

AUTISM: LIVING WITH DIFFERENCE

Introduction



Download the mp3 of this Introduction at newsinreview.cbclearning.ca.

Focus

Autism Spectrum Disorders (ASD) are on the rise in Canada and around the world. This *News in Review* module looks at ASD from a number of perspectives. One of these is that of the researchers and parents who see it as a condition in search of a cure. But we also hear from autistic people themselves who think of ASD as more of a human difference than a disorder.

Autism is a word that strikes fear in the hearts of parents everywhere. In its most severe forms, autism leaves children without basic social skills, without verbal communication, with limited interests in their external environment. People with the most severe forms of autism seem trapped in their own bodies, forced to repeat the same simple behaviours over and over.

Autism was considered relatively rare until fairly recently. In the 1980s, autism was diagnosed only once in every 10 000 children. Today it is believed that at least one Canadian child out of 165 has some form of autism. And autism has a gender bias: four times as many boys as girls are diagnosed with the disorder.

In recent years, autism researchers have made many advances in studying this disorder—which was first identified in 1942. The condition is now referred to as Autism Spectrum Disorders, or ASD. This recognizes that autism is not one but an entire range of disorders, with characteristics ranging from mild to severe. Those with the least severe forms usually require little or no assistance in coping with day-to-day living. To most of the people they meet or with whom they work they appear completely “normal.”

The evidence is also piling up that a large number of the most severely affected individuals are also living interesting and rewarding lives. Many of those incapable of speech have learned to communicate with “normal” people by using a computer. They have been able to share with others a world of fascinating, altered perceptions, a world in which every one of their senses is heightened. Often they describe themselves as using a natural language based on visual, rather than verbal, thought and communication. Seemingly withdrawn from the outside world, they actually relate to it in unusual but meaningful ways.

Many of those with ASD are now suggesting that it is time to rethink the way society treats those with the disorder. They argue that society should make less of an effort to find a “cure” for autism and should devote more time and energy to assisting those who live with ASD. Rather than thinking of them as people who are sick, we should think of them as people who are different: autistic people, rather than people with autism.

Whether or not society is willing to make that adjustment remains questionable. But each of us can make an effort to appreciate the strengths as well as the challenges of autistic people.

To Consider

1. In a discussion of ASD, *School Library Journal* (August 2009) points out that the rate of Autism Spectrum Disorders is now likely as high as one child out of every 150. This means ASD is “more common than pediatric cancer, diabetes, and AIDS combined.”

Does this high rate of ASD diagnosis indicate that we as a society should be spending more money, time, and resources in investigating ASD? And, if we change the way we view ASD—as a difference, rather than a disorder—is this likely to affect the number of resources we invest in trying to understand ASD?

2. Describe any personal knowledge or experience you have of autistic people.

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Video Review

Pre-viewing Activity

During the video you will meet a number of autistic people. At least one would be described as severely autistic; others as highly functional. Before watching the video, jot down three behaviours that you would expect an autistic person to demonstrate. After viewing, revisit this list to determine if your expectations were met. Discuss what you learned from this exercise.

Comprehension Questions

While viewing, answer the following questions in the spaces provided. (It may be helpful to pause the video from time to time to enable a full response.)

1. What is the traditional approach to autism treatment?

2. How does Amanda Baggs say autistic people are treated until they “learn more standard ways of communicating”?

3. What does Michelle Dawson say is the “very common” way of looking at autism?

4. Whom does Ari Ne’eman feel is being left out of discussions about autism?

5. How does Ari Ne’eman define the problem faced by autistic people?

6. Amanda Baggs says there is a “main time” she would like to be non-autistic. What is it?

7. What does Michelle Dawson say that society believes is the only way for autistic people to have a good life?

Post-viewing Activities

1. In 10 words or less, what would you say was the theme of this video presentation? Does each of the participants reinforce this theme? Explain.

2. The video presents the opinions of four individuals: three of them autistic, one the mother of an autistic child. During a second viewing of the video, use the chart below to jot down the main points each individual makes about: (a) Their own condition as autistic people and (b) how they would like society to treat them.

