

Autism



The Statistics

Autistic Spectrum Disorders (ASD) are a group of disorders usually diagnosed in early childhood. Accurate figures are not currently available for Jamaica, but based on the US Centers for Disease Control's (CDC's) rate of one child in every 110 born with autism, we can expect over 400 children with autism to be born in Jamaica each year. Because boys are four times more likely to have autism than girls, one in 60 boys will have ASD. The CDC's rate is an almost 60 per cent increase on the 2007 figure. (Jamaica-Gleaner 2011)

Autism occurs in every community,
in every geographic location, race, religion,
creed, color, and social status.

The impact

Impact on family life

- Harder to get things done because of excess demands
- Strains on marriage and personal relationships
- Increased demands on family members
- Minimal respite options; burnout and or depression can result
- Strains and changes to employment of parent or caretaker
- Increased financial burdens from issues relating to employment, therapies, medical bills, etc.



Impact on family life

continued

- May hurt self esteem as a result of criticism, exclusion, etc.
- Changes in social opportunities (perceived and actual)
- Change in priorities
- Decreased recreation and leisure activities (limited options and time)
- Concerns for future care giving



... and more

Families talk

“ My son has taken a stranger’s food right off his plate. What could I possibly say... to apologize? ”

“ I don't know the last time I've actually seen the end of the movie because of the crowds, sounds, and lights. It just gets too difficult and we have to leave.”

“ When we go to the supermarket, so many people roll their eyes and start whispering. When we have to stand in a long line, she starts making noises and grabbing stuff. So now I just avoid taking her in public.”

“ Simple situations like haircuts, grocery shopping and community gatherings are not so simple at all.”

“ I don't want sympathy or pity like, ‘Oh, I'm so sorry.’ What I do need is for people to be patient, kind, and understanding.”

Societal Impact

Autism Spectrum Disorder
affects many facets of the community

- education
- recreation
- residential options
- self advocacy
- family relationships
- healthcare / wellness
- day care
- employment / vocations
- life planning / management

The disorder

The autism spectrum

Autism is a spectrum. Each person is different.



- Autism Disorder
- Childhood Disintegrative Disorder
- Asperger's Syndrome
- Rett Syndrome
- Pervasive Developmental Disorder - Not Otherwise Specified (NOS)

What is autism?

A person with autism has challenges in 3 areas:

- difficulty interacting with others
may have reduced interest in other people, poor eye contact
- difficulty communicating
delayed or no speech, may echo words or expressions
- restricted or repetitive behavior or interests
unusual interests, rituals, hand-flapping

Understanding the Spectrum

There is a wide-range of skills possible with autism

Some people with autism have an excellent vocabulary and high IQ, but limited conversational and social skills, and restricted interests. Others may be nonverbal with a very low IQ.

Not all people with delayed language or behavior issues have autism

Common behaviors



- not respond when name is called (may seem deaf)
- not share enjoyment
- have repetitive, self-stimulatory or “stimming” behaviors (e.g. hand flapping, spinning, rocking, screaming, humming, etc.)
- have difficulty shifting from one activity to another
- get upset with a change in routine
- over-react to things
- act unexpectedly

Communication Challenges

- have poor eye contact
- have difficulty expressing him or herself or have no language (non-verbal)
- use physical contact to get needs met
- not use gestures such as pointing, nodding yes, shaking head no
- have difficulty following directions
- express themselves by crying or screaming
- repeat something that was heard earlier
- be unable to identify common objects



Social Challenges



- may have trouble modifying activities
- may prefer to isolate self rather than be around others
- may not let others join play
- may have difficulty waiting patiently



Social interactions

People with autism often have challenges with common social experiences

- eating etiquette
- community social rules
- bathroom etiquette
- waiting in lines
- turn taking
- privacy
- personal boundaries
- social language
- dress code
- regard for authority (social hierarchies)

Typically, people on the spectrum do not learn social rules through observation. Social behavior must be taught directly.

