore their potential benefits.

It's important to note that while dietary interventions can play a role in managing certain health conditions, the effectiveness of specific diets varies, and not all dietary approaches have robust scientific support. Individuals considering dietary changes for therapeutic purposes should consult with respective healthcare professionals to ensure that nutritional needs are met and that the chosen diet is appropriate for their specific health condition. It also helps to do some self-study from reliable resources to see if a specific dietary approach will be feasible for the autistic individual and the family.

### 9.10.3 Types of diets for autism

In the light of gut brain connection, many diets have been suggested and tried as a treatment for various disorders including autistic symptoms. Diverse dietary interventions have been proposed for individuals with autism, yet it's crucial to note that the scientific evidence supporting the efficacy of these diets is often limited and varied. Here are some diet types suggested for autism:

- **Gluten-Free, Casein-Free (GFCF) Diet:** This involves removing gluten (found in wheat, barley, and rye) and casein (found in dairy) from the individual's diet. Advocates claim potential improvements in behavior and social interactions. This is the most researched and commonly suggested intervention.
- **Specific Carbohydrate Diet (SCD):** A restrictive diet eliminating complex carbohydrates, disaccharides, and polysaccharides. It permits specific easily digestible carbohydrates, aiming to positively impact gut health and alleviate autism-related symptoms.
- **Ketogenic Diet:** A high-fat, low-carb diet used for epilepsy. Some reports suggest potential positive effects on behavior and cognitive function in individuals with autism. It has been suggested that epilepsy drives the development for ASD.
- **Low-Oxalate Diet:** Restricts foods high in oxalates, compounds found in some fruits, veggies, and nuts. Advocates claim it may alleviate sensory processing and gut-related symptoms in autism.
- **Low-FODMAP Diet:** Designed to reduce fermentable carbohydrates, potentially beneficial for individuals with autism and gastrointestinal issues, though more research is needed.
- **Omega-3 Fatty Acid Supplementation:** While not a specific diet, some individuals with autism are recommended omega-3 supplements for potential benefits in cognitive function and behavior.

Approaching these dietary interventions cautiously is crucial, given the often inconclusive evidence regarding their effectiveness for autism. Individual responses can vary, and restrictive diets may pose challenges in meeting nutritional needs.

#### 9.10.4 Caution

It's essential to clearly understand why a dietary approach is chosen to manage autism symptoms and carefully assess associated costs. The relationship between autism and diet is an ongoing area of study, with existing research often lacking robust methodology, relying on anecdotal reports or personal experiences. The mechanism underlying the effectiveness of a diet for autism remains an unresolved research question, primarily based on the assumption that individuals with autism having an imbalanced gut microbiota contribute to their autism symptoms. Considering autism's multifactorial nature, there is no evidence that only an imbalanced gut causes autism. Accepting an intervention solely based on authority or convenience should be avoided, especially if it compromises the health of the individual with autism. Each diet comes with its own benefits and costs. The side effects or consequences of following these diets can vary, and individual responses may differ. Here are some considerations:

- **Nutritional Deficiencies:** Restrictive diets, especially those that eliminate entire food groups, may increase the risk of nutritional deficiencies. For example, the GFCF diet excludes wheat and dairy, which are sources of essential nutrients like calcium, vitamin D, and fiber. Studies have reported low bone mineral densities among individuals with autism who have excluded dairy from their diets. It's important to ensure that nutritional needs are met through alternative food sources or supplements.
- **Further Gastrointestinal Distress:** Dietary changes, particularly those involving the removal of certain foods, can sometimes lead to gastrointestinal distress. This may include changes in bowel habits, constipation, or diarrhea. It's crucial to monitor and address any digestive issues that may arise.
- **Social and Practical Challenges:** Following a specialized diet can present social and practical challenges. Individuals with autism may already have preferences or sensitivities to certain textures or flavors, and imposing further dietary restrictions may affect their willingness to eat or participate in social activities.
- **Emotional Impact:** Dietary interventions can have emotional implications, particularly for children or individuals who may find it challenging to adapt to changes in their eating habits. It's important to consider the emotional well-being of individuals with autism when implementing dietary changes.
- **Financial Costs:** Some specialized diets may involve increased costs due to the need for specific ingredients, supplements, or alternative food products. Studies suggest that gluten free products are a certain percentage more expensive than products with gluten.

and casein. Considering the longevity of intervention, it would be a sustained expense. Families should be aware of the financial implications and plan accordingly.