Are they in agreement? Do their views complement one another?

Individual	Main Points
Amanda Baggs	
Michelle Dawson	
Ari Ne'eman	
Esteé Klar-Wolfond (mother of Adam)	

3. Amanda Baggs has several videos on YouTube, but the one for which she is best known is called "In My Language" (www.youtube.com/watch?v=JnylM1hI2jc). It is in two parts. The first lacks any verbal language; the second explains what she was attempting in the first part.

The video deserves two viewings. After the first viewing, with Baggs's explanation in mind, watch the first part for a second time.

Does your understanding of Baggs's methodology and intent change the way in which you interpret the video? In what ways does it do so?

4. What, if any, impact has this story made on your views of autism?

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The Autism Spectrum

Further Research

A very useful introduction to Autism Spectrum Disorders is available from the Autism Society Canada Web site at www.autismsocietycanada.ca/pdf_word/info_ASC'swhatisautisminfosheet_27_June_07_e.pdf. Students seeking more detailed information on the varieties of ASD will find this site (www.autismsocietycanada.ca) an excellent place to begin their research. Other sources include the Autism Canada Foundation at www.autismcanada.org and Autism Treatment Services of Canada at www.autism.ca.

Upon hearing the word *autism* many of us think of individuals who share a condition in which they demonstrate several unusual behavioural characteristics. Professionals, however, prefer to talk about Autism Spectrum Disorders, or ASD. Using the term *ASD* recognizes that there are several different disorders, ranging from mild to severe, that demonstrate at least some of the characteristics we call “autistic.”

Classifying ASD

The various forms of ASD are classified by researchers as Pervasive Development Disorders (PDDs). The term is used to describe conditions that result in the delayed development (or non-development) of basic human behaviours. Many of these involve communication and socialization—in other words, how we interact with our fellow human beings.

The Autism Society Canada identifies five differences among those diagnosed with ASD that make up the autism spectrum (www.autismsocietycanada.ca/understanding_autism/what_are_asds/index_e.html). These are:

- Number and kind of symptoms
- Severity: mild to severe
- Age of onset
- Levels of functioning
- Challenges with social interactions

There are actually five different PDDs that make up the autism spectrum, but two of them are extremely rare. The three that most people are referring to when they use the term *ASD* are:

- Autistic Disorder (AD): This is the most common form of ASD, affecting about 20 in every 10 000 Canadians.
- Pervasive Development Disorder Not Otherwise Specified (PDD-NOS): The

second most common form of ASD, it affects 15 of every 10 000 Canadians. Those with PDD-NOS demonstrate many but not all of the same characteristics as people diagnosed with AD.

- Asperger Disorder (AS): Also called Asperger's Syndrome, AS affects five in every 10 000 Canadians. Because those with AS usually develop normal language and learning skills in early childhood, AS is often not diagnosed until children have begun formal schooling. It is then that problems with social interaction become apparent.

Common Characteristics of the Autism Spectrum

It is important to be aware that there are many common characteristics among people with autism. But not every person will have all of them, and the characteristics vary greatly in severity from person to person. However, people with ASD do develop differently from the majority of the population in four main areas: motor, language, social, and cognitive (perceiving and reasoning) skills. This lack of development is often demonstrated by unusual behaviours.

Without early diagnosis and intervention, some people (about 40 per cent) of people with ASD never learn to speak. Many develop their language skills far more slowly than the rest of the population. Most are rarely able to understand the forms of non-verbal communication—smiling and frowning, for example—that the rest of us use daily in our communications with others.

People with ASD usually have real difficulties in social relationships. Some have no interest in other people. Others show no understanding of how to relate

to others and are unable to carry on a simple conversation. They often have difficulty making eye contact.

Those with ASD often demonstrate strange behaviours. They may repeat the same gestures or body movements over and over. They often are obsessive in their interests and become fixated on one activity or one idea. It is this aspect of ASD that usually draws most people's attention to those with ASD.

