THE Parent/Caregiver FIELD GUIDE TO UNDERSTANDING AUTISM

Alt text: A child, man, and woman walking under a tree, smiling.

WHAT YOU NEED TO KNOW FROM THE PERSPECTIVE OF CLINICIANS, PARENTS, AND ACTUALLY AUTISTIC ADULTS

BIG SKY THERAPY & CONSULTING

Table of CONTENTS

Alt text: A child and man laying side by side facing forward.

A note to our readers

This guide was made possible through a joint effort between clinical professionals, parents, and autistic adults. We believe this collaborative approach to parent education will help families see a new autism diagnosis through a strengths-based lens. More specifically, adding autistic voices to this guide is crucial in helping individuals and families understand the challenges of navigating a neurotypical world as a neurodiverse/neurodivergent individual, and therefore create a more holistic approach to supporting Autistic individuals.

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Alt text: photo of the legs of four people working on various projects.

TERMINOLOGY

On your journey thus far, you've probably heard dozens of descriptions and labels of Autism types. This section is to clarify what labels are helpful, which ones should no longer be used, and what the reasoning is behind these details, according to the Adult Autistic community. You will also notice that we use Autism/Autistic, with a capital "A," which is the preference of the Autistic community.

Preferred Terminology

"Autistic Person" or "Autistic Adult"

- This is known as "Identity First Language" (IFL)
- It is strongly preferred by most Autistic adults and therefore will be used in this parent guide.
- The Rationale: Autism is not something to be ashamed of; it's a neurological difference, not a disease.
- It is important to note that an individual should have autonomy over their labels and diagnoses, so deference to their preferences in terminology is always recommended.

Outdated/Offensive Terminology

"Person with Autism"

- Known as Person First Language (PFL)
- Generally acceptable but not preferred by the Autistic community
- Used by mainstream society, and enforced by non-autistic-led groups like Autism Speaks
- Implies Autism is an unwanted affliction, a negative thing that we should "not allow to define us"

"Suffer(s) from/with Autism" or "Living with Autism"

- This is a more offensive variation of person-first language (PFL).
- Autism is not a disease, injury, or cause of a person's suffering.

"On the spectrum"

- This is a euphemism that stigmatizes autistic people's existence by making Autism something that cannot even be spoken of directly.

Key Takeaway:

The preferred terminology of most Autistic adults is "Autistic person."

Other Important Terms

Neurotype describes the way our brains function. An analogy is different operating systems on a computer. (e.g., "My mother and I sometimes have trouble relating to each other because we have different neurotypes.")

Neurodivergent/Neurodiverse (ND) is someone whose neurology is not typical. This includes autism, ADHD, schizophrenia, bipolar, and others.

Neurotypical (NT) is generally someone whose neurology is typical.

Why The Autistic Community is Moving Away from Functioning Labels

Functioning labels are a category of Autism descriptions that includes phrases like “high functioning Autism” and “level 2 Autism”. While many medical and educational service delivery models use these labels, many Autistic adults find them to be harmful.

- Being labeled "high-functioning" can mean your needs get ignored.
- Being labeled "low-functioning" can mean your strengths or skills get ignored.
- Modifiers like mild/moderate/severe autism have the same effects.

In addition to encouraging an unhealthy environment that causes needs and strengths to be ignored, functioning labels just aren’t helpful. There are hundreds of traits that each individual person, Autistic or neurotypical, needs zero to a lot of help with. Functioning labels attempt to reduce something complicated with hundreds of variables to a single spectrum, and that is not a helpful description. Just like everyone else, Autistic people have strengths and struggles. A person may be incredibly talented in some areas and completely disabled in others. The spectrum is not a sliding scale from one extreme to another, but more like an audio equalizer with different levels for different areas of life, just like Neurotypical individuals.

Functioning Labels in the Medical and Academic Models

Some clinical settings will require the use of “levels" as laid out in the DSM-5, which is the standard reference that healthcare providers use to diagnose mental and behavioral conditions, including autism. While functional labels are not useful in the "real world" some facilities use them for funding purposes.

OTHER RECOMMENDED RESOURCES FOR LEARNING ABOUT NEURODIVERSITY AND THE #ACTUALLYAUTISTIC MOVEMENT:

THINKING PERSON'S GUIDE TO AUTISM

ASAN
AUTISTIC SELF ADVOCACY NETWORK

Alt text: Logos for Thinking Person's Guide to Autism and Autistic Self-Advocacy Network

Other Labels

PDD-NOS is not a functioning label, but it is no longer in the DSM, having been merged into Autism.

Pathological Demand Avoidance is not currently In the DSM but Is recognized in some countries like the UK as a subset of Autism.

Sensory Processing Disorder is not currently in the DSM but Is recognized by many occupational therapists as a comorbidity of Autism. It can also exist independently and is sometimes mistaken for autism in young children.

What about Asperger's Syndrome?

"Asperger's Syndrome" has been removed from the DSM as of the DSM5. It has been integrated into Autism. This is because Asperger's Syndrome did not accurately reflect a distinct neurotype from Autism. As a sidenote, Hans Asperger was a Nazi who differentiated Asperger's Syndrome from Autism to separate out boys he viewed from useful from a section of the population of Autistic people he viewed as undesirable. It was part of eugenics and a means of further exploitation. Adult Autistics do not use this label because it is not a helpful label, does not provide any distinguishing traits, and has origins in eugenics.

Giftedness

Terms you may see/hear to describe giftedness in the Autistic community are Autistic Savants or Twice Exceptional (2E.) These terms are largely interchangeable (along with Gifted) to describe Autistic children and adults who display remarkable abilities or splinter skills in one or several domains. These splinter skills may be exhibited in the following skill areas or domains: memory; hyperlexia (the exceptional ability to read, spell and write); art; music; mechanical or spatial skill; calendar calculation; mathematical calculation; sensory sensitivity; athletic performance; and computer ability. These skills may be remarkable in contrast to the Individual's accompanying disabilities, or prodigious in relation to the typical population.

Genetic Syndromes

Rett Syndrome, Mowat-Wilson Syndrome and Phelan McDermid Syndrome are not functioning labels of Autism. The DSM-5 classifies these separately from Autism, due to their genetic natures. However, they are often seen as Autistic and are accepted as part of our community.

So, what do I call my child?

Just say they're Autistic. Autistic is great. It's simple and accurate.

MAKING THE MOST OF AN AUTISM EVALUATION

Goals of the Evaluation
A good evaluation begins with a set of clear goals and objectives. Ask yourself the following questions:

- Why is the evaluation being done?
- What do we hope to accomplish?
- What can be done with the information once it is collected?

The answers to those questions will help define the objectives, which should then be discussed in detail with the evaluator before the assessment begins.