- **Unsubstantiated Claims and Lack of Evidence:** Many of the suggested diets for autism are based on anecdotal evidence rather than robust scientific research. Following a diet without sufficient evidence of its effectiveness may lead to disappointment and frustration if the expected benefits are not realized.
- **Potential for Nutritional Excess:** In some cases, the emphasis on certain food groups or supplements in an attempt to address specific symptoms may lead to an imbalance and excess intake of certain nutrients. This can have its own set of health implications.

Consulting healthcare professionals, including accredited dietitians and specialists in autism, and thoroughly assessing the feasibility of the chosen approach in the context of the child's health and family circumstances is essential to ensure that the selected diet is safe and suitable for overall well-being. It is reiterated that there is no definitive evidence supporting the sole effectiveness of a diet for managing autism. In most studies, the change in behaviors post diet are reports from parents and there has been no objective measurement of the same.

## 9.11 Homeopathy

Homeopathy is a system of alternative medicine that was developed in the late 18th century by Samuel Hahnemann, a German physician. The central principle of homeopathy is the “law of similars,” which states that a substance that can cause symptoms in a healthy person can be used to treat similar symptoms in a sick person. This concept is often expressed by the Latin phrase “*similia similibus curentur*,” meaning “like cures like.” Homeopathic remedies are prepared through a process called potentization, which involves a series of dilutions and succussions (vigorous shaking). The idea is that this process enhances the therapeutic properties of the substance while minimizing its toxic effects. The remedies are crafted for individuals based on the information shared about lifestyle, medical history, and current symptoms. It is thus believed to have a personalized and holistic approach to treatment. Homeopathy relies on the principle of individualization, suggesting that treatments should be tailored to each person's unique symptoms and constitution.

However, this variability makes it challenging to conduct large-scale, double-blind, placebo-controlled studies that meet rigorous scientific standards. Consequently, the lack of standardized protocols and the individualized nature of homeopathy make it difficult to establish its effectiveness across diverse populations. While homeopathy has its proponents, it's essential to acknowledge that its efficacy is a subject of significant debate within the scientific and medical communities.

### 9.11.1 History of homeopathy

Homeopathy was founded by Samuel Hahnemann (1755-1843), who obtained his medical degree in Erlangen in 1779. Despite struggling financially during his initial years as a physician, Hahnemann made a significant discovery that would shape his future. In an experiment, he began taking regular doses of cinchona, also known as ‘the bark’ or quinine. Remarkably, he experienced symptoms similar to those of intermittent fever (malaria) but in a milder form and without the characteristic rigors of the disease. This observation sparked a groundbreaking idea.

In 1796, Hahnemann published his findings in “Essay on a New Principle for Ascertaining the Curative Power of Drugs.” This was followed by his influential work, “The Organon of the Healing Art,” in 1810. These works laid out the fundamental principles of homeopathy, including the “law of similars” and the process of potentization, shaping the foundation of this alternative medical system. Despite initial financial struggles, Hahnemann’s contributions to homeopathy gained recognition and had a lasting impact on the field of alternative medicine. Here is a timeline of how homeopathy progressed:

- 1796: Dissatisfied with the medical practices of his time, Samuel Hahnemann began experimenting with the use of substances to treat various illnesses. He first describes the Law of Similars (“Like cures like”). This principle suggests that a substance that can cause symptoms in a healthy person can be used to treat similar symptoms in a sick person.
- Late 18th Century: Hahnemann conducted a series of experiments on himself and others, ingesting small doses of substances to observe their effects. He systematically recorded the symptoms produced and proposed the use of highly diluted doses of substances to treat similar symptoms in patients.
- 1810: Hahnemann published his foundational work, “Organon of the Healing Art,” outlining the principles and practices of homeopathy. The text underwent several editions, with the final edition, the sixth, published posthumously in 1921.
- 1830s: Homeopathic schools and hospitals begin to open in the United States and Europe.
- 1838: Repertory to the More Characteristic Symptoms of Materia Medica, a homeopathic reference, first appears in English.
- 1842: Oliver Wendel Holmes Sr.—physician, critic of homeopathy and father of a Supreme Court justice—publishes the scathing “Homeopathy and Its Kindred Delusions.”
- 1847: The American Medical Association is founded, offering a decidedly unfavorable view of homeopathy. Homeopathy faced criticism and challenges, particularly from proponents of conventional medicine.
- 1885: Hahnemann Hospital opens as a homeopathic facility in Philadelphia.
- Mid-1900s: Homeopathic schools dwindle and disappear. Hahnemann Hospital is sold to new owners, who switch to allopathic medicine but retain a homeopathic library and some elective courses. The Flexner Report in the early 20th century, which led to the

reform of medical education in the United States, marginalized homeopathy in favor of allopathic medicine.

- 1972: The Center for Education and Development of Clinical Homeopathy was founded with the goal of teaching practical, pragmatic homeopathy at campuses across the country, including one in Philadelphia. In the latter half of the 20th century, there was a resurgence of interest in alternative and complementary medicine, including homeopathy. Some individuals sought out homeopathic treatments as an alternative or complementary approach to conventional medicine.
- Current Status: Homeopathy is practiced in various parts of the world, and homeopathic remedies are available over the counter in many countries. However, its acceptance within the mainstream medical community varies, with skepticism regarding its scientific basis and efficacy. Homeopathy continues to be a subject of debate and controversy within the scientific and medical communities. Research on the efficacy of homeopathic treatments has yielded mixed results, and debates persist on issues such as the mechanisms of action and the significance of highly diluted substances.

### **9.11.2 Why homeopathy for autism?**

The multifaceted nature of autism has led to the exploration of various “cures” for the condition. The application of homeopathy to autism lacks a clear rationale. Considering homeopathy is often considered an alternative medicine, it is applied broadly across different conditions. The decision to try homeopathy for autism might stem from a dissatisfaction with the gradual outcomes of evidence-based management and a natural inclination to explore every possible way for improvement.

Advocates assert that homeopathy enhances behavioral symptoms associated with autism, including aggressiveness, sensory processing issues, language, speech, and communication. However, these claims rely solely on anecdotal evidence. There is a notable absence of valid scientific evidence explaining the mechanisms by which homeopathy works for some individuals and not for others. The lack of a robust scientific foundation raises questions about the reliability and generalizability of reported improvements associated with homeopathic treatments for autism.

Certain homeopathic practitioners argue against the use of randomized controlled trials, stating that patient satisfaction should be the sole criterion for judging the effectiveness of homeopathy. However, when clinical trials and systematic reviews have been conducted, the outcomes remain uncertain. While a few studies suggested slight effectiveness, a majority indicated that homeopathy had no therapeutic effect. It’s important to note that many trials included in systematic reviews were deemed imperfect in terms of design, application, or sample size. This highlights the challenges in establishing conclusive evidence regarding the efficacy of homeopathy through rigorous scientific methods.



