



A PARENT'S GUIDE TO AUTISM SPECTRUM DISORDER





This page is for parents, caregivers, teachers, community, or autistic individuals pre and post diagnosis to learn a bit more about Autism.

Though this guide covers general topics, as Autism is a spectrum, individual experiences may vary, and therefore different pieces may be more relevant to your family and situation.

Autism is a relatively new diagnosis area, and as new research comes out, we aim to reflect this information in the guide. Information in this guide has been reviewed as of December 2023.

All images sourced in this guide have been provided by various artists via Canva.



Table of Contents

Introduction	Page 3
Members of an Interdisciplinary Team	Page 7
What is Sensory Regulation	Page 9
What is Stimming	Page 12
Scripting, Echolalia, and Gestalt Language Processing	Page 13
Regression in Autism	Page 15
What is AAC	Page 16
What is Social Communication	Page 17
What May be the Impacts of Communication Difficulties	Page 19
What are Some Social Issues that Impact Autistic People	Page 20
What is the Difference Between ASD and ADHD	Page 21
Books Related to Autism	Page 22

Introduction

Family members of individuals with recent autism spectrum disorder (ASD) diagnosis can often be confused about what to do next. Navigating a new diagnosis can be challenging and overwhelming, especially when you don't have a clear place to start. There can be so many different paths that one could take to help support the individual in their growth and development. We have created this guide to help families better understand autism, develop a path that fits their needs, and improve their family's quality of life!

What is Autism Spectrum Disorder (ASD)?

Autism refers to a neurodevelopmental condition characterized by pervasive **impairments in social communication** combined with **restrictive, repetitive, and/or sensory behaviours**.

Emerges early in the developmental period and is not better explained by intellectual disability or global developmental delay (American Psychiatric Association, 2013).

A note on language: autistic and autism communities

There are two main groups when we think about stakeholders: the **autistic community**, which is made up of autistic people, and the **autism community**, which is made up of family members (ex., Parents, siblings, caregivers) and various supports (ex., Friends, service providers, community members) who seek to support and create opportunities for autistic people.

Autism Signs and Symptoms

It would be important to talk to your doctor or therapists if your child is showing any of these signs or symptoms. These may be indicators that your child is autistic. Remember that this is a small list of symptoms and your child still may present with ASD if they do not show these specific signs; or may not present with ASD even in the presence of these signs.



They have limited language compared to same age peers.



They demonstrate more interest in toys/objects rather than people.



They have distinct reactions to sound, lights, touch, tastes.



They perform repetitive movements (eg. wiggle fingers near eyes)



They have difficulty engaging with other children.

If you ever have a concern around your child's development, it is always recommended to speak to a professional.

Autism Levels

What do the different levels mean?

When someone is diagnosed with Autism, they are often given a level to categorize the extent of the impact that Autism has on the individual’s communication and activities of daily living (e.g. showering/toileting). Levels of autism spectrum disorder (ASD) are defined in the Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5), which is a clinical guide for diagnosing a variety of mental health concerns. Not all autism diagnoses are accompanied by levels.

There are three levels through which the Autism diagnosis is broken down into:

Level 1 - Requiring Support	Level 2 - Requiring Substantial Support	Level 3 - Requiring very Substantial Support
<ul style="list-style-type: none"> <input type="checkbox"/> Trouble understanding and following social rules <input type="checkbox"/> Rigid or inflexible behaviour <input type="checkbox"/> Some stress during transitions <input type="checkbox"/> May benefit from therapy intervention 	<ul style="list-style-type: none"> <input type="checkbox"/> Atypical social behaviour <input type="checkbox"/> High interest in specific topics <input type="checkbox"/> Noticeable distress when faced with changes <input type="checkbox"/> May need school accommodations (ex., Reading help, social groups) 	<ul style="list-style-type: none"> <input type="checkbox"/> Severe communication deficits <input type="checkbox"/> Repetitive behaviours <input type="checkbox"/> Extreme pain when switching between tasks <input type="checkbox"/> May need external resources to communicate (High/medium/ low tech AAC devices)

What happened to Aspergers?