Some people with ASD respond to sensations in ways very different from the general population. They may have difficulty processing both what they see and what they hear. In some cases, they can be either over-sensitive or under-sensitive to many stimuli. Many people with ASD report that their over-sensitivity to sensations causes them intense fear. This sensitivity has been described as having the volume on one or all their senses turned up as high as it will go.

Some people with ASD also have unusual abilities. These may include an

ability to focus much more attentively on tasks or problems than the average person. They are often very good at paying attention to details. Many have excellent memory skills.

A Neurological Disorder

The cause or causes of ASD and its component conditions are still unclear. It was only in 1942 that the disorder was first recognized. It is generally considered to be a neurological disorder, a disorder of the nervous system.

Modern research is concentrating on several different areas looking for a cause. These range from genetic abnormalities to environmental factors; from fetal brain development to immune system deficiencies. To date, the greatest amount of research has focused on genetic causes. Most researchers, however, now believe that ASD is the result of both genetic and environmental factors. What they still don't know is which factors are involved and how they work together.

Quick Research Activity

The two Autism Spectrum Disorders not discussed in this guide are Childhood Disintegrative Disorder (CDD) and Rett's Disorder (RD). Using the resources recommended in the sidebar on the previous page, prepare a brief written description of one of these disorders. Include symptoms, a discussion of who is affected, and any recommended treatments.

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Traditional Treatment

Further Research

A detailed discussion of current treatment methods is available from Autism Society Canada at www.autismsocietycanada.ca/approaches_to_treatment/overview/index_e.html. See also Autism Central at www.autismcentral.ca/research/index.php?option=com_content&task=view&id=62&Itemid=86.

It may seem a bit odd to speak of “traditional treatment” when discussing a condition that was identified less than 70 years ago. During that period, however, a number of different approaches have been developed to help treat Autism Spectrum Disorders (ASD). While autism societies are reluctant to endorse specific treatment methods, they do endorse the value of “scientifically validated effective treatment.” Here is the treatment statement of Autism Society Canada: “ASC believes that early scientifically validated effective treatment can lead to great improvement for many children with autism. Without appropriate individualized treatment and services many people with autism will not develop effective communication and social skills and will continue to experience serious behaviour and learning difficulties” (www.autismsocietycanada.ca/pdf_word/info_ASC'swhatisautisminfosheet_27_June_07_e.pdf).

Applied Behavioural Analysis (ABA)

Applied Behavioural Analysis is the basis of the traditional treatment for ASDs. Studies have shown remarkable developmental improvement in many children diagnosed with Autistic Disorder who were treated with ABA, provided that they were identified before age three and they received at least two years of ABA treatment before beginning formal schooling.

About half these children were able to begin regular schooling with little or no outside support.

While most effective with younger children, the programs have also proven helpful with older ones. The programs

are very intensive. Children usually work 20 to 40 hours each week with a professional therapist or someone else trained in the methodology (this might be a parent or teacher).

ABA is used in a very specific and sequential fashion: “ABA identifies a person’s individual communication, behavioural, learning, and social strengths and challenges in a variety of situations. The person’s abilities are then used to acquire new skills, as well as to improve and retain others. Using a process called ‘discrete trials,’ each skill is broken down into manageable steps. Each step is taught using positive reinforcement and then chained with the other steps until an entire skill is learned” (www.autismsocietycanada.ca/approaches_to_treatment/behaviour_treatment/index_e.html).

Once a particular skill is learned by the child, he or she is given the opportunity to apply that skill in a number of different and more complex situations. ABA is a program that can be used at home, in schools, or elsewhere in the community. It is often incorporated by teachers and support staff into regular school routines.