### 9.11.3 The Process of homeopathy for autism

Homeopathic treatment for autism follows a personalized approach rooted in the principles of homeopathy. The process involves the following steps:

- Initial consultation: A comprehensive discussion with the individual with autism or their caregivers to collect information on medical history, behavioral symptoms, sensory sensitivities, and emotional well-being.
- Individualized assessment: A focus on understanding the unique expression of symptoms in each person, including their overall constitution, temperament, and responses to various stimuli.
- Choosing the homeopathic remedy: Choosing a homeopathic remedy that aligns with the individual's symptoms and constitutional characteristics. These remedies are often highly diluted substances derived from plants, minerals, or animals.
- Potentization: Subjecting the chosen remedy to potentization, involving dilution and succussion (vigorous shaking) to enhance therapeutic properties while minimizing potential toxic effects. Administration of the remedy: Providing the homeopathic remedy in a highly diluted form, typically as small sugar pellets or liquid drops. The dosage and frequency are determined by the homeopath's recommendations.
- Follow-Up consultations: Regular follow-up sessions to evaluate the individual's response to the remedy and make any necessary adjustments to the treatment plan. These consultations help monitor changes in symptoms and emotional well-being.
- Monitoring progress: Continuously assessing the person's progress, considering changes in behavioral symptoms, sensory sensitivities, and communication skills relevant to autism. Adjustments to the homeopathic remedy may be made based on the individual's response.

### 9.11.4 Caution

Caution should be exercised when contemplating homeopathy as a treatment for autism, given several compelling reasons, despite its popularity in certain alternative medicine circles. Here are key factors contributing to the need for caution:

- Lack of Scientific Evidence: The foundational principles of homeopathy, such as the law of similars and the use of highly diluted substances, lack robust scientific backing. Studies on homeopathic treatments for autism are often limited, with small-scale research producing mixed and inconclusive results.
- Placebo Effect: Perceived benefits from homeopathic treatments may be influenced by the placebo effect, where improvements result from the belief in treatment efficacy rather than the treatment itself. This can lead to subjective reports of improvement that may not be objectively measurable.

- **Individual Variability in Responses:** Responses to homeopathic treatments vary widely among individuals, making it challenging to predict outcomes. This variability is compounded by the diverse nature of autism symptoms, complicating the assessment of treatment efficacy.
- **Risk of Delaying or Avoiding Evidence-Based Interventions:** Relying solely on homeopathy may lead to delays in accessing evidence-based interventions with demonstrated efficacy. Established components of effective autism management, such as early and intensive behavioral interventions, may be postponed.
- **Financial Costs:** Homeopathic treatments, like other alternative therapies, may incur financial costs. Families should consider the potential financial burden, especially when these treatments lack robust scientific support.
- **Potential for Harm:** While homeopathic remedies are generally considered safe due to their highly diluted nature, harm may occur if individuals forego proven medical treatments in favor of homeopathy. Prioritizing interventions with a solid scientific basis is crucial.
- **Unregulated Nature of Homeopathic Products:** Homeopathic products may not undergo the same regulatory scrutiny as conventional medications. Variability in quality control and manufacturing consistency raises concerns about the reliability and safety of these products.
- **Ethical Considerations:** The use of homeopathy for autism raises ethical considerations, especially when individuals or families are led to believe in the efficacy of a treatment lacking strong scientific support. Providing accurate and transparent information about the evidence base for any therapeutic approach is essential.

In summary, exercising caution is important when considering homeopathy for autism, considering the lack of scientific validation, the potential for the placebo effect, individual variability, the risk of delaying evidence-based interventions, financial costs, the potential for harm, and the unregulated nature of homeopathic products. Prioritizing evidence-based interventions and consulting with healthcare professionals ensures informed decisions regarding the management of autism spectrum disorder.

## 9.12 Ayurveda

Ayurveda, an ancient natural system of medicine said to have originated in India over 3,000 years ago, derives its name from the Sanskrit words “ayur” (life) and “veda” (science or knowledge), translating to “knowledge of life”. Advocates of Complementary and Alternative Medicine (CAM), such as Ayurveda, subscribe to the belief that the world operates in a state of balance. According to this perspective, optimal health is achieved when living creatures are in harmony with the universe. Conversely, disruptions in this balance are thought to lead to illnesses. Ayurveda treatment approaches health by focusing on restoring this balance as a means of addressing and treating various health conditions. It advocates for specific lifestyle

interventions and natural therapies to restore balance among the body, mind, spirit, and the environment.