Facts... not fiction

- Not all people with autism act the same way. Each person has unique strengths and challenges.
- People with autism have feelings. Each person displays them differently.
- Because of rigid thinking, they may be less likely to lie.
- Due to difficulty recognizing social cues, they may not recognize when they are interrupting or monopolizing conversations or being overly blunt.
- Most people with autism are not savants. While many have focused interests, skill level may not be high.
- People with autism are able to learn. Methods and pace of instruction may need to be modified.

Taming the “fear” of autism

If a person with autism shows signs of aggression, most often it is a result of frustration or a need for attention



The person may not have the skills to express him or herself appropriately

Behavior can be improved by replacing triggers and teaching skills.

Managing difficulties

- Approach the customer who is having difficulties
Courteously observe the situation and ask simple questions to identify any environmental causes for the challenges. Offer assistance that is helpful and comforting.
- Engage in calm, undemanding social conversation
Predictable conversations can help to focus and reduce anxiety (e.g. “I like your cool shoes.” “What’s your name?” “Where do you live?” “What is your favorite food?”)
- If a situation or task seems to be causing the behavior, calmly and slowly redirect attention to another place or activity.
- Attend to other customers who appear anxious
Without passing judgment or personal comments, discreetly offer to relocate them.

Concerns with safety and disruption

A business operator should intervene when behaviors are...

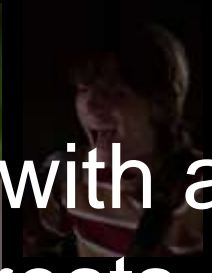
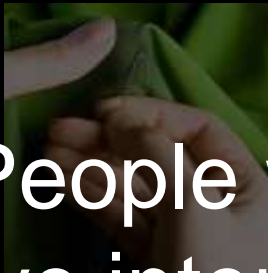
- embarrassing for the individual or family
- stigmatizing to the person
- disrupting core business operations
- tantrumming is injurious to self or others
- destructing property
- offensive interactions with customers and/or employees
- inappropriately sexual in nature

Harmful Behaviors

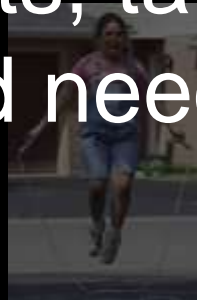
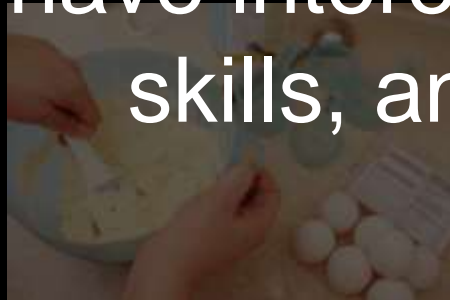
- Ask for help
- If a person is injuring him/herself, another person, or damaging physical property, call security or dial 911
- Protect those who are in harm as you await help
- Provide adequate space
Avoid standing too close



Video



People with autism
have interests, talents,
skills, and needs



Inclusion

Disabilities Act

2.-(1) In this Act, unless the context otherwise requires "access" includes, in relation to

- (a) premises. freedom to enter in. approach, communicate with, make use of or manoeuvre within, any premises;
- (b) benefits. freedom to make use of any benefits;
- (c) communication, the capacity to receive and make use of information,

Plan for Inclusion

Help families prepare for an experience
Offer back-up plans for “the unexpected”

Help families offer
positive and meaningful
reinforcements for
successes –
No matter how small !

Have realistic expectations.
Meet each person at
his/her ability level.

Work with families to use
visual activity schedules
for planned activities.

