



# Autism Society Manitoba

## What is Autism?

Autism is a complex developmental disability that typically appears during the first three years of life. The result of a neurological disorder that affects the functioning of the brain, autism and its associated behaviours have been estimated to occur in as many as 1 in 200 individuals. Autism is four times more prevalent in boys than girls and knows no racial, ethnic, or social boundaries. **Family income, lifestyle, and educational levels do not affect the chance of autism's occurrence.**

Autism impacts the normal development of the brain in the areas of social interaction and communication skills. Children and adults with autism typically have difficulties in verbal and non-verbal communication, social interactions, and leisure or play activities. The disorder makes it hard for them to communicate with others and relate to the outside world. In some cases, aggressive and/or self-injurious behaviour may be present. Persons with autism may exhibit repeated body movements (hand flapping, rocking), unusual responses to persons or attachments to objects and resistance to changes in routines. Individuals may also experience sensitivities in the five senses of sight, hearing, touch, smell, and taste.

Over two thousand people in Manitoba today have autism or some form of pervasive developmental disorder. Its prevalence rate makes autism one of the most common developmental disabilities. Yet most of the public, including many professionals in the medical, educational and vocational fields, are still unaware of how autism affects people and how they can effectively work with individuals with autism.

## Is There More Than One Type of Autism?

Several related disorders are grouped under the broad heading "Pervasive Developmental Disorder" or PDD – a general category of disorders which are characterized by severe and pervasive impairment in several areas of development (American Psychiatric Association, 1994). A standard reference is the *Diagnostic and Statistical Manual (DSM)*, a diagnostic handbook now in its fourth edition. The *DSM-IV* lists criteria to be met for a specific diagnosis under the category of Pervasive Developmental Disorder. Diagnosis is made when a specified number of characteristics listed in the *DSM-IV* are present. Diagnostic evaluations are based on the presence of specific behaviours indicated by observation and through parent consultation, and should be made by an experienced, highly trained team. Thus, when professionals or parents are referring to different types of autism, they are often distinguishing autism from one of the other pervasive developmental disorders.

Individuals who fall under the Pervasive Developmental Disorder category in the *DSM-IV* exhibit commonalities in communication and social deficits, but differ in terms of severity. We have outlined some major points that help distinguish between the specific diagnoses used.

### **Autistic Disorder**

impairments in social interaction, communication, and imaginative play prior to age 3 years, stereotyped behaviours, interests and activities.

### **Asperger's Syndrome**

Characterized by impairments in social interactions and the presence of restricted interests and activities, with no clinically significant delay in language, and testing in the range of average to above average intelligence.

### **Pervasive Developmental Disorder – Not Otherwise Specified**

(Commonly referred to as atypical autism) a diagnosis of PDD-NOS may be made when the child does not meet the criteria for a specific diagnosis, but there is severe and pervasive impairment in specified behaviours.

### **Rett's Disorder**

A progressive disorder which, to date, has occurred only in girls. Period of normal development and then loss of previously acquired skills, loss of purposeful use of the hands replaced with repetitive hand movements beginning at the age of 1-4 years.

### **Childhood Disintegrative Disorder**

Characterized by normal development for at least the first 2 years, significant loss of previously acquired skills.

Autism is a *spectrum disorder*. In other words, the symptoms and characteristics of autism can present themselves in a wide variety of combinations, from mild to severe. Although autism is defined by a certain set of behaviours, children and adults can exhibit *any combination* of the behaviours in *any degree of severity*. Two children, both with the same diagnosis, can act very differently from one another and have varying skills.

Therefore, there is no standard “type” or “typical” person with autism. Parents may hear different terms used to describe children within this spectrum, such as autistic-like, autistic tendencies, autism spectrum, high-functioning or low-functioning autism, more-abled or less-abled. More important to understand is, whatever the diagnosis, children can learn and function productively and show gains from appropriate education and treatment. Autism Society Manitoba provides information to serve the needs of all individuals within the spectrum.

Diagnostic categories have changed over the years as research progresses and as new editions of the *DSM* have been issued. For that reason, we will use the term “autism” to refer to the above disorders.

