



MARE

Autism

A Guide for Parents

**Practical Approaches to
Working With Your Child**



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Introduction

It is perfectly normal for parents to dream about what the future will look like when they bring a new life into this world. However, the reality could look differently for a parent whose child has Autism Spectrum Disorder (ASD).

Despite their developmental differences, children with ASD are able to learn, grow and gain new skills similarly to typically developing children. This will require more deliberate steps to:

1. Educate yourselves as parents/caregivers about this developmental disorder.
2. Adjust your child's home environment to best meet their unique needs and to accommodate their differences.
3. Make them feel loved, safe and secure, and well supported so that they can trust your actions and instructions.

If you suspect that your child has Autism Spectrum Disorder, the next step would be to have your child formally diagnosed. This can be done by a qualified psychologist, child psychiatrist, specially trained pediatrician or paediatric neurologist. Early diagnosis provides more opportunities for accessing age-appropriate support, such as, diagnostic and therapeutic services, and leads to better outcomes. In general, a child with autism can be diagnosed as early as two years old.



**** A verbal statement from a professional stating that your child has Autism, is not sufficient. Proper screening and a written report is necessary for specialized school placement and access to most services. ****



**EMERGENCY ROOM
LABORATORY
RADIOLOGY SERVICES
AMBULANCE SERVICE**



MEDICAL SERVICES

- 24 hrs Accident & Emergency
Emergency Room and Hospitalization Services

- 24 hrs Ambulance Services

- Intensive Care Unit (ICU)

- General surgery

- Maternity and Labor

- General Practitioners

- Outpatient Clinics:

- **Pediatric** - Urology - Dental

- Orthopedic - Internal Medicine

- Gynecology & Obstetrics - Cardiology

- Gastroenterology - Neurology

- Ministry of Health & Wellness Approved:

- Covid-19 Vaccination Center - Covid-19 Testing

- 24 hrs Laboratory

- 24 hrs Radiology Services:

- CT Scan - Mammograms - Ultrasound - X-ray



Autism

Autism Spectrum Disorder is a developmental disorder that impacts how an individual thinks, feels, interacts with others and experiences their environment. The condition is characterized by:

Challenges with Social Communication and Social Interactions

Eg. delayed/limited or lack of speech/ repeat words and phrases stated/difficulty interpreting nonverbal communication/use words inappropriately

Restricted and Repetitive Pattern is one behaviour, interest or activities

Eg. repetitive behaviours, such as, hand flapping, flicking fingers, rocking/overly or under-sensitive to light, sound, smell and touch/need to stick to a routine or extreme preoccupation with activity or object.

Facts

- **1 in 44 children in the USA are diagnosed with Autism**
- **Males are four times more likely to receive an autism diagnosis than girls**
- **Autism affects all races, ethnic groups and social class**

Level 1 Mild

Higher functioning

Requires supervision

eg. able to communicate but may have challenges with conversation, organization and transitioning to new activities

Level 2 Moderate

Requires substantial supervision

Eg. may or may not communicate verbally, may not express emotion in tone or facial expression, difficulty coping with changes and engages in more repetitive behaviour

Level 3 Severe

Very substantial supervision

Eg. little or no verbal communication, much repetitive behaviour

Deficits in communication and social skills, along with repetitive behaviour, impair daily life



**Social
Communication**

How does your child communicate?

Communication is the process of using words, sounds, signs or behaviour to express your ideas, thoughts, feelings or needs to someone else (Britannica Dictionary, 2022).

Children with Autism have a wide range of communication abilities. Some children can express themselves well while others may have challenges. It is not uncommon for autistic children to have difficulty understanding and responding to nonverbal communication, such as, gestures (e.g. waving of the hand) and facial expressions (e.g. a smile).

They may confuse pronouns, use made-up words, use words inappropriately or prefer other non-verbal forms of communication. Depending on the level on the spectrum, there may be limitations to all forms of communication, which if not navigated correctly, can become a barrier. Imagine being in a foreign country and asking someone who speaks a different language for directions. Even with gestures and other nonverbal cues, this can be challenging.

It is not surprising that if the necessary strategies are not put in place, communication can become frustrating for parents, caregivers and especially for the autistic child who is trying to communicate in their own way, but may be misinterpreted or misunderstood.

Children with Autism have a wide range of communication abilities. Some children can express themselves well while others may have challenges.

General Tips to Improve Communication

Learn your child's language Spend some time observing your child. Being able to respond to the following questions will help you to understand more about your child's communication strengths and weaknesses and prepare you to provide support.