How Is Autism Diagnosed?
Currently there is no lab test or biomarker for Autism. Rather, Autism is diagnosed based on a child's symptoms and behavior.

There are two main areas that are considered in order to make an accurate diagnosis:

- Social communication skills (verbal and nonverbal)
- Restricted, repetitive patterns of behaviors, interests, and activities

Individuals must show deficits In both areas In order to receive a diagnosis.

While a diagnosis can offer clarity, it does not necessarily tell us how to support a child.

An evaluation should result in a *comprehensive* written report, which the evaluator should discuss with you in detail. While a report usually contains a great deal of data and technical information, it should also be written in a way that's easy to understand for nonprofessionals. All jargon should be well defined, and if it's not, don't hesitate to ask for explanations. Additionally, clinicians should give in-depth descriptions of your child's unique strengths and challenges, which can then help your family decide what kinds of educational programs and medical interventions/therapies would be most beneficial.

A diagnosis of Autism doesn't always warrant therapies. Interventions should depend on each child's strengths and needs, not their diagnosis.

Components of an Autism Evaluation

A primary care doctor will suggest an evaluation by a specialist that Includes:

- A medical examination
- Questions about your child's family history
- Observation of your child's behaviors
- An in-depth conversation with you and your family about your child's behavior and development
- A review of your child's cognitive skills
- Assessment of your child's communication skills

Medical History and Exam

The medical exam can and often is performed by the individual's primary care physician. In a child's case, this is usually done by their pediatrician. This will usually include a review of the child's medical file, including family history, any medical conditions since birth, and a review of developmental milestones. If warranted, a child's doctor may refer your family to a specialist for neurological imaging or genetic testing. A hearing test is also usually recommended. The clinician or team conducting the Autism assessment will review these records and may perform a more in-depth examination of a child's medical history, including interviewing caregivers.

Observation

The observation portion of an assessment may include observations made during assessment, at home, in the classroom, or even during a structured assessment like the Autism Diagnostic Observation Schedule- Second Edition (ADOS-2). The ADOS-2 is an activity-based assessment administered by trained clinicians to evaluate communication skills, social interaction, and imaginative use of materials in individuals who are suspected to have autism. The ADOS-2 is the most highly researched and accepted instrument in assessment for ASD and can be used at virtually any age (12 months and up).

Family/Caregiver Interviews

Family input is crucial to making an accurate diagnosis. This input may take the form of questionnaires, direct interviews by clinicians, or standardized scales/checklists. Caregivers are often asked the same questions in multiple ways in order to ensure accurate reporting.

Cognitive Skills

Cognition is generally a more clinical term for a child's thinking skills, and is always separate from other skills like language, motor skills, hearing/vision, and social emotional understanding. This portion of an assessment will typically be completed by a clinical psychologist, psychiatrist, or other type of qualified therapist. For younger children, this usually includes their problem-solving skills as it related to manipulation of their environment (e.g., pushing a chair over to reach something in the fridge, solving a complex puzzle, or even turning a block to get it into a container.) For older children and adults, a cognitive assessment can give helpful information on the following areas:

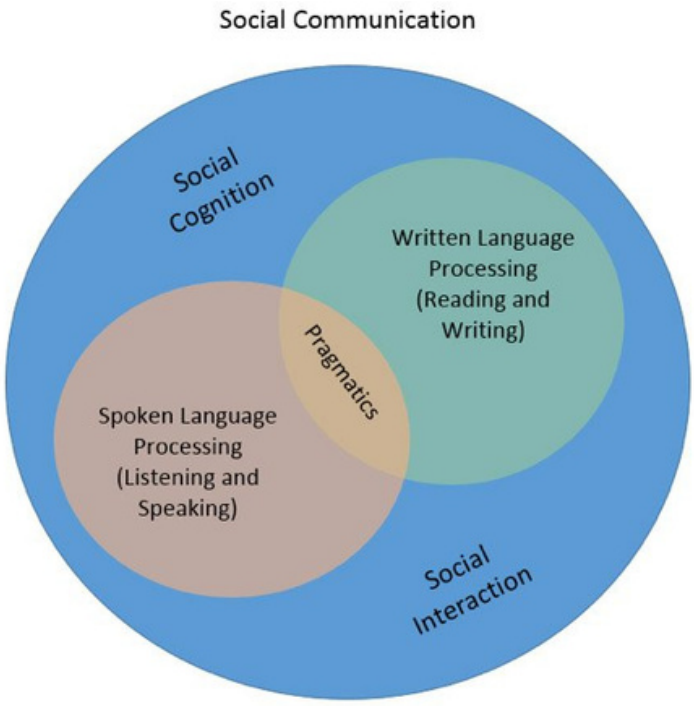
- Memory: Include long term memory, short term memory, and procedural memory. One of the most important kinds of memory is called "working memory", which measures the ability to hold information in mind and be able to work with information held in mind.
- Attention: One component of working memory is attention, which is the first requirement in memorizing information. While attention is generally not measured separately, it can have an impact on most aspects of cognition and should be considered.
- Verbal Reasoning/Problem Solving: Knowledge of words and being able to apply them – verbal concept formation, reasoning, and expression. This is usually measured through a series of verbal tasks and questions.
- Visual Spatial Reasoning/Problem Solving: Seeing visual details, understanding spatial relationships and construction ability, understanding the relationship between parts and a whole, and integrating visual and motor skills. These skills are usually measured through activities like puzzles and mazes.
- Processing Speed: Speed and accuracy of visual scanning and identifying visual objects, short-term memory, and visual-motor coordination. Poor processing skills can affect a child's ability to retain information. Children with slower processing speeds often have the cognitive skills to be successful but may struggle with fast-paced environments like classrooms.

Each of these cognitive skills represents an ability vital to academic performance. Neurotypical children typically score consistently across all cognitive skills; they may have strengths and areas of difficulty, but generally their consistency across cognitive domains helps them to be successful in a traditional classroom environment. Autistic individuals are often not understood due to the variability in cognitive skills. For example, an Autistic child's exceptional memory may allow them to code computers quicker than others; however, if their processing speed is a relative weakness, they may struggle keeping up with the fast-paced directions of their teacher. Another child may have terrific verbal skills, but if their verbal working memory is poor, they could struggle to hold onto what the teacher is saying to take notes or to get the big ideas.