## What Causes Autism?

Researchers from all over the world are devoting considerable time and energy into finding the answer to this critical question. Medical researchers are exploring different explanations for the various forms of autism. Although a single specific cause of autism is not known, current research links autism to biological or neurological differences in the brain. In many families there appears to be a pattern of autism or related disabilities – which suggests there is a genetic basis to the disorder – although at this time no gene has been directly linked to autism. The genetic basis is believed by researchers to be highly complex, probably involving several genes in combination.

Several outdated theories about the cause of autism have been proven to be false. Autism is **not** a mental illness. Children with autism are **not** unruly kids who choose not to behave. Autism is **not** caused by bad parenting. Furthermore, no known psychological factors in the development of the child have been shown to cause autism.

## How is Autism Diagnosed?

There are no *medical* tests for diagnosing autism. An accurate diagnosis must be based on observation of the individual’s communication, behaviour, and developmental levels. However, because many of the behaviours associated with autism are shared by other disorders, various medical tests may be ordered to rule out or identify other possible causes of the symptoms being exhibited.

Since the characteristics of the disorder vary so much, diagnosis is difficult for a practitioner with limited training or exposure to autism. Sometimes, autism has been misdiagnosed by well-meaning professionals. Difficulties in the recognition and acknowledgement of autism often lead to a lack of services to meet the complex needs of individuals with autism.

A brief observation in a single setting cannot present a true picture of an individual’s abilities and behaviours. Parental (and other caregivers’) input and developmental history are very important components of making an accurate diagnosis. At first glance, some persons with autism may appear to have mental retardation, a behaviour disorder, problems with hearing, or even odd and eccentric behaviour. To complicate matters further, these conditions can co-occur in autism. However, it is important to distinguish autism from other conditions, since an accurate diagnosis and early identification can provide the basis for building an appropriate and effective educational and treatment program. Sometimes professionals who are not knowledgeable about the needs and opportunities for early intervention in autism do not offer an autism diagnosis even if it is appropriate. This hesitation may be due to a misguided wish to spare the family. Unfortunately, this too can lead to failure to obtain appropriate services for the child.

In Manitoba, the *Child Development Clinic* at the Health Sciences Centre in Winnipeg conducts formal assessments of children up to the age of 7 years. Paediatricians and family doctors can make referrals to the clinic. A developmental paediatrician will assess the child and interview the parents. A diagnosis may be made at this time or the child may be referred for additional assessments.

## **What are People with Autism Like?**

Children within the pervasive developmental disorder spectrum often appear relatively normal in their development until the age of 24-30 months, when parents may notice delays in language, play or social interaction. Any of the following delays, by themselves, would not result in a diagnosis of pervasive developmental disorder. Autism is a combination of several developmental challenges.

The following areas are among those affected by autism:

### ***Communication:***

language develops slowly or not at all; uses words without attaching the usual meaning to them; communicates with gestures instead of words; short attention span;

### ***Social Interaction:***

spends time alone rather than with others; shows little interest in making friends; less responsive to social cues such as eye contact or smiles;

### ***Sensory Impairment:***

may have sensitivities in the areas of sight, hearing, touch, smell, and taste to a greater or lesser degree;

### ***Play:***

lack of spontaneous or imaginative play; does not imitate others' actions; does not initiate pretend games;

### ***Behaviours:***

may be overactive or very passive; throws tantrums for no apparent reason; perseverates (shows an obsessive interest in a single item, idea, activity or person): apparent lack of common sense; may show aggression to others or self; often has difficulty with changes in routine.

Some individuals with autism may also have other disorders which affect the functioning of the brain such as: Epilepsy, Mental Retardation, Down syndrome, or genetic disorders such as: Fragile X Syndrome, Landau-Kleffner Syndrome, William's Syndrome or Tourette's Syndrome. Many of those diagnosed with autism will test in the range of mental retardation. Approximately 25-30 percent may develop a seizure pattern at some period during life.