**Be patient and flexible with your child
but get support if needed.
We all need help from time to time.**

- ✓ Does your child have specific words that he/she says when calling a specific family member or asking for items?
- ✓ Does your child respond to your gestures or your facial expressions?
- ✓ Does your child always use words inappropriately in sentences or only when anxious?
- ✓ How does your child respond when his/her needs are not met?
- ✓ Does he/she cry, make a statement, have a meltdown or engage in self-harming behaviour?

Get Support if needed If your child has a speech delay or communication challenge, it is best to seek guidance from a speech pathologist/behaviour therapist. Find out what is needed to support your child.

Be Patient Language acquisition takes some time, so manage your expectations and acknowledge small improvements.

Consider the language you are using to communicate As some children with autism can be very literal in their communication, try to avoid speech that may be misinterpreted eg. rhetorical questions, metaphors and sarcasm. Additionally, use of words like 'no', can be quite confusing and may cause frustration because we use it too often for different reasons. If you find your child does not respond well or misinterprets what "no" means, find other words/phrases which can be used, for example, "stop", "don't do that", "not yet" or "danger". This will help your child to understand what is expected and provide prompting on how to act.

Be flexible Trial and error is a natural part of developing functional communication with your child. Be open to trying different methods until you find the best fit for you and your family.

Specific Communication Tips for Autistic Children

Echolalia Echolalia is the tendency to repeat words and statements of others. There are two types of echolalia, immediate and delayed echolalia.

Immediate Echolalia In autistic children, this may present as a child not answering questions asked but repeating a single word or a few words from the question as the response. There are several reasons autistic children engage in echolalia. For example: self-stimulation, an attempt at communication, when unsure of the meaning of what is being asked and when trying to process information, just to name a few. Below you will find a few tips to navigate this challenge.

- 1.** Examine if your child is using echolalia to communicate. For example: by drawing attention to something, asking for something using a question that had resulted in him or her receiving the desired item, responding yes to an item or starting an interaction.
- 2.** Give attention to your child's body language when words are repeated. Is he or she reaching for a specific item or pushing it away? This will aid you in interpreting the intended meaning.
- 3.** Use simple words and phrases when communicating with your child and allow time for processing.
- 4.** Model phrases and sentences for your child. For example, instead of saying "Do you want juice?" Say: "I want juice" or "juice please?" the child is likely to imitate and over time, communicate in that manner. Allow the child to fill in the blank, "Jane wants _____?"

**Use simple words and phrases
when communicating with your child
and allow time for processing.**

Delayed Echolalia/Scripting Delayed echolalia or scripting occurs when words or phrases heard from conversations, television shows, games, radio, books etc. are repeated at a later time. This can be a few hours, days, weeks or even years after hearing the phrase. These phrases are often viewed as being used out of context.

- 1.** Listen and acknowledge that you have heard.
- 2.** Learn your child's script and examine it. When does scripting take place? What purpose is it serving? Is it for fun, soothing, or is your child anxious or trying to communicate something?
- 3.** Provide the child with an alternative script (something else that can be said). Eg. If a child hits his/her feet and states, "It is only for a little while," you could say, "I hit my feet".

Listen and acknowledge that you have heard your child.

Alternative Forms of Communication

Some autistic children may have delayed speech development or be considered nonverbal. This can be very frustrating for the child who will struggle to share his/her thoughts and ideas. Other forms of communication which can be used by these children to share what is on their minds include:

- 1. Sign language** Please note that if the child is learning sign language, persons interacting with the child on a daily basis need to also learn to communicate in this manner for reinforcement.
- 2. Written language** Typing information or using written language can be effective.
- 3. Picture cards** Cards with pictures and text demonstrating what they represent. This can be used by the child to communicate and used by parents to teach.
- 4. Digital communication** There are software, apps and programs which can assist with communication, for example, the proloque2Go app for iPad or Acas AAC for iPad and Android.



**Social
Interactions**

Your child may also have a hard time understanding danger or figuring out who or what is dangerous.

Autistic children often struggle with social skills and seem less interested in interacting with others, but this does not mean that your child does not want to get along with others or participate in activities.

In many cases, it is because they have difficulty expressing themselves and experiencing the world in a normal way. If they aren't taught how to behave, it's possible that they don't know what they should do.

As a result, it's important that you get to know your child and understand what he/she is going through in order to guide their social interactions. Let's look at some of the difficulties your child may face and how you can help him or her get along with others and stay safe.

Eye Contact & Emotions

Some people with autism find it hard to make eye contact, but this does not mean that they are not listening or interested in what you are saying.

