



COMMUNICATION MATTERS

A NEWSLETTER FOR PARENTS, TEACHERS, EARLY LEARNING PROVIDERS AND CAREGIVERS OF PRESCHOOL-AGED CHILDREN.

Autism spectrum disorder

The last time we featured the topic of autism in Communication Matters was 2002.

A lot has changed since then! More people receive this diagnosis now than ever. Scientists are working hard to identify the causes of autism. And in Ontario, the Ministry of Children and Youth funds a range of services for children with autism and their families.

In this issue, we'll look at some of the recent information available about Autism Spectrum Disorder.

What is Autism Spectrum Disorder (ASD)?

Autism spectrum disorder is a neurological condition. It affects the way the brain functions and results in difficulties with social communication. People with the disorder also exhibit unusual patterns of behaviour, activities and interests.

How is ASD diagnosed?

We don't yet have a medical test that can diagnose autism. Instead, specially trained physicians and psychologists administer autism-specific behavioral evaluations. They follow the guidelines laid out in a book called the Diagnostic and Statistical Manual (DSM).

One of the biggest recent changes in the field of autism came in 2013 with the publication of the 5th edition of the DSM, commonly referred to as the DSM-5. All that technical-sounding language boils

The following table highlights the most important differences between the DSM-5 and the previous edition, DSM-4.

	DSM IV	DSM V
Diagnostic Labels	Autism Spectrum Disorders include: <ul style="list-style-type: none"> • Autistic Disorder, • Asperger's Disorder, • PDD-NOS (Pervasive Developmental Disorder Not Otherwise Specified) 	Autism Spectrum Disorder: Level 1, Level 2, Level 3 (Levels are defined by how much support the individual needs)
Criteria for diagnosis	<ul style="list-style-type: none"> • Impairments in Communication • Impairments in Social Interaction • Restricted Interests and Repetitive Behaviours. 	<ul style="list-style-type: none"> • Impaired Social Communication and/or Interaction • Restricted and/or Repetitive Behaviors
Age of diagnosis	Geared towards identification in school-aged children	Symptoms must show in early childhood even if diagnosis isn't made until later.

down to a few things that may have a profound effect on people with ASD and their families:

- People who were previously identified as having Asperger's or PDD-NOS will now be identified as having ASD. That doesn't at all change who they are. But labels are part of our self-identity. If you or your child had come to terms with a diagnosis of Asperger's or PDD-NOS only to have it changed to ASD now, you may experience initial anxiety and confusion. If this affects your family, be sure to discuss it with your child's doctor.
- Social communication problems have long been recognized to be the core problem for people with ASD. But

in the old diagnosis, social skills and communication were considered separately. The new version recognizes the integration of these important skill areas.

- Identification by level may help to ensure that children receive the support they need in social and school settings.
- The new version reflects recent research into the unusual behaviors shown by many people with ASD. It recognizes that people with ASD often have difficulties with sensory processing. You'll find more information about sensory processing later in this newsletter, under the section "What does ASD look like?"



It will take time for clinicians to use the DSM-5 before there's agreement on its value – if there ever is. But it's promising when a clinician like Dr. Stephen Kanne, executive director of the University of Missouri Thompson Center for Autism and Neurodevelopmental Disorders, can say “the new criteria lend themselves to a more careful and tailored approach to diagnosis” instead of “categoriz(ing) people according to an all or nothing checklist.”

The most important take away for families is to realize that doctors can only diagnose ASD – or rule it out as a diagnosis – if they have excellent information about the child. What a doctor sees in his office is rarely the child's best, or even typical behavior.

As a parent, you know your child best. If you are seeing a doctor because you have concerns about your child's social communication and behavior skills, be sure to be specific about your concerns. Write down your observations and bring that paper with you. Bring any reports you have from other people, like a speech pathologist or your child's preschool teacher. Make a note of any questions. Don't be afraid to ask or tell anything!

A diagnosis of ASD doesn't change who your child is, but it may help others understand him better.

How many children have the diagnosis of ASD?

The NEDSAC (National Epidemiological Database for the Study of Autism in Canada) looked at the number of children living with autism every year from 2003 to 2010 in three areas of Canada.

The area closest to Haldimand-Norfolk was Southeastern Ontario. Results there showed an increase in autism in children aged 2 to 5 years from .32 in 1000 (less than 1 in 300) in 2003 to .95 in 1000 (or 1 in 100) in 2010.

If that change wasn't startling enough, the U.S. based Centre for Disease Control now says that 1 in 88 eight-year old children and 1 in 54 eight-year old boys are living with the ASD diagnosis (March 2012).

