



Asperger's and Autism Spectrum Disorders

Providing Support to Individuals
and Families

Caring Network, May 3, 2014

What is Autism?

- Autism is a neurological disorder that affects behaviour and the abilities to communicate and interact socially (Geneva Centre for Autism, Toronto)
- Autism Spectrum Disorder covers the range of disordered thought and behaviour. The severity and nature of symptoms can vary greatly

History of Diagnosis

- Dr. Leo Kanner, a psychiatrist, first used the term *autism* in 1943 to describe children who were socially withdrawn and who had trouble with speech, but clearly were not mentally retarded. In 1944, Dr. Hans Asperger, an Austrian pediatrician, first described children who were verbal and seemingly quite bright, but who displayed obsessive behaviours and were socially impaired

Statistics

- US Centre for Disease Control reports one in 58 American children suffer from autism
- Health Canada reports 1 in 150-160 children suffer from autism and ASD
- No apparent rise in severe cases of autism, but huge increase at milder end of spectrum including Asperger's

You might notice . . .

- Developmental delays
- Odd behaviour
- Perception disturbances
- Rigid routines

Developmental Delays

- Children with autism don't develop social, mental or physical skills in the typical sequence. Unlike other youngsters, many infants and toddlers won't make eye contact or point at what interests them. Language is typically delayed: no babbling at 12 months, no single words at 16 months and no two word phrases by 24 months. Some infants may act quite "normal" until about 18 months when they start losing words they have learned and become less social.

Odd Behaviour

- Older children with autism may engage in solitary scripted play – imitating what they see on TV or elsewhere but refusing to allow other children to be involved in their play. Children often line up toys and move them around. They may be obsessed with a single part of a toy, such as a tiny wheel that they'll spin for hours. Children with severe autism may seem completely lost in their own worlds, banging their heads or rocking back and forth for hours.

Perception Disturbances

- Children with autism may have normal senses; they may see, hear, feel and taste, but somehow this information becomes distorted.

Rigid Routines

- Children with ASD can have terrible tantrums if there is even a minor change in their routines; for example, if Mom takes a different route to the store or Dad orders chicken from someplace other than KFC. It's this kind of behaviour that sometimes gets ASD children branded as "bad kids" and parents as "bad parents" who have failed to discipline their children.

Asperger's Symptoms

- Social Interaction Difficulties
- Communication problems
- Language Skill Challenges
- Cognitive and Motor Skill Impairments
- Limited Interests and Unusual Behaviour
- Sensory Input Issues

Social Interaction Difficulties

- General Social Skills
- Relating to Others
- Difficulty Playing With Others
- Problems With Two Way Conversation
- Inability to Understand Common Social Cues
- Rigid range of Interests for Social Interaction
- Inappropriate Responses

Communication Problems

- Eye contact
- Unusual Gestures
- Facial Expression
- Personal Space Issues
- Monotone Speech
- Easily Distracted

Language Skill Challenges

- Trouble with Language Use
- Unusual Use of Words
- Language Rituals
- Difficulty Processing Language
- Literal Interpretation of Words

Cognitive and Motor Skill Impairments

- Mindblindness
- Problem Solving Issues
- Organizational Skills Difficulties
- Difficulty with Imaginative Play
- Learns Best Visually
- Problems with Coordination

Limited Interests and Unusual Behaviour

- Strict Schedule
- Narrow Range of Interests and Obsessions
- Self-stimulatory Behaviour

Sensory Input Issues

- Odours
- Sounds
- Touch
- Limited Food Choices

Experiencing autism . . .

- Imagine you are trying to read a book on a bus. The bus is stopping and starting, traffic noises are all around you and strangers are getting on and off. You are not able to concentrate on what you are reading. You hear every sound, detect every movement, every smell and even sense the emotions around you. You can't filter out this external information. It's as if your brain is in a perpetual and chaotic state of overstimulation.

A personal experience . . .

- “I was perceived to be subversive for asking so many questions. The reality is this is just a part of having Asperger’s. It’s what we do. Hans Asperger referred to children with Asperger’s as ‘little professors.’ We can and will ask many many questions about anything and everything that doesn’t make sense to us. This can rub some religious types the wrong way as they perceive it as an attack, when in reality we merely crave knowledge and the answers it brings. As it is now, there are questions I don’t share with Christadelphians since when I’ve asked them to other Christians online, it just causes them to have a crisis of faith and/or attack me.”

In the Workplace . . .

- “I sometimes need to do other things in order to focus. For example, I have a collection of Transformers and other items on my desk for when I speak on the phone. If I don’t keep my hands busy, I have a hard time focusing since there is only the voice on the other end of the phone for my brain to process. We have trouble processing auditory information alone.”

In the Ecclesia . . .