Communication Skills

Communication skills are one of the most important areas of assessment, as it contributes to a large portion of the diagnostic criteria. This area is generally assessed by a speech-language pathologist. Areas of assessment include:

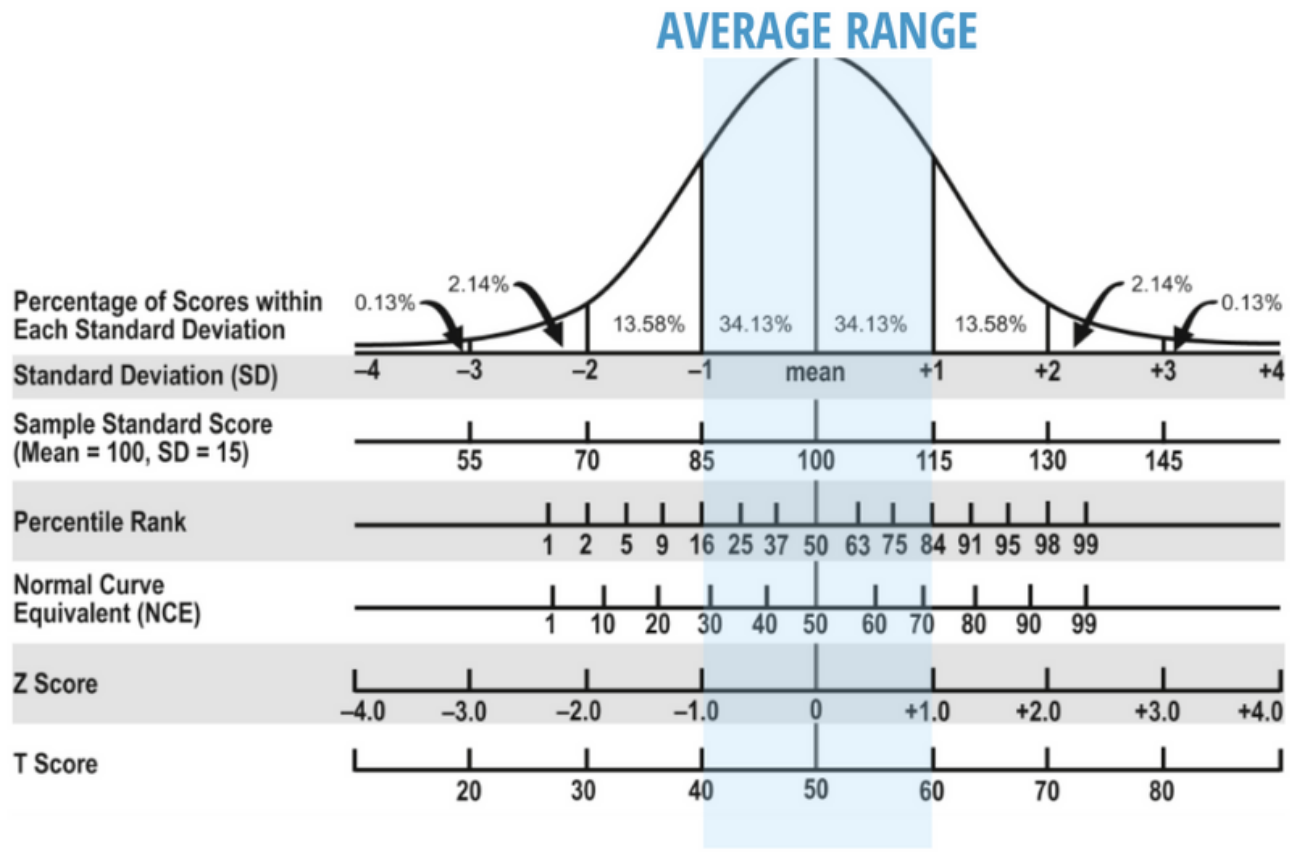
- Speech: A child's ability to perform the motor sequencing to produce specific speech sounds.
- Language: Includes expressive language (how a child uses communication to express themselves) and receptive language (the communication a child understands to receive information from others.)
- Nonverbal Communication: Includes an individual's ability to use and understand facial expressions, gestures, and eye gaze.
- Pragmatic Language: Language used for the purposes of social communication. This includes figurative language, use and understanding of verbal social routines (like greetings, asking for help.) It also includes use and understanding of paralinguistic information like tone of voice
- Social Communication: The skills required to communicate during a sociation interaction. Can include conversational skills like turn-taking and remaining on topic, conflict resolution, and self-advocacy.
- Social Cognition: Include the underlying cognitive processes that help us navigate social situations. Can include Theory of Mind or perspective taking, social inference and problem solving, emotional intelligence, and joint attention.
- Executive Functioning: Some people describe executive function as "the management system of the brain." That's because the skills involved let us set goals, plan, and get things done. When people struggle with executive function, it impacts them at home, in school, and in life. Executive function is responsible for many skills, including organizing, planning, and prioritizing, starting tasks, and staying focused on them to completion, and self-monitoring (keeping track of what you're doing and adapting as needed.)



Alt text: infographic showing social cognition and social Interaction making up social communication. Spoken Language Processing (Listening and Speaking) aand Written Language Processing (Reading and Writing) are within this circle and overlap In a section called Pragmatics.

Understanding Scores

In physical measurement we begin with zero and measure up to higher numbers. In contrast, psychological tests and educational achievement tests begin their measurements of aptitude in the middle (also referred to as the mean, average, or measure of central tendency) and measure out toward each end of the distribution curve.



Alt text: photo of a bell curve with labels for Percentage of scores within each standard deviation, Standard Deviation, Sample Standard Score, Percentile Rank, Normal Curve Equivalence (NCE), Z Score, and T Score.

Test scores are reported in different formats, including:
Standard scores (average = 100)
Scaled scores (average = 10)
Percentile Rank (average = 50th)
Z-scores (average = 0)
T-scores (average = 50)
Test results may also be reported in terms of age or grade equivalency

To understand and be able to discuss your child's test scores appropriately, it is helpful to familiarize yourself with the bell curve or normal distribution curve. The bell curve may be used to make comparisons between one child's score and the scores of their peers. Most educational and psychological tests based on the bell curve report their scores as standard scores and percentile ranks.

The average range is broad, spanning a distance from the 16th to the 84th percentiles, and the learning profiles of children within that average range are equally wide-ranging. Consequently, when you hear an evaluator say your child scored in the average range, recognize that's just the beginning of the discussion that must follow.

Multiple Diagnoses

Occasionally, a child may receive a diagnosis/es in addition to Autism. These are often referred to as comorbid or co-existing disorders. Sometimes these difficulties can fall under the umbrella of their Autism diagnosis, in which cae they are called "accompanying impairments,"

An accompanying impairment is a clinical term and can include:

- Language impairments, which can describe deficits in receptive or expressive language skills compared to same-aged peers. Children with language impairments may have a difficult time expressing themselves, following directions, answering questions, or carrying on a conversation. Augmentative or Alternative Communication (AAC) may be beneficial with Autistic individuals who have an accompanying language Impairment.
- Accompanying mental or behavioral disorder, like depression or anxiety, which will also need to be addressed.
- Accompanying intellectual impairment or other neurodevelopmental disorder, like attention deficits or a learning disability.