According to Ayurveda, every person is made of the five basic elements found in the universe: Air, water, fire, space and earth. Central to Ayurvedic medicine are concepts such as universal interconnectedness, the body's constitution (prakriti), and life forces (doshas). Treatment goals aim to eliminate impurities, alleviate symptoms, enhance disease resistance, reduce stress, and promote harmony in life. Treatment in Ayurveda commences with an internal purification process, followed by a tailored diet, herbal remedies, massage therapy, yoga, and meditation. Ayurvedic practitioners extensively use herbs, plants, oils, and common spices in their treatments.

In India, Ayurveda holds the status of a recognized form of medical care, alongside conventional Western medicine, traditional Chinese medicine, naturopathic medicine, and homeopathic medicine. When utilized as a complementary therapy alongside standard conventional medical care, Ayurveda has demonstrated some positive effects. However, it's crucial to note that many Ayurvedic materials have not undergone extensive research in both Western and Indian contexts. Some products used in Ayurvedic medicine may include herbs, metals, minerals, or other substances that could pose harm if used improperly or without the guidance of a trained practitioner. Therefore, caution and expert guidance are advised when considering Ayurvedic treatments.

### **9.12.1 Ayurveda and Autism**

The idea of using Ayurveda for autism is a relatively recent development and is part of the broader interest in alternative and complementary therapies for managing various health conditions. Ayurveda, as an ancient system of medicine, has a long history, but its application to autism spectrum disorder (ASD) gained attention in the latter part of the 20th century and the early 21st century. There is limited scientific evidence supporting the efficacy of Ayurveda in improving autism symptoms. Ayurveda, a traditional system of medicine, encompasses a holistic approach to health and well-being. While some proponents suggest that Ayurvedic practices may offer benefits for individuals with autism spectrum disorder (ASD), it's crucial to note that research in this area is limited. The scientific community remains cautious about making definitive claims regarding the effectiveness of Ayurveda for autism. Some individuals and families may explore Ayurveda as a complementary or alternative therapy for autism based on the following principles:

- **Holistic Approach:** Ayurveda takes a holistic approach, considering the interconnectedness of the mind, body, and spirit. The belief is that balancing these aspects can contribute to overall health and well-being.
- **Individualized Treatment:** Ayurvedic treatments are often individualized based on a person's unique constitution or dosha. The idea is that addressing specific imbalances in an individual's constitution may promote health and alleviate symptoms.

- **Dietary and Lifestyle Recommendations:** Ayurveda places significant emphasis on dietary and lifestyle practices. Recommendations may include specific dietary modifications, the use of herbal remedies, and the incorporation of practices such as meditation, yoga, and breathing exercises.
- **Stress Reduction:** Stress reduction is considered essential in Ayurveda for maintaining balance and preventing disease. Practices that promote relaxation and reduce stress, such as meditation and yoga, may be recommended.
- **Herbal Remedies:** Ayurveda incorporates the use of herbal remedies, derived from plants and natural substances. Some herbal formulations in Ayurveda are believed to have properties that may support cognitive function and address symptoms associated with neurological conditions.

It's crucial to highlight the need for rigorous scientific research to establish the safety and effectiveness of Ayurveda in the context of autism. While anecdotal reports and individual testimonials may suggest positive outcomes, these do not substitute for well-designed clinical trials with large sample sizes and rigorous methodologies.

If individuals or families are considering Ayurveda for autism, it is strongly advised to consult with healthcare professionals, particularly those with expertise in autism. Integrating Ayurveda into an overall care plan in collaboration with conventional evidence-based interventions is essential. Open communication with healthcare providers ensures that any therapeutic approach aligns with the best interests and well-being of individuals with autism.