- “I used to get into trouble for supposedly not paying attention during talks. I would often have a little notebook I would draw and write in, and it wasn’t related to the talks, but by doing this, I could focus on the talk. When I had to stop, I was unable to focus on the talks and stopped listening altogether. This meant I would go inside my own head (another little trick we can do) and stop paying attention altogether.”

From a parent's perspective. . .

- "We are tired,
we are discouraged,
we are drained financially,
we are scared for our kids . . ."

How Can We Help?

- Listen
- Respect
- Be Tolerant not Critical!
- Seek to Understand
- Provide Support – in practical ways

In The Ecclesia

- Save the back row
- Provide a picture symbol chart for the order of events in meeting
- Provide a safe place
- No perfume or after shave
- Recognize triggers

Support Social Interaction

- Acknowledge
- Listen
- Respect
- Understand Feelings
- Recognize the Need for Control/Choice

Acknowledge

- Acknowledge the child/person. Do not enter their personal space or touch them unless invited – be respectful.
- Find out what they like and give it to them – in terms of interests and preferences

Listen!

- When a child/person with autism starts to talk they might use repetition and/or long involved dialogues of narrow interest. Be prepared. If you know of their area of interest, research it so that you have something to say in a conversation. If not, be a friend and just listen. If you see someone in a “conversation” with the person with autism for a long time, go over and enter it and let them go on meeting other people. Otherwise it is hard to get out of a conversation

Respect

- Don't talk about the person as if they are not there. They are listening to everything you say even if they are non-verbal and unable to respond. Most are above average in intelligence. They have feelings although they do not show them in conventional ways, and they are affected by the same things in terms of acceptance and acknowledgement.

Understand Feelings!

- Many (if not most) people with autism, even on the higher end of the spectrum, do not think to tell others how they feel or what is bothering them. Those who are able to speak could be asked about how they are. Those without speech may act out their pain and discomfort. Be careful not to judge, rather seek to understand why they might be acting this way.

Sunday School Lessons

- Lessons need to be visual, with minimum of language and with tolerance for movement.
- Use videos/animations to tell the stories – Hanna Barbera, for example.
- Set up a resource centre/people with technical abilities and skills in computer/animation/art.
- Use computer, non-verbal kids can learn to type and communicate. .
- Help teacher deal with outbursts, educate ecclesial members about child's capabilities/limitations.

Recognize the Need for Movement

- Recognize and identify the need for movement: “Billy, I know that you need to run around, but I will keep reading the story and you can listen!”

Recognize the need for control/choice

- They are so vulnerable that they need to have a sense of control/choice which gives them a positive feeling about the situation. E.g. "Billy, I know that you need to run around, but I will keep reading the story and you can listen *if you want to!*"

Sensory Overload

- If Billy is in sensory overload he might show signs of distress at the continued reading, so acknowledge that: "Billy, I can see that you are upset, so I will stop reading for now and start again when you are ready." Never force a child with autism, they are not being deliberately defiant! They are trying their best to handle the world they are in.

Sensitivity to Mood

- If the general mood is unhappy they will sense that and act out. For teachers, have a positive upbeat manner and celebrate each aspect of development or connection as it develops even in an exaggerated manner 😊
- See Celebrating – The Son-Rise Technique on www.youtube.com. www.autismtreatment.org. Have an emphasis on joining and being joyful!

Ecclesial Activities

- **Ecclesial activities:** Swimming is an activity suitable for many individuals – try to find a salt water pool or go to a beach as pool chemicals can cause distress.
- **Be Aware of Health Concerns:** Talk to the parents. Provide healthy, gluten-free, casein free snacks. Many individuals are sensitive to foods. Be aware of dietary restrictions!

Ecclesial Support

- Vet resources that are out there so that parents don't have to do all the research themselves
- Support, connect, enable, advocate in the best senses of those words
- Provide respite care if possible or facilitate it
- Help with doctor's appointments, meals, time out, something special (a massage, fruit basket, flowers)
- Help individual find meaningful employment, network, and connect with others

Make friends and family count

- Help kids to befriend the child with autism. Pairing “neurotypical” kids with kids with autism helps kids to develop kindness and compassion. Use positive reinforcement for kindness.
- Support the siblings and family. They need to be able to talk about their unusual family member without being judged.

Hope on the Horizon

- Research Registry
- Gene Identification
- Siblings at Risk
- Epidemiological Studies
- Increased Funding

Resources

- Autism Society Canada provides access to resources www.autismsocietycanada.ca
- Geneva Centre for Autism is a clinical training and support centre www.autism.net
- Autism Treatment Center of America home of the Son-Rise Program www.autismtreatmentcenter.org
- Shining Through Centre uses Applied Behaviour Analysis www.shiningthrough.ca