These will likely need to be assessed and treated Independently and are not present with all autistic children and adults, just like neurotypical children and adults.

Key Takeaways:

While a diagnosis is helpful, the most important information is about your child's strengths and needs

Each Neurotypical and Autistic child has a variety of strengths and needs that can rarely be quantified In a single phrase or sentence; therefore functioning labels, while sometimes necessary, are not all that helpful

Your child may walk away with more than one diagnoses OR an accompanying impairment. This is just an added piece of information that should be considered for Interventions.

WHO TO TELL, WHEN TO TELL, & HOW TO TELL

Before you read this section, it's important to know some unfortunate realities about our society. Autistic people are routinely discriminated against in education, healthcare, social services, and the workforce. In addition, respecting privacy is important. You should not reveal a person's status of being autistic without a good reason. With that in mind, sometimes you do have to disclose that someone is autistic. This section is meant to be a guide on this.

Ultimately, the core questions in disclosing your child being autistic to others are "Why are you considering this disclosure?", "Is your child ok with you disclosing this?" and "What do you hope to achieve from this disclosure?"

Other Frequently Asked Questions:

Should we tell our child that they are autistic?

Yes. According to Autistic Adults, most autistic people determine on their own that they are different, typically before the age of 7. Finding out they're Autistic is can actually be a relief.

What if I don't want to tell them because I don't want them to think they're different?

On a broader scale, a person being different isn't anything to be ashamed of or scared of. It's simply a fact of life. First, humans simply vary in general. Knowing that such variety exists is a basic product of awareness.

What If they use it as an excuse?

An excuse for what? Different individuals have different limits and capabilities. This is true for Autistic people and Neurotypical people. A human with type-1 Diabetes isn't "using an excuse" when they can't make enough insulin on their own. A person with dyslexia Isn't "making an excuse" when they can't read or decode a word. Autistic people have strengths, weaknesses, capabilities, and incapabilities. Autistic people knowing they are Autistic does not change this.

What happens if I don't tell my child they're Autistic?
As stated above, Autistic people almost always know when they're different and they might figure it out on their own. Imagine your parents knew something really important about you and kept said information from you, like being born intersex, being infertile, or having a different genetic history than your siblings.

How should I tell my child they're autistic?
This varies based on maturity and when you find out, but the general approach is the same. Just tell your child that, like skin and hair, human brains can vary from person to person, and we have categories for them, and your child is in this category. Your child will probably have questions. And that's ok. You might not have all the answers. That's also ok. It's ok to say "I don't know", and is in fact, necessary sometimes for trusting healthy relationships. If you feel uncomfortable having this conversation with your child, you can reach out to one of your child's existing therapists or find a family therapist that can help.

When should I share my child's diagnosis with others?
Ultimately, the core questions in disclosing your child being autistic to others are "Why are you considering this disclosure?", "Is your child ok with you disclosing this?" and "What do you hope to achieve from this disclosure?" For example, are there specific accommodations required to allow your child to participate in school or be employable? Does It benefit a medical provider to know your child Is autistic?

If you can't explain to yourself a reason to disclose your child being autistic, then you shouldn't disclose it. If your answer to "why are you considering this disclosure" is "I think it might help", then ask yourself "help with what?". If you can give specific answers about something your child actually needs help with, and you think this disclosure will help with those needs, then it may be worth sharing. Additionally, as children get older and more comfortable with self-advocacy, he or she should ultimately determine when, to whom, and how their diagnosis/es get disclosed.

NOW WHAT?

Here are some action items (these are designed to be done WITH your child if they are able and willing to participate.)

Action Items:

1. Compile a list of your child's strengths and needs. Make sure you fully understand their evaluation. If needed, reach out to the evaluator to get clarification or further interpretation.
2. Sit down with your family and establish some family goals.
    a. If your family is in crisis (either your child, you, or part or all of the family unit) figure out a way to implement some self-care. This could include speaking to a family therapist, going on a short vacation, calling in some extended family members, or briefly separating the family unit.
    b. Figure out some short term goals. What is your hope for your child in a year? Try and be as specific as possible. What therapies, school interventions, medical supports, or recreational activities can help you reach that goal? Keep in mind your child may not need extra interventions to achieve this.
    c. Figure out some long term goals. What Is your hope for your child in five years? What about ten? How can you get there?
3. Create a list of people you would like to share the diagnosis with. This could Include extended family members, other caregivers, school/daycare staff, existing therapists, medical professionals, or even friends.
4. Prioritize 1-2 interventions. These could Include speech/occupational therapy, a structured social group, family therapy, equine therapy, or vocational training.
5. Decide if your child's educational plan is adequate to meet their needs. If your child is already in special education or receiving extra supports in school, contact their teacher or case manager. If not, a special education evaluation may be warranted, even if you just want some accommodations and modifications.
6. Decide if you need to speak with your doctor about supplements or medications for diet, sleep hygiene, digestive issues, attention deficits, depression/anxiety, or other common conditions associated with autism.
7. Follow up on any additional recommended testing.

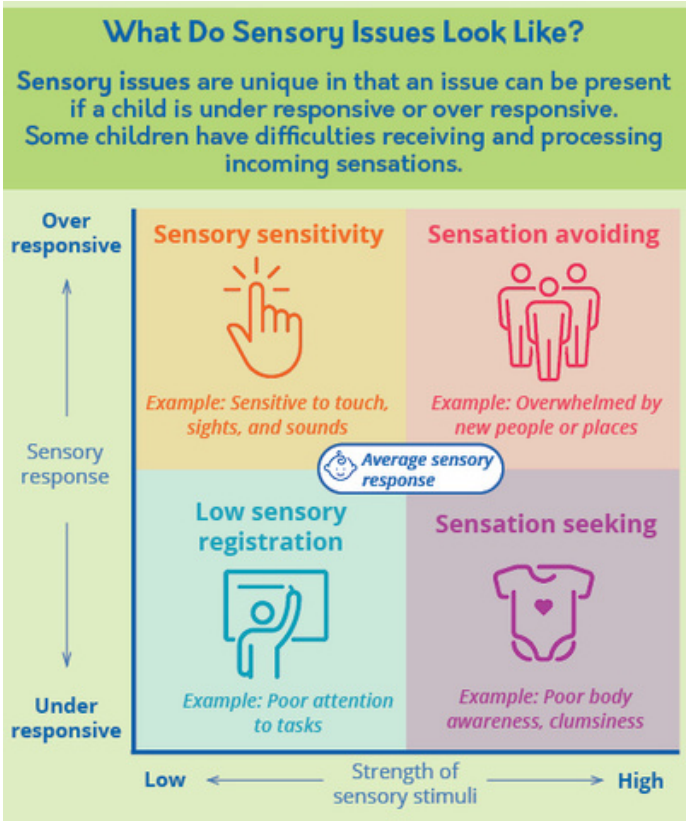
A GUIDE TO THERAPIES & TREATMENTS

General Therapy Rule

This is the general rule for autism and therapy: Autism is not a disease and thus does not require treatment. Autism is simply a case of humans being different, like being left-handed or having blonde hair. It is not a problem you need to solve. That said, if your child is experiencing issues that they require help with, then helping them is a good idea. For example, if they experience motor control issues, then occupational therapy could be a good choice. If they are experiencing challenges with relationships or communication, speech therapy could be a good choice. "Preventative" therapy Is also not recommended.