Asperger’s Syndrome was retired as a diagnosis in 2013. One reason it was retired is that DSM authors wanted to avoid the misconception that Asperger’s was a different condition from autism. A child who previously would have been diagnosed with Asperger's would now be diagnosed with Autism Level 1.

Autism Levels

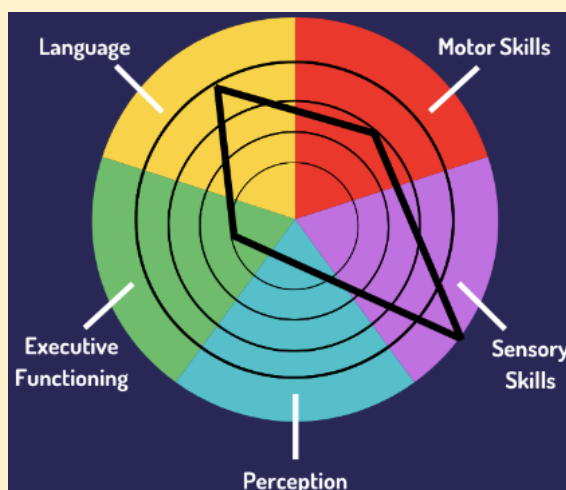
A Different Approach to Levels

Currently, there is discussion in the Autistic community regarding the use of levels and the limitations which come with the help of levels. In addition, levels compare abilities to neurotypical peers, which can dismiss the strengths that a neurodiverse individual may have.

Recent discourse in the Autistic community is related to making the Autism spectrum, not a binary, which is a strengths-based approach to looking at Autism.

The Autism Spectrum Wheel

The autism spectrum wheel allows for a more fluid understanding of the autistic person's abilities with various categories of abilities that the individual may demonstrate strength in or require support with.



Members of an Interdisciplinary Team

When a child is diagnosed with Autism, and a family is ready to receive support, the family needs to know who to contact. Building a team can be difficult, and it is crucial to reach out as soon as possible, as many clinicians and organizations have waitlists to initiate services.

We recommend parents take a holistic approach and include multiple professionals on their team when feasible. Many of the professional's scopes will overlap, allowing the team to take various techniques through different professional lenses. The professionals on a therapy team work with individuals on the spectrum and their families to build skills, foster independence and provide strategies that may help the individual navigate the world.



Speech Pathologists: support the child's ability to understand what is being said, communicate their wants and needs, engage in social interactions, improve executive functioning abilities, and support with feeding.



Occupational Therapists: help with activities of daily living such as eating, dressing, showering, toileting and more. They also assist in finding tools and techniques for sensory and emotional regulation. Like speech therapists, they can support feeding and picky eating.



Psychologists: help find tools and techniques for social and emotional regulation, supporting children's mental health and behavioural adaptation.



Physiotherapists: aid and improve strength and endurance, target

increasing range of motion, and identify and provide intervention for muscle weakness and imbalances.

More Professionals on an Autism team:



Behaviour Therapists: help with a child's maladaptive and dangerous

behaviours, which may be harmful to themselves or others around them, such as hitting or biting.

Therapy Assistants/Aides: help practice the skills and goals set by therapists. Therapy assistants can be crucial members of the team, as they interact with the child the most, and are able to form close bonds with the child.

The professionals will work collaboratively to establish goals to support the child and family best.