What's going on?!

NEDSAC feels that changes in diagnostic criteria and better diagnostic skills are factors in this increase. For example, doctors are better now at picking up the more subtle signs of autism in girls. The Redpath Centre, a diagnostic centre in Toronto, reports that in the past five years the male-to-female ratio of their 600 clients a year has risen from 80-20 to 60-40. But improved diagnostics doesn't tell the whole story. There is continued work on finding the core cause of autism.

What causes ASD?

There is no known single cause for autism, but it is generally accepted that the brain of a person with ASD is different in shape, structure and function than the brains of people without ASD. Researchers are investigating a number of theories, including the links among heredity, genetics and medical problems.

In many families, there appears to be a pattern of autism or related disabilities, further supporting the theory that the disorder has a genetic basis.

But is genetics the sole cause? Some researchers are exploring environmental factors such as viral infections, metabolic imbalances and exposure to environmental chemicals.

British doctor Andrew Wakefield caused a lot of families a lot of heartache when he published a “study” in 1999 claiming that vaccines caused autism.

Even though it has since been proven that the data in the Wakefield study was false, it frightened many parents away from potentially life-saving vaccines. It made some parents of children with ASD experience tremendous guilt wrongly blaming themselves for their children's difficulties.

Even though a specific gene has yet to be identified, and researchers aren't sure about environmental “triggers” that cause autism to develop, we are getting closer to understanding the causes of autism.

What does ASD look like?

“If you've seen one child with autism, you've seen...one child with autism.” Like all children, each child with ASD is a unique and precious individual. People with ASD may share certain behavioural, social and communication characteristics, but they can vary widely in the effect that autism has on their day-to-day lives. Sensory processing may be an important

factor in creating the behaviours like lack of eye contact and hand flapping that worry parents.

Temple Grandin, one of the world's best known and most accomplished adults with autism, has identified sensory issues as an area that needs much recognition and research. She writes about her own experiences of being overwhelmed by her brain's perception of the sounds and sights of her environment. Grandin suggests that differences in sensory processing may even contribute to the social problems of people with ASD. In her book, *The Autistic Brain*, Grandin asks "...how can you socialize people who can't tolerate the environment where they're supposed to be social – who can't practice recognizing the emotional meanings of facial expressions in social settings because they can't go into a restaurant?"

Children with sensory processing difficulties may be over-sensitive or under-sensitive to sensory information. Children who are over-sensitive may have big reactions to a small amount of sensation. Examples of over-sensitivity include:

- fear of sounds, like a vacuum cleaner or the siren of a passing fire truck
- frequent hands over ears
- aversion to having hair washed or cut
- resisting a change in seasonal clothes (e.g. hats and mitts in winter)
- avoiding movement activities like swings, a merry-go-round, an escalator
- frequent car sickness
- gagging or crying in response to some perfumes, cleaning products, food smells
- refusing crunchy or chewy foods, or any attempt to introduce "new" foods
- preferring bland foods
- showing light sensitivity; frequent blinking, preference for dark rooms

Children who are under-sensitive seek out sensation because they need a lot of it before they respond. Examples of under-sensitivity include:

- constant movement: running, jumping, rocking, spinning

- bumping into people and things
- squeezing into tight places (e.g. behind the couch)
- giving and wanting very tight hugs
- teeth-grinding or chewing on non-food items
- seeming to ignore things that are said to him
- wanting the TV turned up loud
- banging doors
- flicking lights on and off
- lining things up
- looking at things from unusual angles
- exploring things and people by smelling or licking them

Children with motor planning difficulties have trouble organizing their responses to sensory input. Examples of motor planning difficulties include:

- bumping into people and things
- playing with the same toy over and over in the same way
- not imitating gestures or sounds
- doing an activity just once (e.g. going down a slide one time)
- wandering aimlessly
- lying down a lot
- trouble blowing out candles
- understanding much more than he can say
- saying words that are hard to understand
- saying a word only once, or losing words he used to say

You can see that a person with sensory processing and motor planning difficulties would behave in ways that seemed odd to others, just because he was trying to respond to the way the world impacted on his senses. Recognizing your child's sensory preferences and dislikes can make it a lot easier to interact with him.

How is ASD treated?

Some people with mild forms of autism may never need treatment. They function well and may even excel in life. However, those with more significant forms of the disorder may benefit from active therapy. There are several ways people with autism are treated and there is plenty of debate over what kinds of

News Flash!

Check out our new ONLINE REFERRAL FORM!