Different people may or may not benefit from different therapies. This list is not an endorsement of individual therapies and especially not individual therapists. You should always be in direct communication with therapists about their goals for your child and therapy techniques to achieve those goals. Below is a description of different types of therapy available for Autistic *and* neurotypical Individuals:

Occupational therapy Assists development of fine motor skills that aid in daily living. May focus on sensory issues, coordination of movement, balance and self-help skills such as dressing, eating with a fork, grooming, etc. May address visual perception and hand-eye coordination. Although research on sensory Integration therapy Is limited, many autistic adults have reported this type of therapy to be helpful In mitigating and accommodating for sensory differences.



Alt text: An infographic showing four quadrants of sensory response with "Average sensory response being in the middle.
Text: What do Sensory Issues Look Like? Sensory issues are unique in that an issue can be present if a child is under responsive or over responsive. Some children have difficulties receiving and processing incoming sensations. Sensory Responses: Sensory sensitivity (over responsiveness to low sensory stimuli), sensation avoiding (over responsiveness to low sensory stimuli), low sensory registration (under responsiveness to low sensory stimuli), and sensory seeking (under responsiveness to high sensory stimuli).

Play therapy Involves children engaging in play activities of their choice. The play therapy environment gives the client opportunities to express themselves in ways that are most comfortable. Instead of the therapist leading therapy, children are in charge of the pace, direction, and content of the therapeutic journey. This type of therapy can also be called child-centered therapy and can encompass any therapy that uses the relationship as an intervention, rather than training children to engage in specific behaviors that may conflict with their natural ways of being.

Feeding therapy we don't have evidence that gastrointestinal or feeding issues occur more in children with ASD than in other children. (Some studies have shown that, but then could not be replicated, that is, new research studies trying to duplicate those findings could not.) Feeding problems, however, do occur more often in children with all kinds of developmental disabilities, including ASD. It Is Important to clarify the difference between a feeding/swallowing disorder and a picky eater.

- A Feeding/Swallowing Disorder (AKA Dysphagia) involves a structural or neurological condition and Is usually diagnosed by a speech-language pathologist or, sometimes, an occupational therapist. This type of disorder can often cause additional health Issues If untreated.
- Picky Eating can occur when children avoid certain foods or food groups, usually based on an underlying Issue like sensory differences or behavior. This should only be "treated" by a therapist If a child's diet Is not sufficient for adequate nutrition OR If a child asks for help with expanding his/her food repertoire.

Social skills therapy Assists with development of prosocial communication skills necessary for initiating and maintaining relationships, self-advocacy, and job/school participation. This type of therapy should generally utilize a Cognitive Behavioral Therapy (CBT) approach and not a behavioral approach (e.g. teaching compliance- see notes on next page about ABA therapy.) Children should consent to this type of therapy and be active in setting goals for themselves. For example, if their goal Is to make friends, they should be taught the skills to find appropriate peers and build a friendship. Goals should not consist of skills like eye contact, which Is considered "masking" and can be detrimental.

Speech and/or Language Therapy A therapy with the goal of improving an individual's ability to communicate. This includes verbal and nonverbal communication. The treatment is specific to the individual's needs. This would include any therapy required to learn to use alternative or augmentative communication (e.g. sign, picture exchange, or using a device to generate speech.)

- **Individual and/or family counseling** A large portion of Autistic youth also struggle with anxiety, depression, eating disorders, sleep Issues, and other mental and behavioral health Issues. Just like their neurotypical counterparts, these should be treated Individually, with a licensed therapist, as they manifest. Additionally, It can often be beneficial for whole families to participate In counseling to strengthen the communication within the family.
- **Behavioral therapy or ABA therapy** ABA Therapy has become an incredibly controversial form of therapy and adult autistics, parents, and researchers have not come to a consensus on its effectiveness.
    - Traditional ABA Therapy Is a type of therapy that relies on compliance. It Is the type of therapy most Autistic adults refer to when they discuss their PTSD related to participation In ABA Therapy.
    - Modern ABA Therapy Is a type of therapy that relies on changing the behavior of a child based on extrinsic rewards and consequences. This type of therapy does not generally consider underlying causes of a behavior, rather focuses on Increasing or decreasing that behavior. For example, Increasing the use of words or decreasing self-injurious

If you are unsure about a particular type of therapy, ask a medical or clinical professional you trust or search the #ActuallyAutistic resources above. If you are unsure about a therapy your child Is currently participating In, be sure to ask questions and demand accountability. If for any reason you or your child feel uncomfortable with a particular provider, know you have the right to request or seek out another one.

Key Takeaway:

The goal of therapy should be to provide a child with tools to navigate the neurotypical world around them. The long-term goal should always be independence, self-advocacy, and emotional wellbeing.

"FRINGE" THERAPIES

There is a long history of snake oil products and techniques that claim to help autism or Autistic people. This section is a guide to these services and products to preemptively explain what is legitimate, a scam, or questionable. While the following interventions may be viable interventions for other medical conditions, there is no strong research linking these interventions to "curing" or "treating" Autism. Additionally, many of these interventions can be harmful or deadly to Autistic children. If you choose to research these interventions, please be mindful that some of the content you find may be disturbing.

Fringe Therapies common for Autistic Individuals

- Dietary Supplements (e.g. Fish Oil, Magnesium, or anything that doesn't fill a specific nutrient deficiency)
- Gut Health
- Miracle Mineral Solution
- Stem Cell Treatment
- Essential Oils
- Hyperbaric Medicine
- Chelation Therapy
- Chiropractic Care
- Detoxification Products or Processes
- Illegal (for persons under 18) Drugs such as Cannabis or Ketamine

A General Guide For Anything Not Listed:

Before going over individual things, here is a general guide to determining if something is a legitimate product or service:

- Any product that does not describe how it works or provide a list of ingredients should be considered a harmful scam product.
- Any product which claims to cure or treat autism should be treated as a dangerous scam.
- Any product advertised to deal with parasites as a treatment for autism is a scam and probably violates federal laws.
- Any product or service which claims to treat harmless behaviors such as stimming should be treated as an abusive, harmful scam.