Every person with autism is an individual, and like all individuals, has a unique personality and combination of characteristics. There are great differences among people with autism. Some individuals mildly affected may exhibit only slight delays in language and greater challenges with social interactions. The person may have difficulty initiating and/or maintaining a conversation, or keeping a conversation going. Communication is often described as talking at others (for example, a monologue on a favourite subject that continues despite attempts of others to interject comments). People with autism process and respond to information in unique ways. Educators and other service providers must consider the unique pattern of learning strengths and difficulties in the individual with autism when assessing learning and behaviour to ensure effective intervention. Individuals with autism can learn when information about their unique styles of receiving and expressing information is addressed and implemented in their programs.

The abilities of an individual with autism may fluctuate from day to day due to difficulties in concentration, processing, or anxiety. The child may show evidence of learning one day, but not the next. Changes in external stimuli and anxiety can affect learning. They may have average or above average verbal, memory or spatial skills but find it difficult to be imaginative or join in activities with others. Individuals with more severe challenges may require intensive support to manage the basic tasks and needs of living day to day.

Contrary to popular understanding, many children and adults with autism may make eye contact, show affection, smile and laugh, and demonstrate a variety of other emotions, although in varying degrees. Like other children, they respond to their environment in both positive and negative ways. Autism may affect their range of responses and make it more difficult to maintain eye contact with others. Some individuals with autism use peripheral vision rather than looking directly at others. Sometimes the touch or closeness of others may be painful to a person with autism, resulting in withdrawal even from family members. Anxiety, fear and confusion may result from being unable to “make sense” of the world in a routine way.

With appropriate treatment, some behaviours associated with autism may change or diminish over time. The communication and social deficits continue in some form throughout life, but difficulties in other areas may fade or change with age, education, or level of stress. Often, the person begins to use skills in natural situations and to participate in a broader range of interests and activities. Many individuals with autism enjoy their lives and contribute to their community in a meaningful way. People with autism can learn to compensate for and cope with their disability, often quite well.

While no one can predict the future, it is known that some adults with autism live and work independently in the community (drive a car, earn a college degree, get married); some may be fairly independent in the community and only need some support for daily pressures; while others depend on much support from family and professionals. Adults with autism can benefit from vocational training to provide them with the skills needed for obtaining jobs, in addition to social and recreational programs. Adults with autism

may live in a variety of residential settings, living with other family members or more structured residential care. An increasing number of support groups for adults with autism are emerging around the country. Many self-advocates are forming networks to share information, support each other, and speak for themselves in the public arena. More frequently, people with autism are attending and/or speaking at conferences and workshops on autism. Individuals with autism are providing valuable insight into the challenges of this disability by publishing articles and books and appearing in television specials about themselves and their disabilities.

## **What are the Most Effective Approaches?**

Evidence shows that early intervention results in dramatically positive outcomes for young children with autism. While various pre-school models emphasize different program components, all share an emphasis on early, appropriate, and intensive educational interventions for young children. Other common factors may be some degree of inclusion, mostly behaviourally-based interventions, programs which build on the interests of the child, extensive use of visuals to accompany instruction, highly structured schedule of activities, parent and staff training, transition planning and follow-up. Because of the spectrum nature of autism and the many behaviour combinations that can occur, no one approach is effective in alleviating symptoms of autism in all cases. Various types of therapies are available, including (but not limited to) applied behaviour analysis, auditory integration training, dietary interventions, discrete trial teaching, medications, music therapy, occupational therapy, Picture Exchange Communication System, physical therapy, sensory integration, speech/language therapy, and vision therapy.

Studies show that individuals with autism respond well to a highly structured, specialized education program, tailored to their individual needs. A well designed intervention approach may include some elements of communication therapy, social skill development, sensory integration therapy and applied behaviour analysis, delivered by trained professionals in a consistent, comprehensive and coordinated manner. The more severe challenges of some children with autism may be best addressed by a structured education and behaviour program which contains a one-on-one teacher to student ratio or small group environment. However, many children with autism may be successful in a fully inclusive general education environment with appropriate support.