What is Sensory Regulation

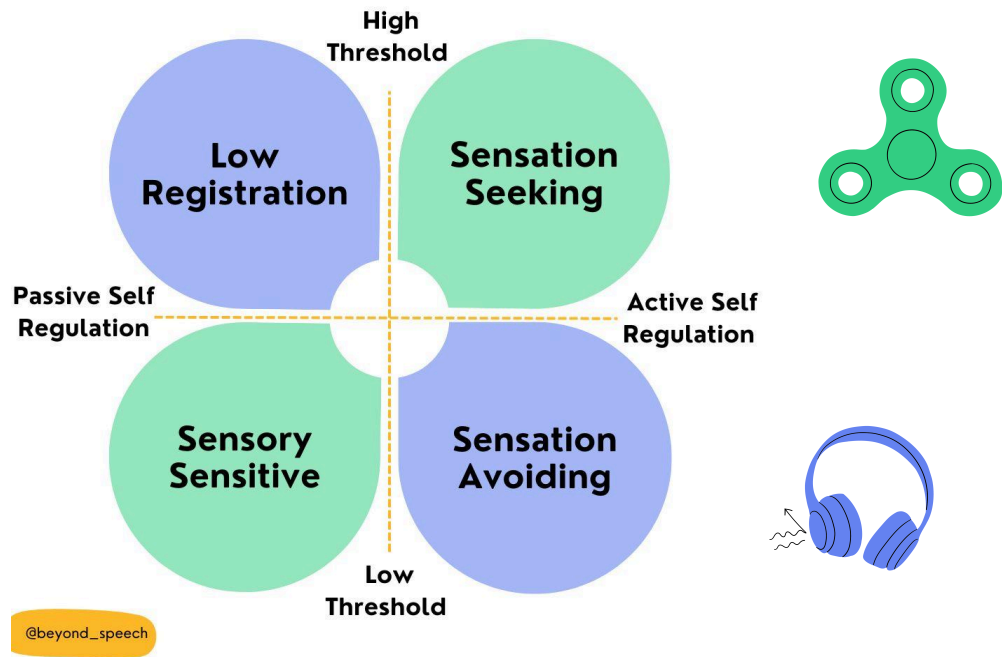
Sensory Regulation plays a massive part in autistic people's processing of their environment and impacts their ability to learn and regulate their emotions. Sensory regulation relates to a person's ability to increase or decrease their alertness, or level of arousal, to match the situation or environment. Some autistic children have difficulty regulating themselves which could indicate difficulties with sensory regulation and/or emotional regulation. Understanding your child's sensory preferences and obtaining appropriate sensory strategies (such as sensory bins or a sensory diet) can help autistic children to maintain focus, respond appropriately to sensory input, transition smoothly, and regulate emotions.

What is Sensory Regulation?

Sensory Regulation is the process of **managing arousal levels** (ex., Memory, attention, emotion responses) **through adjusting sensory input** (ex., Adding sensation by flapping hands or removing feeling by wearing noise-cancelling headphones).

Sensory regulation is crucial for autistic children's self-regulating ability and engagement in an environment.

Four Patterns of Sensory Processing:



<p><u>Low Registration</u></p> <ul style="list-style-type: none"> • Do not process all sensory information or try to gain more sensory input. • May seem uninterested or inattentive to surroundings 	<p><u>Sensation Seeking</u></p> <ul style="list-style-type: none"> • Do not process all of the incoming sensory information, but actively try to achieve more sensory input needs • May seem easily distracted, irritable, or engage in unsafe activities (ex. jumping from high places)
<p><u>Sensory Sensitive</u></p> <ul style="list-style-type: none"> • Overwhelmed by sensory information, but do not avoid sensory details • May be easily distracted, cautious, and uncomfortable in loud or bright environments 	<p><u>Sensation Avoiding</u></p> <ul style="list-style-type: none"> • Overwhelmed by sensory information and actively avoid sensory stimulation • May benefit from ear plugs gloves to avoid sensory input. May run away or avoid touching certain materials (e.g. slime, play-doh)

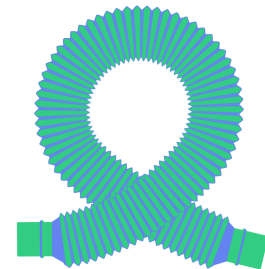
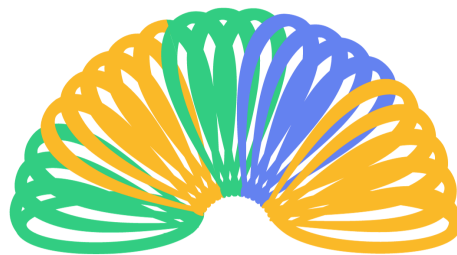
Sensory Activities to Do at Home:

<p>1</p> <p>FINGER PAINTING</p> <p>For mess free painting, place non-toxic paint in a zip lock bag, close it and tape it to a table.</p> <p>Let your child explore mixing the colours together, and label the actions your child is completing</p>	<p>2</p> <p>SLIME</p> <p>Mix together cornflour and water in a bowl and watch as it shifts from solid to liquid as you play with it!</p> <p>Optional, add food colouring and glitter for a super sensory experience</p>	<p>3</p> <p>SENSORY BINS</p> <p>Fill a bin with various items (eg. bouncy balls, LEGO people, Easter eggs) and textures (eg. rice, pasta) and have your child find the hidden items!</p> <p>For more ideas check out "little bins for little hands"</p>	<p>4</p> <p>POURING STATION</p> <p>Pour water into different size bottles, jugs, cups and containers and set them up in a bathtub or on a large tray. Optionally, add food colouring.</p> <p>The idea is to get children to pour water from one jug to another, mixing the colours and working on fine motor skills!</p>	<p>5</p> <p>TOYS IN JELLY</p> <p>This is an edible sensory activity that involves hiding toys inside bowls of jelly!</p> <p>Place toys in different jelly moulds, pour the jelly solution in, and chill in the fridge.</p>
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What is Stimming?

Stimming is an emotion regulation technique used by autistic people which can block out excessive sensory input, provide sensory stimulation, help process emotions, and help distract from physical discomfort or pain.

Stimming is short for self-stimulatory behaviours: is the repetitive performance of physical movements or vocalizations. This can look like hand flapping, rocking back and forth, spinning or tapping objects, and so much more! Not just autistic people stim, in fact, most people stim, this can look like clicking a pen or jiggling your leg while waiting!



Should we stop our child from stimming?

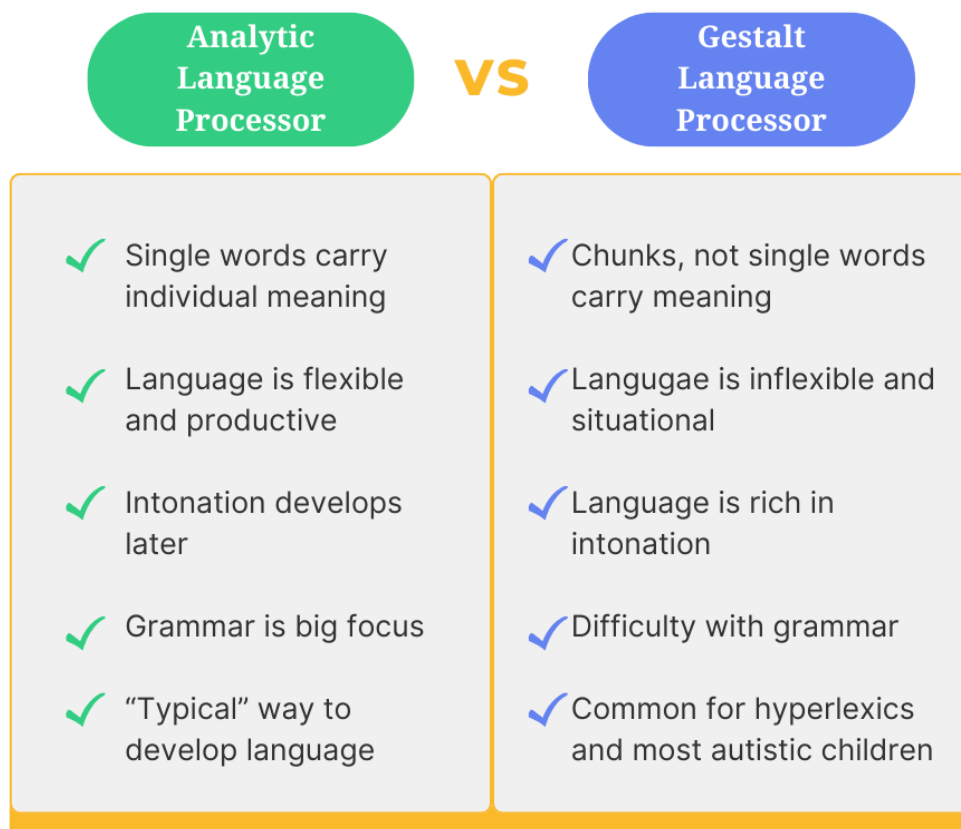
For harmless behaviours, as it is an emotion regulation technique, and helps your child regulate their stress, it's ok for them to stim. When children stim it allows for them to be better able to learn! However, when the stim is self-injurious (eg. biting their hand, hitting their head or excessive scratching), providing an alternative behaviour to get sensory input (eg. squeezing your child, sensory brushes) is advisable. An Occupational Therapist will be able to provide more personalized advice to you and your family!