CAN AUTISTIC PEOPLE BE SUCCESSFUL?

yes!

One of the reasons the Autistic community continues to push for representation in media Is that it can be helpful to a child to see people like them. It can also encourage acceptance of different kinds of people for Neurotypical children.

This list of Autistic Individuals was compiled in hopes of showing Autistic children and their families the myriad possibilities for them/their child. Note that some of these people are assumed to have been autistic based on period description; others are diagnosed.

- Greta Thunburg: A swedish environmental activist who has received numerous honors and awards, including an honorary Fellowship of the Royal Scottish Geographical Society. She is the youngest person ever placed in Time Magazine's list of 100 most influential people, was included in Forbes' list of The World's 100 Most Powerful Women (2019), and has had three consecutive nominations for the Nobel Peace Prize (2019–2021).
- Dan Aykroyd: An actor who is famous for working on Saturday Night Live and The Blues Brothers.
- Hans Christian Andersen: A prolific author. He's most famous for writing The Ugly Duckling and The Little Mermaid.
- Henry Cavendish: The chemist who discovered hydrogen.
- Paul Dirac: A quantum physicist.
- Albert Einstein: Creator of relativistic physics and created some of the foundations of quantum physics.
- Daryl Hannah: An actor who won the Saturn Award. She has had roles in Kill Bill and Blade Runner, among others.
- Satoshi Tajiri (田尻 智): Creator of the Pokemon franchise. He has also served as an executive on all of the pokemon games and co-created several early Mario games.
- Nikola Tesla: An electrical engineer and mechanical engineer.
- Anthony Hopkins: Actor, Philanthropist, and Composer.
- Andy Warhol: Maybe you should wait until your child is in their teen years to introduce them to Andy Warhol. He was a painter and filmmaker.
- Barbara McClintock: A Nobel prize winning geneticist. She discovered the telomere.
- David Byrne: singer of the new wave band Talking Heads, and film/tv composer for films like the Last Emperor and the show Big Love.

OTHER HELPFUL RESOURCES

2E (Twice Exceptional) Children) and giftedness:
https://childmind.org/article/twice-exceptional-kids-both-gifted-and-challenged/
https://www.agnesian.com/blog/giftedness-and-autism-savant-skill-fact-sheet

Behavior:
https://childmind.org/topics/concerns/behavior/
https://childmind.org/article/strategies-for-managing-disruptive-kids/ (video)
https://www.kqed.org/mindshift/43049/20-tips-to-help-de-escalate-interactions-with-anxious-or-defiant-students
https://www.understood.org/articles/en/what-are-positive-behavior-strategies

Executive Function:
https://developingchild.harvard.edu/resources/what-is-executive-function-and-how-does-it-relate-to-child-development/
https://developingchild.harvard.edu/resources/activities-guide-enhancing-and-practicing-executive-function-skills-with-children-from-infancy-to-adolescence/

Neurodiversity and Universal Design for Learning
https://www.neurodiversityhub.org
https://www.understood.org/articles/en/universal-design-for-learning-what-it-is-and-how-it-works

Other Parenting Resources:
https://www.understood.org/hub/en
TILT Parenting
https://autisticmama.com/blog/

For the most up-to-date resources, check out our resources page at:
https://www.bigskytherapyassociates.com/online-resources

Or scan here!

GLOSSARY OF TERMS

These are some terms or acronyms you may hear In the medical or academic setting in the United States:

504 plan Section 504 of the Rehabilitation Act of 1973. This is specific to the United States education system. 504 Plans are legal documents which are made to protect a disabled student's right to receive an education. It is possible for students to have both, one, or neither. Section 504 Plans cover adapting an environment or instruction methods to accommodate a disabled student, do not cover curriculum adaptation, may extend into post secondary education, and also cover associated extracurricular activities. Section 504 applies to any agency or entity receiving money from the United States federal government, but we are only covering the education specific components. 504 plans can be temporary for temporary disabilities, such as a broken bone. 504 plans can also be converted into IEPs. Note that state, territorial, and municipal law may also affect these. These plans may be updated annually and lawful guardians have the right to be involved in them. **Accommodations** Changes or adjustments that help meet a person's individual needs.
Actually Autistic/AA A term that many autistic people use to describe and advocate for themselves
Adaptive Device Any piece of equipment designed to improve a function of the body
Adaptive Skills current skill levels and abilities of individual skills related to participating in community life, such as self-advocacy, safety, transportation and leisure
Americans with Disabilities Act (ADA) U.S. law that ensures rights of persons with disabilities with regard to employment and other issues.
Antecedent An outside stimulus that triggers a "behavior." An antecedent can Include a specific demand, sensory overload, hunger, thirst, fatigue,
Anxiety Strong feelings of worry or fear about everyday activities. Anxiety disorder affects an estimated 30% of individuals with autism.
Applied Behavior Analysis (ABA) A style of teaching using series of trials to shape desired behavior or response. Skills are broken into small components and taught the individual through a system of reinforcement.
Asperger syndrome A developmental disorder, no longer used in the DSM-5, on the autism spectrum defined by impairments in communication and social development and by repetitive interests and behaviors, without a significant delay in language and cognitive development. The DSM-5 indicates that individuals with a "well-established diagnosis" of this condition "should be given the diagnosis of autism spectrum disorder."
Assisted communication device A tool that helps you communicate with others. Examples include picture cards and electronic tablets that speak words that you type. Assistive Technology Device Any Item, piece of equipment, or product system, to that Is used to maintain, Improve, or Increase the functional capabilities of a child with a disability.