In addition to appropriate educational supports in the area of academics, students with autism should have training in functional living skills at the earliest possible age. Learning to cross a street safely, to make a simple purchase or to ask assistance when needed are critical skills, and may be difficult, even for those with average intelligence levels. Tasks that enhance the person's independence and give more opportunity for personal choice and freedom in the community are important.

To be effective, any approach should be flexible in nature, rely on positive reinforcement, be re-evaluated on a regular basis and provide a smooth transition from home to school to community environments. A good program will also incorporate

training and support systems for parents and caregivers, with the generalization of skills to all settings. Rarely can a family, classroom teacher or other caregiver provide effective habilitation for a person with autism unless offered consultation or in-service training by an experienced specialist who is knowledgeable about the disability.

A generation ago, the vast majority of people with autism were eventually placed in institutions. Professionals were much less educated about autism than they are today; autism specific supports and services were largely non-existent. Today the picture is brighter. With appropriate services, training, and information, most families are able to support their son or daughter at home. Group homes, assisted apartment living arrangements, or residential facilities offer more options for out of home support. Autism-specific programs and services provide the opportunity for individuals to be taught skills that allow them to reach their full potential.

Families of people with autism can experience high levels of stress. As a result of the challenging behaviours of their children, relationships with service providers, attempting to secure appropriate services, resulting financial hardships, or very busy schedules, families often have difficulty participating in typical community activities. This results in isolation and difficulty in developing needed community supports. **Autism Society Manitoba is here for you.**

Members of ASM represent all walks of life from rural to urban communities. Embracing the *diversity* of our group, ASM seeks to provide an open forum for the exchange of ideas. At the very core of ASM's philosophy is the belief that no single program or treatment will benefit all individuals with autism. Furthermore, the recommendation of what is "best" or "most effective" for a person with autism should be determined by those people directly involved – the individual with autism, to the extent possible, and the parents or family members.

ASM provides information and education to assist parents, educators, and others in the decision-making process. Providing information on available intervention options, rather than advocating for any particular theory or philosophy, is the focus at ASM.

## **Is There a Cure?**

Understanding of autism has grown tremendously since it was first described by Dr. Leo Kanner in 1943. Some of the earlier searches for "cures" now seem unrealistic in terms of today's understanding of brain-based disorders. To cure means "to restore to health, soundness, or normality." In the medical sense, there is no cure for the differences in the brain which result in autism. However, better understanding of the disorder has led to the development of better coping mechanisms and strategies for the various manifestations of the disability. Some of these symptoms may lessen as the child ages; others may disappear altogether. With appropriate intervention, many of the associated behaviours can be positively changed; even to the point in some cases, that the child or adult may appear to the untrained person to no longer have autism. The majority of

children and adults will, however, continue to exhibit some manifestations of autism to some degree throughout their entire lives.

## **What is Autism Society Manitoba?**

Founded in 1977 by a small group of parents, Autism Society Manitoba continues to be the leading source of information and referral on autism and the largest collective voice representing the autism community in Manitoba for more than 29 years. Autism Society Manitoba is a non-profit association committed to education and support on behalf of and for the benefit of individuals within the autism spectrum, their families, and service providers. ASM is a registered charity, directed and operated by volunteers. We receive no government or on-going agency funding. The work of ASM is supported through memberships, donations, and fundraising ventures.

The mission of ASM is the promotion of quality of life for people with autism spectrum disorders and their families, to be fully included, participating members of their communities through public awareness, advocacy, and education. The goals of the society are:

- To raise awareness of the public concerning persons with autism spectrum disorders,
- To advocate the needs of persons within the autism spectrum in the areas of health, education, and labour,
- To act as a resource to parents and interested professionals and organizations,
- To establish a supportive network for parents and families of persons with autism spectrum disorders, and
- To foster and encourage the inclusion of persons with autism into the community.

## **Where Can I Get More Information?**

Educating yourself and others about autism is a critical way to assist with the education and development of the individual with autism and to help society understand the nature of this common developmental disorder. To request additional information or to find answers to other questions on autism, please call or write Autism Society Manitoba. *We are here to help.*

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