Go to hnhu.org/speech-referral-form. To access other information like our Communication Checklist, if you're not sure what skills to expect at different ages, visit hnhu.org/speech. You can also find our Referral Form there if you'd like your child to be seen for assessment.

treatments offer the most success. Applied Behavioural Analysis (ABA) and Intensive Behavioural Intervention (IBI) are designed to actively engage children with communication, socialization, learning and behavioural problems.

IBI is an intensive treatment approach that breaks complex skills (like playing with toys, playing with other children, self-care) into small, simple steps that are then taught to children through a variety of techniques. The intention of IBI is to improve the child's verbal and non-verbal communication skills, self-help skills, play skills, and socialization skills. ABA involves the use of principles of learning to improve socially important behaviours such as toilet training, eating, dressing, paying attention to the teacher or sharing toys. It is a short-term, specifically goal-directed approach.

In our area, both IBI and ABA services are provided by the Autism Program of Haldimand-Norfolk REACH. There are eligibility requirements for some services. Call HN REACH CONTACT at 1-800-265-8087 ext.350 to enquire.

Other types of treatment available locally include:

- Occupational Therapy for sensory processing and fine motor skills (doctor's referral not required but there is a waiting list; call Lansdowne Children's Centre, 519-753-3153 ext. 206)

- Speech-Language Therapy. Children with ASD are eligible to receive services through our program until the September of the year they turn five (their Senior Kindergarten eligibility year). We partner with parents, teachers and other community professionals to help children develop their social communication skills. Two of the primary interventions we provide are highlighted below.

“More Than Words,” the Hanen® Parent Training program

The More Than Words Program was designed specifically for parents of children ages 5 and under on the autism spectrum. Addressing the unique needs of these children, the program provides parents with the tools, strategies and support they need to help their children reach their full communication potential.

More Than Words does this by empowering you to help your child reach the following three goals:

1. Improved social skills
2. The ability to engage in back-and-forth interactions
3. Improved understanding of language

Here are some of the valuable things you'll learn when you attend the More Than Words Program:

- How your child learns best and what motivates him to communicate
- Why your child behaves in certain ways, and what you can do to either increase or reduce those behaviours
- How to use your knowledge about your child to set realistic goals
- How to make interactions with

- your child last longer and be more meaningful
 - Tips for using pictures and print to help your child's understanding
 - Tips on how to talk so that your child understands you
 - Strategies for developing your child's play skills
 - Ways to help your child make friends
- All three of our program SLPs are certified by the Hanen® Centre to provide a full or modified More Than Words curriculum in group or individual sessions. If you're interested in more information about More Than Words, speak to your child's SLP or visit the Hanen® website at www.hanen.org.

The Picture Exchange Communication System

People with limited language skills, and especially people with social communication problems such as people with autism, often find it hard to initiate, or start, conversations. Try to imagine what that would be like. If you didn't know how to approach another person to get something you wanted, and you couldn't get it by yourself, your frustration level would rise quickly. You might learn to wait until someone approached you, and become a passive communicator. You might develop other, possibly inappropriate behaviours in your attempts to express yourself. Either way, your ability to interact with other people would be severely restricted.

In the initial phase of the Picture Exchange Communication System (PECS) users learn to exchange an actual thing (a picture) for another actual thing (the item they want) in the same way that someone with spoken language abilities would exchange

a spoken word for a desired item. Picture exchange becomes a means for them to initiate conversations. In later phases, users learn not only to request but to make comments, opening up their conversations with others. For many users, the use of pictures also increases the use of speech. Note that PECS is a system that uses pictures. The pictures themselves are not PECS. They're often taken from the Picture Communication Symbols (PCS) collection, available through the Boardmaker program. The similarity of PECS and PCS can be confusing, but they're different things. Not everyone who uses PCS is following the PECS training model.

If you're interested in learning more about PECS, speak to your child's SLP, or visit the website www.pecs-canada.com.

We'll give the last word in this newsletter to Temple Grandin, again from her great book, *The Autistic Brain*:

“We've come a long way from the days of doctors telling the parents of autistic children that the situation was hopeless...I have confidence that whatever the (future) thinking about autism is, it will incorporate a need to consider it brain by brain, DNA strand by DNA strand, trait by trait, strength by strength, and maybe most important of all, individual by individual.”

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Communication Matters is published biannually by the Haldimand-Norfolk Preschool Speech and Language program. It has been developed to increase awareness for services available and tips on the prevention of speech, language or hearing disorders in the preschool population. This newsletter is intended for parents, teachers and caregivers of preschool-aged children. You are invited to contact the Health Unit with your articles and ideas.



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