



# **AUTISM TOOLKIT**

## **CAREGIVERS GUIDE TO AUTISM**

VANDERBILT CONSORTIUM LEND



The goal of this toolkit is to provide information about autism spectrum disorder to caregivers of young children. This toolkit describes what autism is, what behaviours or signs to look for in children, and what caregivers can do if they have concerns. This toolkit focuses on young children but recognizes autism as a lifelong neurodevelopmental difference.

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# WHAT IS AUTISM?

**AUTISM AND AUTISM SPECTRUM DISORDER (ASD) ARE GENERAL TERMS FOR A GROUP OF COMPLEX NEURODEVELOPMENTAL DISORDERS.**

Signs of autism are present early in life. Autistic children and adults have difficulty with social communication/interaction and restricted/repetitive patterns of behaviour or interest.

*Autism is a spectrum.*

- Autism is a “spectrum” disorder because the characteristics of autism vary across people.
- Autistic people can have different symptoms ranging from mild to severe.
- Each person has different strengths and challenges.
- Autistic children and adults have different skills and they follow different developmental paths.

# WHAT TO LOOK FOR

Below are examples of behaviours you can look for if you have concerns about autism. It is important to note that a child who displays warning signs may not meet the criteria for a diagnosis of autism.

## **SOCIAL SKILLS**

- Does not respond to someone calling their name by 9 months old
- Does not show facial expressions, like happy, sad, and surprised by 9 months old
- Does not play simple, interactive games, like peek-a-boo, by 12 months old
- Does not use gestures, like waving goodbye, by 12 months old
- Does not share interests, like showing a caregiver a toy that they like, by 15 months old
- Does not point by 18 months old
- Does not look at something a caregiver points to by 18 months old
- Does not notice when others are hurt or sad by 24 months old
- Does not pretend play, like feeding a doll, by 30 months old
- Has trouble understanding others' feelings and/or own feelings by 36 months old
- Does not play turn-taking games by 60 months old
- Prefers to play alone

## **RESTRICTED/REPETITIVE BEHAVIOURS OR INTERESTS**

- Lines up toys or other objects and gets upset when someone changes the order
- Repeats parts of another person's speech
- Plays with toys the same way each time
- Focuses on parts of objects or toys, like spinning the wheels of a toy car instead of rolling the toy car on the ground
- Gets upset with minor changes, like a change to the day's schedule or going to a new place
- Has specific, obsessive interests
- Must follow certain routines
- Flaps hands, rocks body, or spins in circles
- Has unusual reactions to the way things sound, smell, taste, look, or feel
- Does not show pain even though they may get hurt

## **OTHER CHARACTERISTICS**

- Speaks later than children their age
- Reaches movement milestones later than children their age
- Has difficulty learning
- Has trouble paying attention
- Only eats a few types of food
- Unusual sleeping habits

# COMMUNICATION IN AUTISM

Caregivers know their child best and are the best people to support and help their child. Below are some specific ways that caregivers can continue to support and help their autistic child.

<b>WHAT IS HARD FOR THE CHILD:</b>	<b>WHAT YOU CAN DO:</b>
<b>Nonverbal communication skills (gestures, body language, facial expressions, emotions)</b>	<ul style="list-style-type: none"> <li>• Encourage your child to imitate gestures to express wants and needs, like pointing at an object.</li> <li>• Praise child for use of nonverbal communication.</li> <li>• Explain emotions in interactions to help your child understand.</li> <li>• Combine gestures with words to help your child understand. An example is nodding your head while saying yes.</li> <li>• See a speech-language therapist for extra support.</li> </ul>
<b>Language learning</b>	<ul style="list-style-type: none"> <li>• Read with your child. This encourages language development.</li> <li>• Teach your child about different sounds in language(s) spoken at home.</li> <li>• Teach your child how to pronounce words correctly.</li> <li>• Teach your child about how to make sentences. Teach them the rules for the way words are arranged in a sentence.</li> <li>• Teach vocabulary words and use pictures or objects.</li> <li>• Ask your child to verbally label objects.</li> <li>• Practice using your pitch and tone while you talk to your child to show emotion.</li> <li>• Talk as you bath, feed, and dress your child. Talk about what you are doing, where you are going, what you will do when you arrive, and who and what you will see.</li> <li>• Offer your child opportunities to respond to you.</li> <li>• Let your child know to take his turn.</li> <li>• Expand on single words your child uses. For example, if your child says "Dog," expand by saying "You see the brown dog."</li> <li>• Repeat what your child says indicating that you understand.</li> </ul>
<b>Understanding non-literal language</b>	<ul style="list-style-type: none"> <li>• Teach your child about when a person uses different words to say what they mean. For example, "raining cats and dogs" means "raining very hard." Practice using examples at home.</li> </ul>