That is why it might be stressful for your child with autism if you force him/her to look at you while you talk to him/her. On the other hand, if your child doesn't pay attention unless he or she is looking at you, teaching him or her how to make eye contact may be helpful.

In this case, gently encourage him or her to make eye contact or find another way for your child to show that he or she is listening, for example, by nodding their head, saying "yes" or "okay", or turning their body toward you.

Your child may also struggle to identify, tell or show what they are feeling, or to understand what others around them are feeling. So, it is important to find ways to help them to learn about facial expressions and how to communicate their feelings and interpret how others are feeling.

Perspective Taking

It is very important to know that many autistic children have trouble understanding the points of view of others and may not know that their behaviour is inappropriate.

Your child may also have a hard time understanding danger or figuring out who or what is dangerous. Because of this, it is important that you remind yourself not to take your child's actions or behaviours personally and take steps to keep them safe.

Ways you can teach or support good social interactions in your child with autism

1. Many children with autism seem to respond better to visual information than voice commands. So, teaching your child how to interact with others through the use of pictures, and videos may be helpful. Use pictures and videos to teach your child social skills, such as: how to take turns, how to greet others, and how to identify different facial expressions, such as, happy or sad.
2. Model social interactions by showing your child what to do or say in different situations and have them practise with you.
3. You may use a First/Then Chart or visual schedules to help your child stick to daily routines like: getting ready for school, getting ready for bed, completing chores, and many other activities. A morning, afternoon, or evening schedule may also be helpful.



First/Then Chart tool courtesy of Autism Circuit

Social Stories can be used to teach your child how to act in many situations.

- 4.** Highlight good behaviours in your child and celebrate your child's strengths.
- 5.** Help your child to make friends by taking them to places where they can interact with other children their own age, such as, a park or a church.
- 6.** Pay attention to your child's surroundings to make sure the space is comfortable and secure, show your child how to get around safely, and teach them how to ask for help.
- 7.** Social Stories can be used to teach your child how to act in many situations. You can find examples of these types of stories on the internet or you can create your own.





**Crisis
Management**

Having a clear understanding of the difference between a tantrum and a meltdown can help you respond in the right way.

Having a plan in place for dealing with and surviving a crisis is critical. A crisis is any extremely challenging or dangerous situation or event that can affect your child and those around them. These include tantrums, meltdowns, wandering, and other issues that can affect your child's safety. The most important thing to consider when facing a crisis is the safety of your child, the people in their immediate surroundings, and the protection of property. Your family can work together to make a plan to manage these difficult situations as well as learn skills that can help you foresee and correct the problem if a situation seems to be getting worse. The following are a few examples of situations that could be considered crises and how to handle them.

Tantrum vs Meltdown

Having a clear understanding of the difference between a tantrum and a meltdown can help you to respond in the right way. Your child may have a tantrum by screaming, yelling, and throwing things when they are not allowed to participate in a game or have their own way. A tantrum is when a child is reacting to something specific, a behaviour that he/she can learn to control in the future, or it can end when your child gets something that he/she wants.

A child's meltdown, on the other hand, is often caused by too much sensory information coming at them, as well as a lack of understanding about what they want or why they are feeling that way, and it can last even after they have received the item(s) requested. Changes in routine, loud noise, bright lights, itching on the body, and many other things can cause a child to have a meltdown. This makes it hard for them to cope and may be confusing for you as a parent to know what to do. Often, these meltdowns end when the child is tired, finds a quiet place with less sensory stimulation, or when people around him or her react in a different way than they usually do.

Keep in mind that your child might not be able to think clearly or learn new skills while he or she is having a tantrum or meltdown. This is why having a good understanding of your child will help you to identify the cause of a

tantrum or meltdown and the best action to take. Here are some things you can do:

- 1.** To help your child during a tantrum, try to figure out what your child wants, then calmly help them to express their needs in a clear way to get what they want or to choose a different option.
- 2.** To handle a meltdown, it's best to take your child somewhere quiet so that they can process what's happening. Sit or stand with your child and do what you can to help ease their discomfort from sensory experiences.
- 3.** You may also consider putting together a calming kit with tools that will help your child to stay calm when he/she is in stressful situations like loud noises, crowds, bright lights, or other things that make them feel uncomfortable. This may include dark sunglasses, a soft blanket, stress ball, fidget toys, or noise blocking headphones.

**If your child is seriously hurt, get help right away.
Otherwise, treat the injuries as best as possible.**

Self-harm

Some autistic persons may self-harm because of certain symptoms, situations, and other conditions that they have. Self-injurious behaviour is any behaviour that causes physical harm to the person. This includes hitting, scratching, head banging, biting, pinching, and any other behaviour that results in physical harm to self.