Attention deficit hyperactivity disorder (ADHD) A disorder that affects approximately 1 in 5 children with autism. Symptoms include chronic problems with inattention, impulsivity and hyperactivity. Can present as Inattentive, Hyperactive, or Combined type.
Audiologist A professional who diagnoses and treats individuals with hearing loss or balance problems.
Augmentative and alternative communication (AAC) Methods of communication for people who can't use speech (talking) to communicate; examples include sign language and using a computer for speech.
Baseline data Measurement of a behavior before an intervention is begun. Progress is measured by comparing current behavior to baseline data.
Behavioral intervention An intervention focused on increasing positive behavior and limiting challenging behavior, such as Applied Behavior Analysis.
Biomedical interventions A range of treatment methods that address underlying medical conditions and biological processes, such as the gastrointestinal system, diet and nutrition, immune function and sleep.
Board-certified behavior analyst (BCBA) A professional specialized in autism, certified and trained to write, implement and monitor a child's individualized ABA program.
Body language Nonverbal communication through physical movements and gestures.
Cognitive behavioral therapy A form of therapy that seeks to make changes in thoughts and perceptions of situations through a change in cognition or how thinking is processed.
Cognitive deficit An inclusive term to describe any characteristic that acts as a barrier to mental skills such as acquiring information and knowledge.
Cognitive skills Any mental skills that are used in the process of acquiring knowledge; these skills include reasoning, perception and judgment.
Comorbid conditions Different conditions that occur in the same person.
Compulsions Deliberate repetitive behaviors that follow specific rules, such as those pertaining to cleaning, checking or counting. In young children, restricted patterns of interest may be an early sign of compulsions.
Consequence A result or effect of an action or condition. Consequences are used in behavioral therapy and can include positive reinforcement of the desired behavior or no reaction for incorrect responses.
Daily living skills Also called life skills or independent living skills. Skills that you need to manage your everyday life. Examples include self-care, home care, cooking and managing money and time.
Developmental evaluation A thorough assessment of current developmental concerns. It is often the first step of the autism diagnosis process.
Developmental pediatrician A doctor who treats children with learning, developmental and behavior problems.
Diagnostic and Statistical Manual of Mental Disorders (DSM-5) The official system for classification of psychological and psychiatric disorders published by the American Psychiatric Association in 2013 that, among other changes, established new criteria for an autism diagnosis, eliminated the previously separate subcategories on the autism spectrum, including Asperger syndrome, PDD-NOS, Childhood Disintegrative Disorder and Autistic Disorder and added a new category called Social Communication Disorder (SCD)

Discrete Trial Training (DTT) An ABA technique that involves teaching individual skills one at a time using several repeated teaching trials and reinforcers that may or may not be related to the skill that is being taught. DTT is the most traditional ABA technique.
Due Process Legal steps and proceedings carried out according to established rules and principles; designed to protect Individual's legal rights. Parents can seek due process In the school system If they disagree with the educational team about their child's educational plan
Early Intervention services Services and supports for children from birth through age 3 who have developmental delays and disabilities. EI services can help children learn important skills for school and daily life. They can include programs to help a child learn physical and self-help skills and to communicate and interact with others.
Electroencephalogram (EEG) A test using electrodes on the scalp to record electrical brain activity. For diagnoses of seizure disorder or abnormal brain wave patterns.
Environmental factor Any nongenetic influence. The role of environmental factors in the development of autism is a crucial area of study.
Executive functioning Brain processes that allow you to focus on a task, organize your ideas and solve problems.
Expressive language Communication of intentions, desires or ideas to others, through speech or printed words and includes gestures, signing, communication board and other forms of expression.
Extended School Year (ESY) Services Services provided during breaks from school, such as during summer vacation, for students who experience substantial regression in skills during school vacations.
Feeding therapy An intervention that helps teach people with feeding issues how to eat or eat better. This type of therapy is usually provided by a trained occupational or speech therapist.
Free appropriate public education (FAPE) Means that education must be provided to all children ages 3 to 21 at public expense.
Functional Behavior Assessment Refers to a variety of behavior assessments for determining the environmental variables that are preceding challenging behaviors, such as self injury. This information helps a team create a plan to help the child manage his/her behaviors.
Functional skills Daily living skills.
Gestures Hand and head movements, used to signal to someone else, such as a reach, wave, point or head shake. They convey information or express emotions without the use of words.
Global developmental delay A diagnosis in children younger than 5, characterized by delay in two or more developmental domains.
Hyperactivity Characterized by constantly increased movement and impulsive actions.
Hyperlexia The ability to read at an early age. To be hyperlexic, a child does not need to understand what they are reading.
Hyper-reactivity (hypersensitivity) A tendency, outside the norm, to react negatively or with alarm to sensory input which is generally considered harmless or non-irritating to others.
Hypo-reactivity (hyposensitivity) Lack of a behavioral response, or insufficient intensity of response, to sensory stimuli considered harmful and irritating to others.

Identity-first language Terminology that leads with a specific part of a person's identity, such as "autistic adult". Many people with ASD prefer this type of language.
Impulsivity A tendency to act with little or no consideration of the consequences. A defining symptom of ADHD.
Inattention A lack of attention or difficulty sustaining focus. A defining symptom of ADHD.
Inclusion Involves educating all children in regular classrooms, regardless of degree or severity of disability. Effective inclusion takes place with planned system of training and supports; involves collaboration of multidisciplinary team, including regular and special educators.
Inclusion The involvement of a student with disabilities in the typical activities of the school, including placement in regular classes, involvement in extracurricular activities and relationships with age-appropriate peers
Individual Family Services Plan (IFSP) A plan developed by a multidisciplinary team including family as primary participant. Describes child's level of development in all areas; family's resources, priorities and concerns, services to be received and the frequency, intensity and method of delivery. Must state natural environments in which services will occur.
Individualized Education Program (IEP) A plan that identifies programs, goals, services and supports to make sure a student with a disability gets a free and appropriate education at school.
Individualized Transition Plan (ITP) Transition Plan goals in a student's IEP that help plan for life after high school. Schools must measure and report on the goals**.** Transition IEPs should address the skills students need to learn while they are still in high school that prepare them for work and living as independently as possible. The Individualized Transition Plan should indicate when the student will graduate and how he or she will achieve a high school diploma (e.g., earning credits, completing IEP goals)
Individuals with Disabilities Education Act (IDEA) A U.S. law that makes sure that students with disabilities get free and appropriate education in public schools that meets their individual needs.
Intellectual disability A term used when there are limits to a person's ability to learn at an expected level and function in daily life. An estimated 31% of children with ASD have an intellectual disability.
Joint attention The process of sharing one's experience of observing an object or event, by following gaze or pointing gestures. Impairment in joint attention is a core deficit of ASD.
Least restrictive environment (LRE) Education for students with disabilities in a setting with students who aren't disabled (also known as mainstreaming), for as much time as possible and with additional services provided for success in school.
Life Skills Classroom a classroom where special education students learn skills necessary to lead independent lives. Activities may include cooking, washing clothes, personal grooming, banking, jobseeking skills, and communication skills.
Manifestation Determination A review of the relationship between a student's misconduct and his/her disability; required by IDEA whenever school officials seek to discipline a student In a manner that would result In a change In placement, suspension, or expulsion.