### 9.12.2 History of Ayurveda

The history of Ayurveda is deeply rooted in ancient Indian civilization, and its principles have been passed down through oral traditions and written texts. Its foundations are deeply rooted in the ancient schools of Hindu Philosophical teachings, specifically the Vaisheshika school and the school of logic known as Nyaya. Additionally, Ayurveda is closely connected to the manifestation framework, commonly recognized as Samkhya. It emerged during the same period when the schools of Nyaya and Vaisheshika were flourishing. Ayurveda is also said to have a divine origin, believed to come from the Hindu God Brahma, who is considered the creator of the universe. Before the establishment of philosophical schools, this holistic knowledge of healing was passed from Brahma to sages, who then shared it with their disciples and the general population through writings and spoken stories. They described the healing properties of herbs in poetic verses called "Shlokas."

Ayurveda's foundation lies in four important collections of knowledge called Vedas. The Rig Veda, the most famous among them, talks about 67 plants and 1028 Shlokas. The Atharva Veda and Yajur Veda mention 293 and 81 plants with medicinal uses, respectively. Ayurveda's practice is deeply rooted in the insights gained from these ancient Vedas. Following is an overview of the history of Ayurveda:

- Vedic Period (1500 BCE - 600 BCE): The earliest roots of Ayurveda can be traced back to the Vedic period in ancient India. The knowledge of Ayurveda is believed to be part of the Vedas, the oldest sacred texts of Hinduism. The Rigveda, one of the Vedic texts, contains hymns related to healing and the use of medicinal plants.
- Compilation of Ayurvedic Texts (600 BCE - 200 CE): The foundational texts of Ayurveda, known as the “Samhitas,” were compiled during this period. The most significant among them are the Charaka Samhita, attributed to the sage Charaka (physician), and the Sushruta Samhita, attributed to the sage Sushruta (surgeon). These texts cover various aspects of health, disease, diagnosis, treatment, and surgical procedures.
- Golden Age of Ayurveda (200 CE - 1200 CE): During this period, Ayurveda flourished and became more organized. The works of influential scholars such as Vagbhata contributed to the development and systematization of Ayurvedic knowledge. The Ashtanga Hridaya, written by Vagbhata, is an important compendium that synthesized earlier Ayurvedic teachings.
- Islamic Influence (1200 CE - 1800 CE): With the advent of Islamic rule in India, Ayurveda faced challenges but continued to evolve. Some Ayurvedic texts were translated into Arabic, and Unani medicine, influenced by Ayurveda, emerged as a distinct medical tradition.
- Colonial Period (17th Century Onward): The colonial period saw the arrival of European powers in India. The British East India Company established control, and Ayurveda faced challenges during this period. The British colonial authorities initially viewed Ayurveda with skepticism.
- Revival Efforts (Late 19th Century - 20th Century): The late 19th and early 20th centuries witnessed efforts to revive and institutionalize Ayurveda. Key figures such as Swami Dayananda Saraswati and Mahatma Gandhi emphasized the importance of traditional Indian systems of medicine, including Ayurveda.
- Post-Independence Era (1947 Onward): After India gained independence in 1947, there were renewed efforts to promote and modernize Ayurveda. The establishment of institutions, research centers, and government initiatives aimed at preserving and promoting Ayurvedic knowledge.
- Global Recognition and Integration (Late 20th Century Onward): In recent decades, there has been a growing global interest in Ayurveda. It has gained recognition as an alternative and complementary system of medicine worldwide. Ayurvedic practices, including herbal remedies, dietary recommendations, and lifestyle interventions, have found a place in integrative medicine approaches.

Today, Ayurveda continues to be practiced in India and other parts of the world. It has influenced various alternative and complementary medicine practices and is recognized for its holistic approach to health and well-being. Despite its rich history, it's important to note that scientific validation and standardization of Ayurvedic practices remain ongoing challenges.