How to deal with self-harm

First, you need to figure out what may be causing these behaviours to happen in the first place. Could it be a way of communicating something?

Is it a means of expressing pain, discomfort, or displeasure? Or, is it simply a learned behaviour? Knowing what triggers these behaviours is the first step in figuring out how to address them. Then, you can consider using some of the following tips where necessary:

Make a safety plan with your neighbours, schools, police, and other people in the community for your child.

- 1.** If your child is seriously hurt, get help right away. Otherwise, treat the injuries as best as possible.
- 2.** Use signs, pictures, gestures, or a communication device to teach your child how to express what is happening.
- 3.** Take the time to teach your child how to deal with discomfort and frustrations.
- 4.** You can help your child to feel less stressed by telling them about what will happen next using a Social Story.
- 5.** Giving your child options can also give them a way to express their needs and preferences.
- 6.** Teach your child a different way of getting their needs and wants met, such as, pointing, leading you to an item or place, or using pictures or gestures.
- 7.** Remove anything that you think could trigger the behaviour.
- 8.** Get help from an expert when needed.

Wandering

It is common for some children with autism to wander off on their own and find themselves in dangerous situations. This is called elopement. Some children may just like to go out and explore, go to a place they love, or get away from too much sensory input. If your child tends to do any of these, then it is important to put steps in place to keep him or her safe.

- 1.** Secure your home using locks and other devices that can alert you when your child leaves a room or goes outside.
- 2.** Encourage your child to use a specific gesture, word, picture card, or other ways to ask for a break when they are having a hard time or need to explore.

3. Make a safety plan with your neighbours, schools, police, and other people in the community.
4. Provide ID jewellery (such as bracelets or necklace charms) or wearable technology with GPS so that you can keep track of where your child is.

Repetitive & Restrictive Patterns of Behaviour, Interests and Activities in Autism Spectrum Disorder

Repetitive and restrictive patterns of behaviour are often seen in individuals with Autism Spectrum Disorder. Children with ASD can find that their lives are impacted by these behaviours and the extent of this may vary.

Areas of daily lives that can be affected include social interaction, learning, leisure activities, developing friendships and communication. While individuality and uniqueness are to be accepted and celebrated, a strong emphasis must also be placed on improving functionality so that you can help your children reach their highest level of potential. The information below will provide an outline about repetitive and restrictive patterns of behaviour along with strategies that can be incorporated at home to minimize them where necessary.

Things that you should know about repetitive patterns of behaviour:

1. They may also be described as stereotypic behaviours, stereotypy or 'stimming' (self-stimulatory behaviours) (Deweerd, 2020).
2. They may be observed in the context of speech, motor movements and the use of objects.

Some children may just like to go out and explore, go to a place they love, or get away from too much sensory input.

3. The frequency and intensity of these behaviours can increase or decrease depending on age and situation. (LaBarbera, 2019)

4. They may occur constantly or be a response to stress, anxiety, worry or frustration.

5. Stereotypic behaviours associated with speech are also known as a vocal stereotypy. This is the use of nonfunctional speech that is unrelated to the present situation or repetitive vocal responses. (Ahearn, Clarke, Macdonald & Chung, 2007).

Information about restricted patterns of behaviour, interests and activities.

Individuals with ASD may insist on ‘sameness’ and have strict adherence to routine. For example, some children may:

1. Have an inclination for their daily lives to be the same and for their environment to be predictable.

2. Become overwhelmed when faced with unpredictable events resulting in behaviours, such as, withdrawal, running away or what appears to be “meltdowns” [a very intense response to overwhelming circumstances] (LaBarbera, 2019).

| MOTOR | SPEECH (Vocal Stereotypy) | OBJECT USE |
|-----------------------------|---|---|
| Body rocking | Squeaking | Become attached to and carry around objects or parts of objects eg. trucks, figurines or model |
| Spinning in a circle | Grunting | May become attached to more unusual objects, such as, a roll-on deodorant, bottle caps, bottle tops, stones or shoes |
| Hand flapping | Talking about the same subject repeatedly | |
| Shaking objects | Repeating previously heard words and phrases (echolalia) | |
| Covering one's ears | | |
| Head banging | | |
| Humming | | |

Examples of Stereotypic Behaviours (LaBarbera, 2019)

3. Have preoccupations with discussing and exploring particular topics and interests, such as, math, trucks or penguins. These can often take precedence over social interaction and learning and can become the dominant topic of conversation when interacting with others (LaBarbera, 2019). The following are examples of situations that may affect a child with ASD: making an unplanned stop instead of going straight home from school, doing reading assignments instead of their preferred subject of math and missing a television show because of an electric outage.