Scripting, Echolalia, and Gestalt Language

Some autistic individuals repeat words just spoken by another person, a TV show, or a song. They may repeat these words once, or multiple times in a row. This is called echolalia.

Delayed echolalia can be used functionally for communication purposes, or to support regulation through stimming. This is also sometimes referred to as scripting.

Gestalt Language Processor (GLP) is common in Autistic children, where they **learn words in chunks or phrases**. These chunks and phrases can be echolalic in nature.



Scripting, Echolalia, and Gestalt Language

Are Gestalts/Scripts Meaningless?

Gestalts and scripts are not meaningless! They have a particular meaning to your child and what they want to communicate. For example, they may say, ‘We don’t like that’ when they don’t like something or want to be done with an activity because they have heard a teacher or adult say that phrase. It can also be less obvious, such as “row row row your boat” to mean “I want the iPhone”

What do I do when my child says a Gestalt?

Acknowledge

- Repeating the phrase back to them
- Commenting on the script they said
- Acknowledging what they said by saying ‘yes’

Model

- Model what they could say instead
- For example, if your child is upset and uses a script, model “I am frustrated” or “I am upset”

Using Core Words

- Less is more!
- Model to them using “Let’s”, “There’s” and “It’s” phrases
- Such as “Let’s go”, “there’s a cat”, “it’s big!”

Match + 1

- Adding on one word to whatever they say!
- For example if they says “Cat”, model “Black Cat” etc
- This demonstrates more complex sentences that they can copy

Regression in Autism

What is Regression: Regression is when the child appears to be typically developing but suddenly loses their speech and/ or social skills. About one-third of autistic children lose some skills, around the age of entering preschool. Multiple skills can be affected such as speech, nonverbal communication, social or play skills. (Al Backer, 2015).

What are the expected outcomes of regression?

This varies child-to-child. Research has found that children who develop language, social skills and attachment behaviours earlier, doesn't impact the later recovery of skills or better development outcomes (Al Backer, 2015). Further research is still being done to help discover why regression occurs, and why there is the variation of outcomes.

Regression happens over time, not as a once off event.

What is the cause of regression?

More research is still being done to help discover why regression occurs. Possible causes, such as seizures, imbalance in brain activations, and childhood vaccines were shown to **not impact regression**. (Al Baker, 2015).

citation: (Al Backer N. B. (2015). Developmental regression in autism spectrum disorder. *Sudanese journal of paediatrics*, 15(1), 21–26.)

Augmentative and Alternative Communication

Augmentative and Alternative Communication, or AAC, is a term that refers to all the ways someone communicates outside of talking.