### 9.12.3 Caution

While some individuals and families may consider exploring Ayurveda as a complementary or alternative therapy for autism, it's important to approach it with caution and consider several factors. Here are some key points to keep in mind when seeking Ayurveda for autism:

- **Limited Scientific Evidence:** There is limited scientific evidence supporting the efficacy of Ayurveda specifically for autism. Rigorous research, including well-designed clinical trials, is needed to establish its safety and effectiveness.
- **Individual Variability in Responses:** Responses to Ayurvedic treatments can vary among individuals. Autism spectrum disorder (ASD) is a complex and heterogeneous condition, and what works for one person may not work for another. Factors such as the severity of symptoms and overall health can influence individual responses.
- **Integration with Conventional Care:** Ayurvedic approaches should be viewed as complementary rather than a substitute for evidence-based interventions recommended by healthcare providers. It's important to communicate openly with healthcare professionals, including those with expertise in autism, to ensure that Ayurveda is integrated into an overall care plan.
- **Safety Considerations:** While Ayurveda is generally considered safe when practiced by trained practitioners, it's crucial to ensure that any herbal remedies or dietary recommendations align with the individual's overall health. Consult with healthcare professionals, especially if the individual is on any medications or has pre-existing health conditions.
- **Consultation with Qualified Practitioners:** Seek Ayurvedic treatments from qualified practitioners who have training and experience in Ayurveda. Professional Ayurvedic practitioners may have certifications or qualifications from recognized institutions. Verify their credentials before starting any treatment.
- **Transparency and Informed Consent:** Practitioners should be transparent about the nature of Ayurvedic treatments, potential benefits, and possible risks. Informed consent is essential, and individuals or caregivers should be fully informed about what to expect from Ayurvedic interventions.
- **Monitoring Progress:** Regularly monitor the individual's progress and communicate with healthcare providers. If any concerns or unexpected changes arise, it's important to discuss them with both Ayurvedic practitioners and conventional healthcare professionals.
- **Financial Considerations:** Consider the financial implications of Ayurvedic treatments, as some interventions may involve costs. Be aware of any potential financial burden and ensure that the chosen approach aligns with the overall budget for healthcare.
- **Cultural Sensitivity:** Ayurveda is deeply rooted in Indian culture, and cultural sensitivity is important. Ensure that practitioners understand and respect the cultural context and preferences of the individuals and families seeking Ayurvedic care.
- **Ongoing Communication:** Establish open and ongoing communication between Ayurvedic practitioners and other healthcare providers involved in the individual's care. Collaboration can contribute to a more comprehensive and integrated approach.

It's important to recognize that individual experiences with Ayurveda may vary, and what works for one person may not work for another. For individuals or families considering Ayurveda for autism, consulting healthcare professionals, especially those knowledgeable about autism, is strongly advised. Integrating Ayurveda into an overall care plan should be a collaborative effort with healthcare providers familiar with both Ayurvedic principles and conventional evidence-based approaches to autism. Open communication ensures that any therapeutic approach aligns with the best interests and well-being of individuals with autism.

# 10 Education & Schooling

When considering schooling and education options for their children on the autism spectrum, parents often start with: “Can my child go to school?” Sometimes this question is also phrased as a need - “my child needs to go to school. How will he get an education otherwise?” This seemingly simple thought opens the doors on a variety of questions and concerns that parents often struggle with.

However, before addressing this question, it’s important to think about what schooling and education mean and how they are different. Education is the acquisition of knowledge through formal learning and instruction. In contrast, schooling pertains to obtaining an education within a formal school setup. This difference is important as it helps us move beyond mere attendance and focus on a comprehensive educational journey for children on the autism spectrum. While we are at a point to choose between the both, it is worthy to note that education is more important than schooling.

Recognizing that traditional education systems may pose challenges for autistic children is the key. Unlike neurotypical children, the learning experience for autistic children can be difficult within conventional educational frameworks. This realization sets the stage for reimagining education to better suit the unique needs of children with autism.

In this section, we address a few questions, concerns and thoughts relating to education and schooling for children on the spectrum. For the purposes of this section, the children we are talking about are 5-16 year olds.



**10.1 Early Intervention vs Schooling**

**10.2 Goals of Education**

**10.3 Schooling issues**

**10.4 A few options**

**10.5 Pushing children through mainstream school**

**10.6 Inclusive Schools**

**10.7 Homeschooling**

**10.8 A mix of approaches**

## **11 Finding Work, Keeping It**

## **12 Adulting on the Spectrum**

## References