Mainstreaming Where students are expected to participate in existing regular education classes, whereas in an inclusive program classes are designed for all students. May be gradual, partial or part-time process (e.g., student may attend separate classes within regular school or participate in regular gym and lunch only).
Masking A term used to describe an Autistic person hiding his/her Autistic traits for the purposes of meeting external expectations or norms.
Measurable outcomes Specific results that can be clearly assessed using data and observation to evaluate the progress a person is making toward their goals.
Multi-disciplinary team A team of professionals often involved in the diagnosis or treatment of a person with autism across a variety of specialties, such as a neurologist, psychiatrist, developmental pediatrician and social worker.
Nonverbal communication Things people do to convey information or express emotions without words, including eye gaze, facial expressions, body postures and gestures.
Perseveration Repetitive movement or speech or sticking to one idea or task, that has a compulsive quality to it.
Pica Persistent eating or mouthing of non-nutritive substances for at least 1 month when behavior is developmentally inappropriate (older than 18-24 months). Substances may include items such as clay, dirt, sand, stones, pebbles, hair, feces, lead, laundry starch, wood, plastic and more.
Picture Exchange Communication System (PECS) A tool that helps people communicate with pictures.
Pivotal Response Treatment (PRT) A therapeutic teaching method using incidental teaching opportunities to target and modify key behaviors related to communication, behavior and social skills.
Positive reinforcement The introduction of something positive, such as praise or a reward, for completing a behavior or assigned task as a way of motivating the individual. An integral part of most behavioral therapy programs.
Pragmatics Social rules for using functional spoken language in a meaningful context or conversation. Challenges in pragmatics are a common feature of spoken language difficulties in children with ASD.
Prompt In behavioral therapy, a cue or hint meant to induce a person to perform a desired behavior.
Psychiatrist A medical doctor who helps children and adults with mental health conditions, including problems with thinking, feeling and behavior. These doctors are generally responsible for prescribing medication when needed.
Psychologist A doctorate level clinician who diagnosis and treats mental and neurodevelopmental disorders.
Receptive language The ability to comprehend words and sentences. It begins as early as birth and increases with each stage in development. These skills commonly emerge slightly ahead of expressive language skills.
Regression Any loss of skills, including speech or social skills, academic knowledge, or motor skills.
Related Services A term used in the school system to describe developmental, corrective, and other support services required for a child with disabilities to benefit from special education. Can Include a variety of services, Including speech therapy, physical and occupational therapy, transportation, and medical services.

Resource Room A separate classroom in which special education students spend part of the school day to receive individualized special education services.
Respite care Temporary, short-term care provided to individuals with disabilities, delivered in the home for a few short hours or in an alternate licensed setting for an extended period of time. Respite care allows caregivers to take a break in order to relieve and prevent stress and fatigue.
Restrictive and repetitive behavior One of the first two diagnostic criteria for ASD, includes stereotyped or repetitive motor movements, insistence on sameness or inflexible adherence to routines, highly restricted, fixated interests or hyper- or hypo-reactivity to sensory input.
Rett syndrome A very rare disorder in which patients have symptoms associated with PDD along with problems with physical development. They generally lose many motor or movement skills – such as walking and use of hands – and develop poor coordination. The condition has been linked to a defect on the X-chromosome and as a result, almost always affects girls.
Self-advocacy Being able to communicate your needs and preferences to others. It includes understanding your needs and legal rights, knowing what help and support you need, and communicating your needs to others.
Self-injurious behavior A type of repetitive behavior that results in physical injury to a person's own body, often used for self-stimulating or self-soothing.
Self-regulation Refers to both conscious and unconscious processes that have an impact on self-control.
Self-soothing behavior (See stimming.)
Self-stimulating behavior (See stimming.)
Sensory defensiveness A tendency, outside the norm, to react negatively or with alarm to sensory input which is generally considered harmless or non-irritating to others. Also called hypersensitivity.
Sensory input (sensory stimulation) Action or condition, internal (e.g., heart rate, temperature) or external (e.g., sights, sounds, tastes, smells, touch and balance) that elicits physiological or psychological response. Response depends on ability to regulate and understand stimuli and adjust emotions to demands of surroundings.
Sensory integration The way the brain processes sensory stimulation or sensation from the body and then translates that information into specific, planned, coordinated motor activity.
Sensory integration therapy A therapy program used to improve ability to use incoming sensory information appropriately and encourage tolerance of a variety of sensory inputs.
Sensory Processing Disorder (SPD) A neurological disorder causing difficulties processing information from the five classic senses (vision, hearing, touch, smell and taste), sense of movement (vestibular system) and positional sense (proprioception). Sensory information is sensed normally, but perceived abnormally. SPD is not currently a medical diagnosis.
Separation anxiety Excessive fear or worry about separation from home or an attachment figure, such as a parent or teacher.
Sign language A complete, natural language that has the same linguistic properties as spoken languages, expressed by movements of the hands and face.
Social communication Verbal or nonverbal language used to interact with people.

Social communication skills Skills needed to communicate with people. Examples include being able to have a conversation with someone; using non-verbal communication, like body language; and using language for different reasons, like to give information or to ask a question.
Social communication disorder (SCD) A new diagnostic category established in the DSM-5 that applies to individuals who have deficits in the social use of language, but do not have the restricted interests or repetitive behavior you see in those with Autism
Social cue A verbal or nonverbal message communicated through ways such as body language, spoken expressions or facial expressions, that can be difficult for people with autism to interpret.
Social reciprocity Back-and-forth flow of social interaction. How behavior of one person influences and is influenced by behavior of another and vice versa.
Social skills Skills needed to communicate and interact with people; skills can be verbal (talking) and nonverbal (gestures, body language and appearance).
Special education services Instruction designed for children with disabilities. The services can include counseling and speech, physical and occupational therapy.
Speech-generative device Unit of technology that allows a person to communicate by electronic voice generation.
Speech-language pathologist Also called a speech therapist. A trained professional who helps people with communication, language and social skills. They can do evaluations and provide treatment.
Spoken language The use of verbal behavior or speech, to communicate thoughts, ideas and feelings with others. Involves learning many levels of rules - combining sounds to make words, using conventional meanings of words, combining words into sentences and using words and sentences in following rules of conversation.
Stereotyped behaviors An abnormal or excessive repetition of an action carried out in the same way over time. May include repetitive movements or posturing of the body or objects.
Stimming (self-stimulating behaviors) Stereotyped or repetitive movements or posturing of the body that stimulate ones senses. Some “stims” may serve a regulatory function (calming, increasing concentration or shutting out an overwhelming sound).
Tactile defensiveness A strong negative response to a sensation that would not ordinarily be upsetting, such as touching something sticky or gooey or the feeling of soft foods in the mouth. Specific to touch.
Theory of mind Refers to a person’s ability to understand and identify the thoughts, feelings and intentions of others.
Transition Refers to the changes which occur when a student leaves high school and enters the adult community. For some students transition involves receiving services from adult social services agencies. Other students make the transition without help from agencies but with the support of family and friends.
Visual schedule A support that uses pictures to show the steps needed to complete a task.
Vocational training Instruction and skills related to specific vacations like mechanics, graphic design, wood shop, etc.