Intensive Behavioural Intervention (IBI)

In Canada, in discussions of ASD and children, one often hears the term *Intensive Behavioural Intervention* (IBI). IBI is a form of ABA that applies ABA principles and methods in a highly intense setting for a minimum of 25 hours per week. It is designed specifically to prepare children for regular school. Like other intensive behaviour-based intervention programs, IBI programs concentrate on five

Quote

“Researchers say it is possible to recognize the signs of autism in babies before the age of two. Here are some common signs:

- No ‘baby talk’ or babbling by 11 months
- Lack of simple gestures, such as waving, by 12 months
- No response to sounds; inability to say single words by 16 months
- Limited imaginative play
- Selective interest in food” — “What to watch for” (*The Globe and Mail*, April 2, 2008)

specific behavioural areas (www.autismsocietycanada.ca/approaches_to_treatment/range_interventions/index_e.html):

- Attention to social stimuli
- Imitation skills
- Language use and comprehension
- Appropriate play
- Social interaction skills

Diagnosing ASD

It seems fairly clear that the earlier the intervention, the more likely that behaviour intervention will help autistic children to live normal lives.

Recent research is making it possible to diagnose children with ASD at younger and younger stages. For example, researchers at McMaster

University in Hamilton, Ontario, have developed a test that tracks children’s eye motion as they look at eyes and faces—a measure of social development in children as young as six months. By nine months, babies whose eyes failed to focus on eyes and faces were found likely to be later diagnosed with ASD.

Children diagnosed with ASD need to begin their treatment as young as possible. These treatments, because they are intensive and require professional leadership, are extremely expensive. Currently, the costs range anywhere from \$30 000 to \$80 000 per child per year. Often the full costs are not assumed by government medical plans. In some jurisdictions the costs are only assumed for a limited period.

For Discussion

Given the range of disorders in the autism spectrum, should governments be assuming the costs of any and all treatments? Should public medical providers use a blanket funding formula or approach each case separately? Offer carefully supported responses.

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Rethinking Autism

Did you know . . .

More on Simon Baron-Cohen is available at www.autismresearchcentre.com/arc/staff_member.asp?id=33. And yes, actor Sacha Baron Cohen is his first cousin. Note that the latter spells his name without the hyphen.

Do Autism Spectrum Disorders always require treatment? Do autistic individuals require intervention and “repair,” or are they only different from what society has decreed is normal?

Autism Society Canada, which endorses early behavioural intervention, acknowledges that not all people with ASD require treatment: “The term *autism* is frequently used as a catch-all term for a wide variety of symptoms, disabilities, and special abilities. There are people with Asperger’s Syndrome, ‘high functioning’ autism and PDD-NOS who may enjoy a very high level of functioning and who may need little or no special treatment or educational programming” (www.autismsocietycanada.ca/pdf_word/info_ASC'swhatisautisminfosheet_27_June_07_e.pdf).

Simon Baron-Cohen

One of the leaders in ASD research is Simon Baron-Cohen. When he began his research work, autism was often viewed as a simple case of either you were autistic or you weren't. It was Baron-Cohen who, in the 1990s, introduced the idea of the autism spectrum. He sees everyone as at least a bit autistic, falling somewhere on a scale between mild and severe. Baron-Cohen's Autism Research Centre at Cambridge University has developed an Autism Spectrum Quotient questionnaire; almost everyone would answer at least some of its questions positively.

Baron-Cohen and his colleagues are also leaders in promoting the theory that genetics is a major cause of ASD. They have, to date, identified nine genes as being associated with ASD. Most researchers now accept this link

and believe that certain environmental factors—yet unidentified—are also associated with the severity of the condition.

Baron-Cohen has also proposed a theory that the autistic brain is an extreme version of the normal male brain. He points out that autistic people tend to be better at things that men do well (such as systematizing) and worse at things that women do well (such as empathizing). He also notes that four times as many boys as girls are diagnosed as autistic. He is currently doing advanced research in an attempt to test this theory.

Baron-Cohen does not argue in favour of eradicating autism. He believes that some of the genes that make people good at jobs like math, physics and engineering—systematizing occupations—may also be some of the ones that contribute to ASD. Eradicating autism, he suggests, would likely mean also weakening the gene pool. He also points out that many higher-functioning autistic people, like those with Asperger Disorder (AS), have no desire to be “cured.”