# BEHAVIOURS IN AUTISM

WHAT IS HARD FOR THE CHILD:	WHAT YOU CAN DO:
<b>Staying calm</b>	<ul style="list-style-type: none"> <li>• Redirect to a safer behaviour. For example, if your child is biting their hand, provide something safe to chew on.</li> <li>• Consider what you can do before the behaviour begins to decrease the chance it will happen. Can you:               <ul style="list-style-type: none"> <li>◦ Leave an environment that is too loud or overwhelming?</li> <li>◦ Use words, signs, or another way of communicating to say that they need a break?</li> </ul> </li> <li>• Some behaviours are not safe for the child and they don't realise that. Can you:               <ul style="list-style-type: none"> <li>◦ Change the way you say things or how you respond?</li> <li>◦ Use visual or auditory cues?</li> <li>◦ Change the order of events or do activities for shorter periods of time?</li> <li>◦ Use long sleeves, gloves, pillows, etc. to help your child to stay safe, even when the behaviour occurs?</li> <li>◦ Move any objects that would be dangerous out of reach?</li> <li>◦ Think about what causes the child to get upset? Or what happened right before any aggressive behaviour?</li> </ul> </li> </ul>
<b>Moving from one activity to the next</b>	<ul style="list-style-type: none"> <li>• Give your child a warning before it's time to change activities. Try saying, "We're going to stop playing in 2 minutes."</li> <li>• Use visual supports, like a visual schedule or a timer so your child knows what will happen next.</li> <li>• Use a first-then board. The board should show a picture of a less desirable task first and a more desirable task next. For example, a picture of a bed, followed by a picture of a toy. This show that <b>first</b> the child must make their bed. <b>Then</b>, the child can play with their toy.</li> </ul>
<b>Eating</b>	<ul style="list-style-type: none"> <li>• The aim is to make eating a positive experience for child and family. Have your child prepare and cook the food with you.</li> <li>• Eat the new food in front of your child.</li> <li>• Reward your child for trying a new food.</li> <li>• Start with small steps. First, have the child touch and smell the food. Next, have them put the food to their lips. Then have them touch it with their tongue. Then have them take a small bite.</li> </ul>
<b>Routine changes</b>	<ul style="list-style-type: none"> <li>• Talk to your child in advance about a change in their routine to prepare them. This will help your child not get upset.</li> <li>• Give your child options. Let them pick between two snacks, two toys, two activities, etc. when you want to add something to their routine/schedule so they can choose what to do next.</li> <li>• Use a daily visual schedule.</li> </ul>

# SOCIAL SKILLS IN AUTISM

<b>WHAT IS HARD FOR THE CHILD:</b>	<b>WHAT YOU CAN DO:</b>
<b>Talking to others</b>	<ul style="list-style-type: none"><li>• Provide visual plans to help your child practice phrases to use in conversation. These can be pictures, images, or written cues.</li><li>• Practice talking about one topic at a time at home. Help your child understand what is related or unrelated to the topic of discussion.</li><li>• Practice taking turns listening and speaking.</li></ul>
<b>Playing with others</b>	<ul style="list-style-type: none"><li>• Encourage your child to participate in activities with others in and out of the home.</li><li>• Engage in your child's play with them.</li><li>• Take note of special interests of your child and participate in activities with your child that incorporate these interests.</li><li>• Praise your child when they engage in play with others.</li></ul>
<b>Understanding others' point of views</b>	<ul style="list-style-type: none"><li>• Teach your child about how others may feel in various situations.</li><li>• Practice recognizing facial expressions and feelings.</li></ul>
<b>Engaging with others</b>	<ul style="list-style-type: none"><li>• Engage in topics and items of interest to the child.</li><li>• Create opportunities for interaction with your child, like a play date.</li><li>• Ask questions that require answers and requests. For example, "Do you want to play with this or that?" or "What is your favorite color?"</li></ul>



# WHAT TO DO IF YOU HAVE CONCERNS

Early intervention and support for autistic children is important. Research shows that getting help early in life can have a positive impact for autistic children.

## PUBLIC SYSTEM

- To receive help in the public system, visit a community health care clinic to talk with a doctor.
- From there, you will likely receive a referral to another provider, often a pediatrician.
  - If the child needs further assessment, they may be referred to a specialist. These specialists may include a psychologist, psychiatrist, or developmental pediatrician.
- Children diagnosed with autism are added to an autism waiting list for school placement.

## PRIVATE SYSTEM

- When navigating the private system, see a healthcare provider of your choice. This may be your child's general doctor, a pediatrician, psychologist, or psychiatrist.
- If you prefer, you may also seek evaluation from an occupational therapist or speech therapist.
- If your child receives an autism diagnosis, you may choose to join a waiting list for a school placement. You may also send your child to private school.



# OTHER RESOURCES

- **Autism South Africa:** An organization in South Africa focused on autism acceptance, support, advocacy, and building relationships
  - <https://aut2know.co.za/>
- **Els for Autism, South Africa Facebook page:** A foundation that focuses on support and training for caregivers, created by golfer Ernie Els
  - <https://www.facebook.com/ElsforAutismSA/>
- **Centre for Autism Research in Africa:** A research program based at the University of Cape Town focused on teaching and training caregivers, professionals, and members of the community to support autistic individuals and their families
  - <http://www.cara.uct.ac.za/>
- **Southern African Academy of Childhood Disability (SA-Child):** An organization focused on improving the health and well-being of individuals with disabilities
  - <https://www.sa-child.org/>
- **Autism Parenting Magazine article:** An article about autism and supports in South Africa
  - <https://www.autismparentingmagazine.com/autism-support-south-africa/>

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