Plan for Inclusion

continued

Develop/use Social Stories to increase understanding and comfort level

- provides information about a place, activity or situation
- specifies appropriate social cues and expectations
- explains the order of events or layout of a location
- helps give appropriate responses to situations



Sometimes I can buy a snack at the theater.
There can be popcorn and drinks.
I should only buy one or two snacks. I can not buy all of them.
When watching the movie, I can eat snacks while sitting in my seat.
I shouldn't take any food or drinks from other people.
I should eat the snacks that belong to me.

inclusion strategies



- Recognize each person's challenges and abilities
- Provide appropriate modifications
- “Special” programs are appropriate but should not take the place of inclusive approaches

“With appropriate resources, sensitivity, and support, community organizations can include individuals with disabilities as regular and active participants without the need to create separate and specialized programs.”

Coalition for Inclusive Communities

Inclusion Strategies continued

Inclusion does not need to cost more money

Often it requires only basic adaptations and accommodations

- slower pace
- adjusted rules
- altered lighting, sounds, movement
- simplified, direct instruction, activities, handouts
- use of photographs and other learning tools
- understanding and flexibility
- being open and prepared for the need to “escape” and/or return as needed

focus on the family

Don't



- assume or presume
- pass judgment
- ask a family to participate separately

Families with autism are passionate about being accepted within their community.

Encourage Participation

- Value the dignity of each individual
Maintain the respect of all participants.
- Break tasks into small parts. Avoid multi-step directions. Be patient and allow person time to complete each task.
- Offer ways to signal when a break, or help is needed.
- Clearly define boundaries (circles of intimacy).
- Provide signals or cues to prepare for transitions in schedules, events, and locations.
- Use respectful and age-appropriate ways to modify activities.



Interacting

Personal Interactions

- Talk directly to the person, not a family member or caretaker
- Listen carefully to understand the real meaning
- Don't speak too forcefully or loudly
- Don't use slang, sarcasm, or complex language
- Try to keep the conversation on topic
- Pause between statements to allow for processing
Allow sufficient time for them to respond
- Using pictures helps understanding

Distractions

- Limit environmental distractions
 - loud, unexpected, unnecessary sounds/noises
 - visual challenges (bright lighting, complex layouts, numerous colors, excessive wording, etc.)
 - sudden transitions
 - unnecessary interactions, movements, changes in a physical arrangement or a schedule



Alternative Communication

Some people with autism use alternate forms of communication

Here are some examples:

- gestures
- sign language
- sounds
- objects
- photographs / pictures / symbols
- voice output devices
- computerized and technological devices
- writing
- physical contact

Approaches

Win–Win Approaches

- Be flexible
- Have a family-centered approach – discourage criticism, judgment, exclusion
- Ensure front-end employees are understanding and compassionate
- Make personal connections
- Offer inclusive and adapted programs and events
- Offer respite or childcare opportunities
- Build life-long relationships, creating potential vocational opportunities