Ari Ne'eman

In 2006, the year after he graduated from high school, Ari Ne'eman founded the non-profit Autistic Self-Advocacy Network in the U.S. Ne'eman has AS and was diagnosed as high-functional in childhood. He sees ASD as a disability, but also as a different way of being—what he calls a “neurodiversity”—and wants society to accept this definition (*Newsweek*, May 25, 2009). Rather than treat autism as some sort of “medical mystery,” society should provide autistic people across the spectrum with

Further Research

The Autistic Self-Advocacy Network's Web site is at www.autisticadvocacy.org. Autism Speaks' website is at www.autismspeaks.org.

Further Research

Temple Grandin's Web site is at www.templegrandin.com.

support—in the classroom, workplace, and for independent living.

Ne'eman is critical of many of the mainstream autism organizations in the U.S. He is especially critical of Autism Speaks, the largest of the advocacy groups in the country. He accuses them of spending most of their resources on research to discover the causes of autism. He feels they should instead devote their efforts to improving the quality of life for all autistic people.

Temple Grandin

Since 1986, when she published her first book, Dr. Temple Grandin has been the most prominent example of what autistic people can accomplish. In 1950 she was diagnosed as autistic, and her parents were told she should be institutionalized.

Despite the diagnosis, Grandin found support from both her schools and her parents. She began talking at four, and speech therapy led to further progress. She was teased and picked on in middle and high school (other students called her “tape recorder” because she repeated

things over and over). Grandin went on to university, ultimately obtaining a PhD in animal science from the University of Illinois.

Grandin has become an advocate for early intervention to treat autism; she believes that the fixations of autistic children can be redirected in productive directions. Like many autistic individuals, she calls what most of us think of as language (verbal communication) her “second language.” She describes herself as a visual thinker.

Grandin has become a world leader in the design of humane equipment for handling livestock. She notes that her own fears and sensitivities have made her more aware of how animals also can feel fearful and threatened.

Grandin acknowledges that emotional relationships with other people play no part in her life. She also has said that her autism affects every part of her life. Nevertheless, if a “cure” were available she would refuse it. Like Ari Ne'eman, she would not support a cure for the entire autism spectrum.

To Consider

Many people who were born deaf make a similar argument to the one some autistic people make: their deafness makes them different, not in need of a “cure.” They are content not to hear and are readily able to communicate without verbal language.

1. Does this attitude offer any indications on how society should approach those with ASD?
2. Are there other aspects to ASD that make it difficult to compare with deafness?
3. What is your personal view?

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Intolerance for Difference

Quote

"The effects of an ASD on a person's life vary for each individual on the spectrum. For some people with ASDs who are 'high functioning,' societal reactions to social 'differences' may be more disabling than any actual 'symptoms' or problems caused by ASD." — Autism Society Web site, "Approaches to Treatment & Education: Overview" (www.autismsocietycanada.ca/approaches_to_treatment/overview/index_e.html)

A major problem faced by almost everyone with Autism Spectrum Disorders is social intolerance.

It is an unfortunate truth that people who are different in some way from what is considered normal are often singled out. Sometimes we fear them; other times they can become objects of misplaced humour or ridicule.

Many autistic people and their parents can tell stories of how others have reacted negatively to their behaviour, either through ignorance or maliciousness. Parents encounter adults who accuse them of poor parenting because their autistic child, frustrated in an attempt to communicate, has a public tantrum. Children are often teased mercilessly by their peers because of their obsessive behaviours.

Sometimes negative reactions are the result of misunderstanding. A Newfoundland teenager recently spent a night in jail because he encountered police officers who mistook his autistic behaviour for public drunkenness.

The "Mental Illness" Label Factor

Complicating matters is the fact that autism is considered a mental disorder, and mental illness remains poorly understood and feared by society. Yet one in five Canadians will experience some form of mental illness in his or her lifetime. And mental illness can affect people of all ages, levels of education, or social and economic status.

For most people, mental illness is considered to be a stigma—a mark of disgrace or shame. Those who are mentally ill are stigmatized and valued negatively as individuals by society.