Augmentative = **supplementing** verbal language

Alternative = **Instead** of verbal language

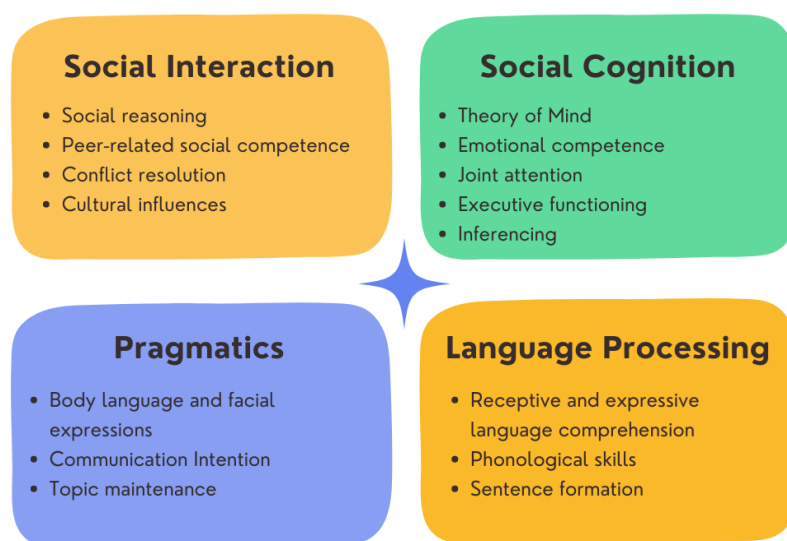
We all use AAC in our daily lives including gestures, emails, text messages, writing. Some autistic individuals benefit from additional AAC, which can be through high tech, mid tech, and low tech methods.

LOW TECH	MID TECH	HIGH TECH
<p>Non-electronic options</p> <p>Communication boards or books</p> <p>Symbol charts</p> <p>Picture Exchange Communication System (PECS)</p> <p>Pen and Paper</p>	<p>Battery Operated with Simpler Functions</p> <p>Single buttons</p> <p>Single overlay displays</p> <p>Big Mack, Step-By-Step, Go Talk</p>	<p>Computer technologies with dynamic language abilities</p> <p>Computers or tablets</p> <p>Speech Generating Devices</p> <p>Touch-Chat, Proloquo2Go, LAMP</p>

Why use AAC?	How to model the use of AAC:
<ul style="list-style-type: none"> • Provides an outlet for personal expression • Increased autonomy and independence • Positive effects on speech and language development • AAC is personalized and adaptable • Supports social skills and interactions • Improved quality of life 	<ul style="list-style-type: none"> • Use the AAC system to talk to the user • Start small by focusing on a few words at a time • Use keywords instead of complete sentences • Be consistent: Use the AAC system during everyday activities • Be patient! All learning takes time.

Social Communication

Social communication is how the way we speak varies depending on the social situation (eg. talking to a friend vs talking to your doctor) Social communication is commonly considered to be comprised of 4 components:



Does my Autistic child need to follow societal norms?

No and they have the right to choose how they participate socially! At Beyond Speech, we will help them with the elements of social communication, however, their choice is always theirs as to how they participate.

What is Engagement? Engagement is the degree of participation in social interactions and social exchange. Autistic children tend to want to engage socially with peers; however, they may have difficulty with communication or social interactions. Engagement in social interactions tends to be focused on “reading the room” which can be difficult for Autistic children, as it emphasizes the neurotypical standards of interactions.

What is the Difference Between Non-Verbal and Verbal Communication:

NON-VERBAL COMMUNICATION

- ✓ **Facial Expressions** (Ex. scowling, winking)
- ✓ **Gestures** (Ex. pointing)
- ✓ **Body Movement and Posture** (Ex. leaning away from someone)
- ✓ **Eye contact/ looking at someone's face**

VERBAL COMMUNICATION

- ✓ **Tone** (Ex. casual vs formal settings)
- ✓ **Voice** (Ex. present tense vs past tense)
- ✓ **Inflection** (Ex. the DOG is walking, vs the dog is WALKING)

How does Non-Verbal Communication affect Engagement?

Nonverbal communication shows to the people we are communicating with that we are interested in what they are saying. Nonverbal communication is tricky as it requires “reading the room” skills that can be difficult for autistic children.