Pre-vocational Skills

Offer pre-vocational activities to teach functional, employable skills

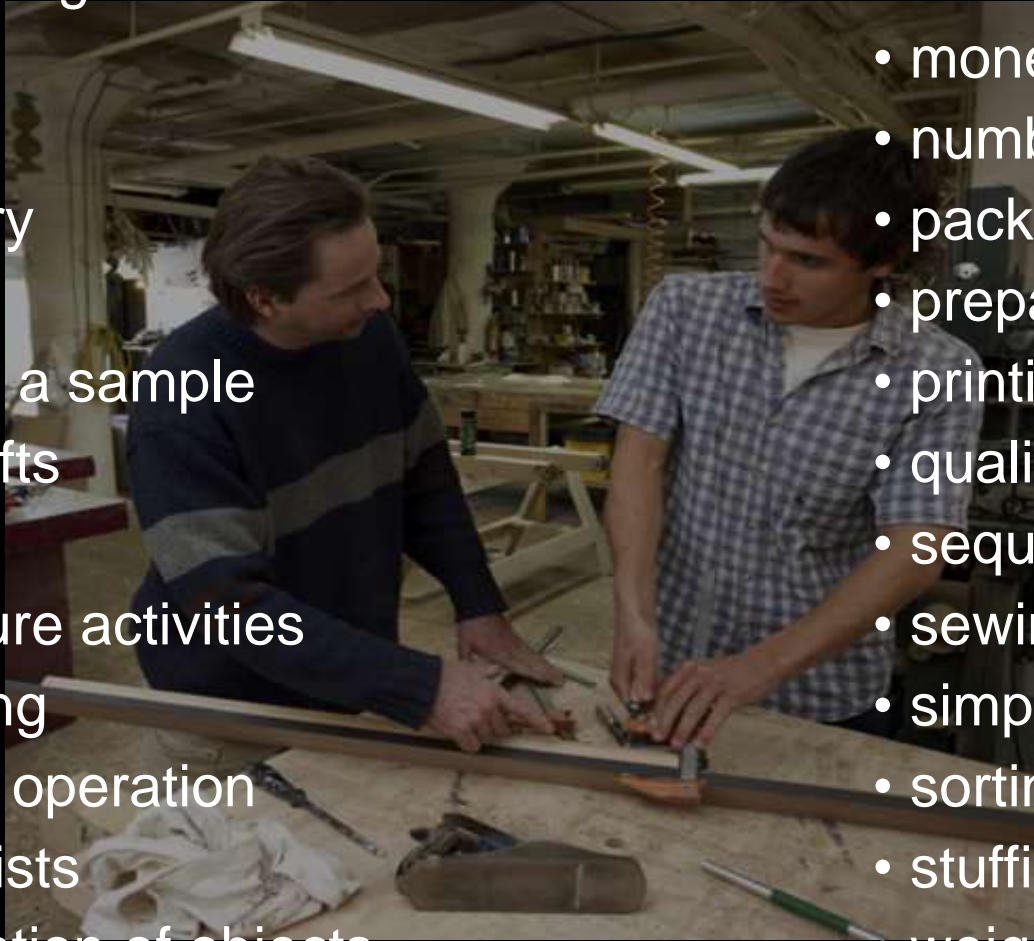
Task level may start at a basic level, gradually increasing the level of difficulty and independence

Partnerships can be made with schools, therapeutic providers, and others as needed



Functional Skill Sets

- categorizing
- collating
- copying
- data entry
- folding
- following a sample
- handicrafts
- handling
- horticulture activities
- laundering
- machine operation
- making lists
- manipulation of objects
- matching
- money exchange
- number application
- packaging
- preparation
- printing
- quality control
- sequencing
- sewing
- simple assembly
- sorting
- stuffing
- weighing



Assistance

Autism Resources



Children's
Specialized
Hospital



Jamaica Council for
Persons with
Disabilities



Jamaica Autism Support Association

Make Friends with Autism

For more information about this initiative, call 1-888-CHILDREN Extension 5343
www.makefriendswithautism.org

Make Friends with Autism is made possible
by the Kohl's KidsAbilities program at
Children's Specialized Hospital
through the generosity of Kohl's Department Stores.



KOHL'S
expect great things[®]

References

- Samms-Vaughan, Maureen. **AUTISM IN JAMAICA - Boys More Affected Than Girls**. Published: Wednesday | April 20, 2011. Jamaica-Gleaner. Retrieved from: <http://jamaica-gleaner.com/gleaner/20110420/health/health1.html>
- The Disabilities Act. www.mlss.gov.jm/download/DISABILITIESACT.pdf
- Chaste P, Leboyer M (2012). "Autism risk factors: genes, environment, and gene-environment interactions". *Dialogues in Clinical Neuroscience* **14**: 281–2. [PMID 23226953](https://pubmed.ncbi.nlm.nih.gov/23226953/). [PMC 3513682](https://pubmed.ncbi.nlm.nih.gov/3513682/).
- Autism Spectrum Disorder, 299.00 (F84.0). In: American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition*
- Jamaica Autism Support Association. <http://www.jamaicaautism.org>
- Jamaica Council For Persons With Disabilities. Ministry of Labor and Social Security. Retrieved from: <http://www.mlss.gov.jm/pub/?artid=26>