The Ontario branch of the Canadian Mental Health Association asks the

question "Why does stigma surround mental illness?" and answers it as follows (www.mentalhealthworks.ca/facts/sheets/stigma.asp):

"We all have an idea of what someone with a mental illness is like, but most of our views and interpretations have been distorted through strongly held social beliefs. The media, as a reflection of society, [have] done much to sustain a distorted view of mental illness. Television or movie characters who are aggressive, dangerous, and unpredictable can have their behaviour attributed to a mental illness. Mental illness also has not received the sensitive media coverage that other illnesses have been given. We are surrounded by stereotypes, popular movies talk about killers who are 'psychos,' and news [covers] mental illness only when it relates to violence. We also often hear the casual use of terms like *lunatic* or *crazy*, along with jokes about the mentally ill. These representations and the use of discriminatory language distort the public's view and reinforce inaccuracies about mental illness."

Being stigmatized because of mental illness can have a number of effects on an individual. Most significant is rejection or exclusion by one's community, because of fear, discomfort, or mistrust. The damage to self-esteem is considerable.

Fighting Labelling

As we saw in the "Rethinking Autism," section on page 54 some autistic people would like to see ASD considered a "neurodiversity"—a different way of being—rather than a mental illness. Currently, Autism Spectrum Disorders are listed among hundreds of other

disorders in the *Diagnostic and Statistical Manual of Mental Disorder* (DSM), published by the American Psychiatric Association (APA). First published in 1952 and frequently revised, this is the “bible” of mental illnesses for most North Americans who work in psychiatry and psychology. Many autistic people would like to see at least some of the Autistic Spectrum Disorders removed from the DSM.

Some groups have already had success in having “disorders” removed from the DSM. The gay and lesbian community is one of these. Until 1974, homosexuality

was listed as a category of disorder in the manual. A series of well-organized protests at APA conventions, combined with the publication of new research data, led the association to drop homosexuality as a listing in the DSM. It was replaced with a new category, now called gender identity disorder (GID). GID is used to describe people who have true discontent with the gender with which they were born.

While gays and lesbians continue to face a certain amount of social stigma, that stigma no longer includes the stigma of having a certified mental illness.

Inquiry

1. Would removing at least some Autistic Spectrum Disorders from the DSM lessen negative public perceptions of ASD? Why?

2. Is the removal of homosexuality from the DSM a good predictor of what would happen if ASD were also removed? Why or why not?

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IV *Activity: Drafting a School Policy*

Most schools or school boards have written policies that deal with and promote the inclusion of students with special needs. Your task is to create or amend such a policy for your school in order to assist students with Autism Spectrum Disorders (ASD).

If your school or board of education has a written policy for dealing with students with special needs, you will want to begin by reviewing it (it should be easy for your teacher to obtain copies for the class). It will also be helpful if you review the information provided in “The Autism Spectrum” on page 50 of this guide.

Your objective should be to produce a policy that integrates those students with ASD—or other neurological disorders—into the regular school system to the fullest extent possible.

In small groups (no larger than four students), begin by reviewing and assessing the existing policy. Does it meet the needs of autistic persons as described in the video and viewing guide? Why or why not? Are there changes or additions that need to be made? Be specific in your suggestions.

As you draw up a new policy, you will need to consider a variety of questions:

- Are there physical modifications that need to be made to school facilities?
- Are special seating arrangements required if ASD students are accompanied by an assistant or therapist? Should these assistants be welcome in every classroom?
- Will additional training and support be required for teachers with ASD students in their regular classrooms?
- Will a public awareness campaign be required to ensure the successful integration of ASD students into regular classrooms? Should this campaign be aimed at students alone, or must parents and the community be included?
- Are new policies required to ensure that ASD students are not subjected to teasing or bullying by their peers?
- Are there general school rules or regulations that will need to be modified for ASD students?
- Will these changes require additional funding?

In your discussion, you may well think of other questions and situations that your policy needs to address.

Once you have put together a written policy, choose one member of your group to present it to the entire class. Following the presentations, it will be useful to determine the common elements and put together a single policy summing up the class’s work. You may wish to share your findings with your school administration or school board.