What is the Impact on Functional Communication and Education?

What is Functional Communication? Functional communication is asking for your wants and needs to be met. This can be requesting water, asking for food, or needing a break.

How can Functional Communication be Impacted?

It varies greatly between autistic children as autistic children have a range of communication skills and abilities. Some autistic children have excellent communication skills, while others find it harder to express their needs. Some communication challenges affect their ability to effectively express themselves which may result in the child resorting to behaviours for communicating their thoughts and feelings.



How can Education and Academics be Impacted? Autistic students may have heightened sensitivity to sights and sounds, making loud classrooms overwhelming and distracting from learning activities. Autistic students may struggle to understand and remember information presented to them. These challenges may make it difficult for autistic students to keep up with their peers in the classroom, leading to frustration and feeling overwhelmed. With the proper support and understanding from teachers and peers alike, autistic students can still succeed in traditional classrooms.

Social Issues Relevant to the Autistic Community

Consent: When your child knows about getting and giving consent, they're more likely to have healthy, respectful, safe and enjoyable experiences when they're ready for them. Knowing about consent can also protect autistic children of all ages against bodily abuse and prevent them from engaging in harmful bodily behaviour. The best way to help your autistic child understand body consent is to introduce ideas about support early. It's best to start in the toddler years and have many little conversations over time. This helps your child get used to being aware of personal boundaries and talking with you about relationships with other people.. It also makes it more likely that your child will come to you if they have questions about relationships and their body.

Ways you can practise consent with your child:

- Respecting your child's "no" for hugs for you and unfamiliar people
- Asking your child if they want help, before you give them hand-over-hand support
- Give them choices between activities

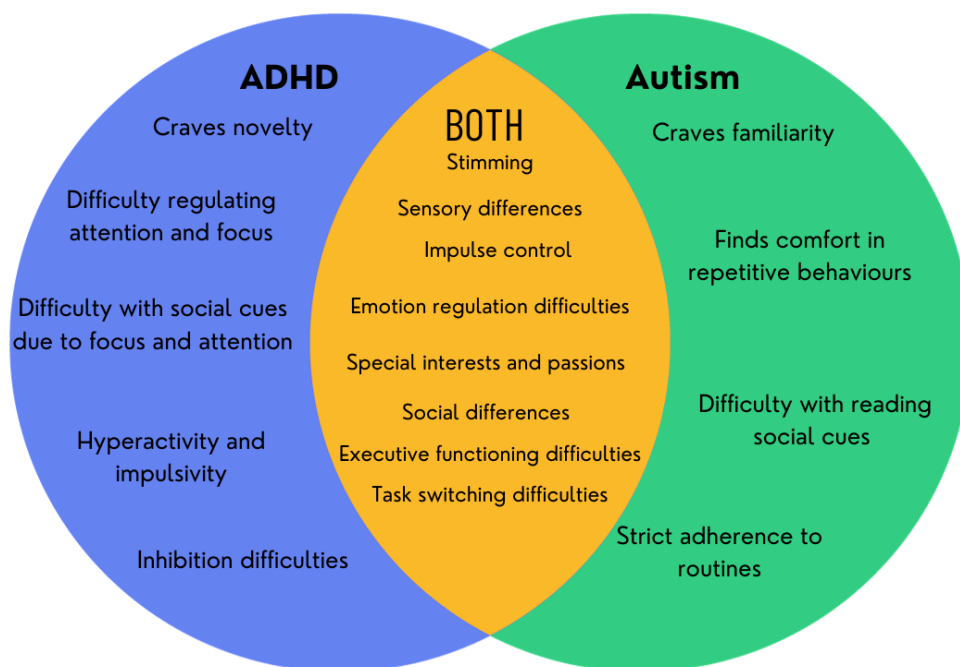
Identity First vs Person First Language: Identity-first language (ex. Autistic person) puts a person's condition or disability before the person while person-first language (ex. Children with Autism) puts the person before their condition or disability. Many autistic people and people in the autism community prefer identity-first language for autism because it indicates that being autistic is an inherent part of a person's identity, not an addition to it. Person-first or identify-first language is equally appropriate depending on personal preference. **When in doubt, ask the autistic person which they prefer.**

Differences Between ADHD and Autism

Attention- Deficit Hyperactive Disorder (ADHD) ADHD is a neurodevelopmental disorder. People with ADHD may have trouble paying attention, controlling impulse behaviour or being overly active.