Here are things you can do at home to help address your child's repetitive behaviours and restricted patterns of behaviour, interests and activities.

- 1.** Learn more about your child's habits and behaviours. Since these behaviours may be caused by particular situations or feelings, such as, happiness and fearfulness, it is important to take note of the situation the behaviours occur in, how often they occur and how intense the reaction is. The goal of this is to identify what triggers the behaviour so that the environment can be adjusted. You can document these in a book or use a symptom tracking app.
- 2.** Adjust and structure your child's environment to minimize triggers that may result in repetitive/restrictive behaviours. This may look like allowing your child to bring a favourite object, toy or squeeze ball into an unfamiliar environment or helping your child prepare for a change in schedule in advance through repeated gentle warnings, discussing feelings and getting input. This is also an opportunity to use sensory integration techniques. Bright lights? Try a pair of sunglasses or incorporate window shades/less bright lights. Loud noises? Try headphones that can help to minimize the sounds in the outside environment. Banging the head? Use a helmet which still allows for the act to occur but also protects the head.
- 3.** Use soothing stimuli or 'replacement' behaviours to address or substitute repetitive/restrictive behaviours (the ones that interfere with social interaction or learning).

Your child may prefer a consistent environment and for routines to remain unchanged.

This may look like encouraging your child to clap their hands instead of hitting their head and using a squeeze ball instead of flapping hands. Another variation is delaying these behaviours until the time is appropriate such as when they are at home or in their 'safety zone'. It is likely that this will take a lot of practice and experimentation so be patient, encouraging and innovative.

4. Channel preoccupations or intense interests in subjects or topics into meaningful interests, such as, using their favoured trucks to learn math, to practice writing sentences or working on oral presentations in the classroom (Rudy, 2022).

5. Create home safety zones where your child is comfortable and able to engage doing their repetitive behaviours and explore their interests. Ideally, this environment should be free of triggers so that your child can feel relaxed, in control and free to interact with and make sense of their sensory environment.

For everything that you do for your children, always remember to not be afraid to seek professional help, do your own research, join support groups and get creative. You can also join online parenting forums and connect with other parents who have children with Autism Spectrum Disorder. Every child is unique but there may be shared experiences and commonalities that may be applicable to your child. So be open, seek information, experiment and keep doing the best you can as a parent.



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Resources for Autism Support

Screening/Assessment for Autism

Spectrum Disorder

Child and Family Clinic (University Hospital of the West Indies)

Mico University C.A.R.E Centre
(876) 929-7720-2 (Kingston)
(876) 972 - 1174 (St. Ann)

McCam Child Development and Resource Centre
(876) 977 - 0189

Sam Sharpe Diagnostic and Early Intervention Centre (Montego Bay)
(876) 616-3371

Hospiten Jamaica (Montego Bay)
(876) 618-4455

One of A Kind Kids JA
(876) 886-4851

Caribbean Tot to Teens
(876) 978-8535

Paediatric Occupational Therapy Services

The McCam Centre
Dr. Pauline Watson Campbell
(876) 977-0189

Therapy Plus
Ms. Lisa Stoddart
(876) 946-9083

Hearing Test

Jamaica Association for the Deaf (Kingston)
(876) 926 - 7709 • (876) 929 – 7001 • (876) 906-6808

Caribbean Hearing Centre
(876) 755-3838 (Montego Bay)
(876) 755-1507 (Kingston)

Speech and Language Pathologists

Mrs. Kerine Chin Campbell
(876) 490-1104

Ms. Michelle Skeete
(876) 895-6071

Ms. Ann Marsha (Montego Bay)
(876) 810-9213

Ms. Andrea Wray
(876) 968-3548

Mrs. Tracey Rattary Neil
(876) 978-9881

Supporting Groups and Foundations

Caribbean Autism Support for Education (CASE) www.caribbeanautismsupport.com

Jamaica Council for Persons With Disabilities
(876) 968-8373 • www.jcpdja.com

Early Stimulation Program (Birth - 6 years)
(876) 922-5585

[Jamaica Autism Support Association \(JASA\)](http://www.jasa-jm.com)
(876) 776-6827

[Maia Chung Autism and Disabilities Foundation](http://www.mcadf.org)
(876) 435-5961 • www.mcadf.org

SpeechEatLearn
info@speecheatlearn.com

Central Autism Action Group
(876) 376-7211

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Please note this list is not exhaustive so additional research may be necessary.