Autism Spectrum Disorder (ASD) Autism is a developmental disability caused by differences in the brain. Autistic people often have problems with social communication and interactions and restricted or repetitive behaviours or interests.

ADHD VS AUTISM



Disclaimer: this diagram represents trends and patterns however, may not be representative to every child. There can be differences in each individuals experiences

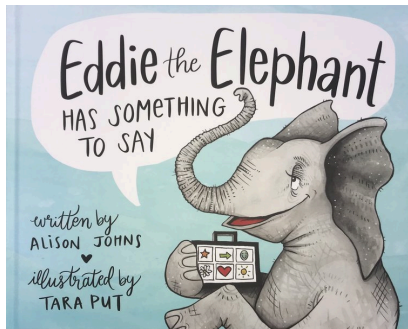
Books Related to Autism



Congratulations You're Autistic

By: *Katie Bassari and Alex Bassari*

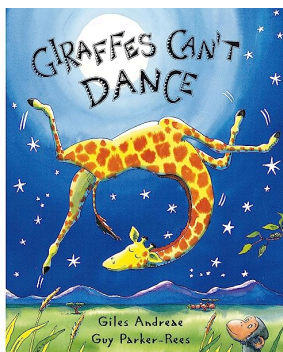
This picture book celebrates a variety of different ways a person can play, think, and be. A book unlike any other, it gives the reader a positive way of talking openly about Autism using an affirming perspective.



Eddie the Elephant has Something to Say

By: *Alison Johns*

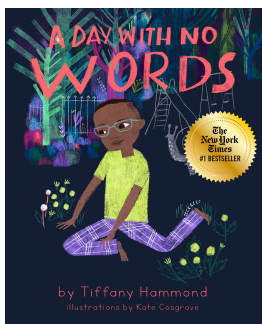
This book follows Eddie, who has a lot to say, but is frustrated when his friends can't understand him. Eddie creates an AAC device to help him and his friends communicate.



Giraffes Can't Dance

By: *Giles Andreae and Guy Parker-Rees*

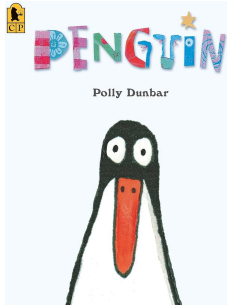
Gerald the giraffe, who wants nothing more than to dance. With crooked knees and thin legs, it's harder for a giraffe than you would think. Gerald is finally able to dance to his own tune.



A Day with No Words

By: *Tiffany Hammond*

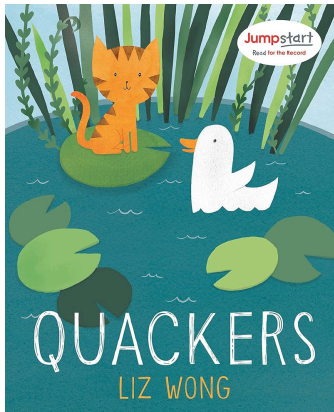
Aidan shares what life can look like for families who use non-verbal communication, utilizing tools to embrace their unique method of "speaking".



Penguin

By: Polly Dunbar

When Ben rips open his present, he finds a penguin inside. "Hello, Penguin!" he says. "What shall we play?" But Penguin says nothing. Even when Ben tickles its belly, does a dizzy dance, and sticks out his tongue, Penguin makes no response. What will it take for Penguin to say something – or for Ben to understand what Penguin has to say?



Quackers

By: Liz Wong

Quackers is a duck that has whiskers, and meows. Until he meets another animal that looks just like him. This follows Quackers as he discovers his own identity.