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Parents for Children's Mental Health

Autistic Disorder in Children, Youth and Adults: Information for Families

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Summary: Autistic DIsorder is a condition where individuals have severe problems with language, communication and social interactions, and typically have problems with repetitive behaviours, as well as sensory processing problems.

This handout is specifically focused on Autistic Disorder (aka Autism, or Pervasive Developmental Disorder), which is one of the Autism Spectrum Disorders (ASDs).

For more information about 'high functioning' Asperger's Disorder or Pervasive Developmental Disorder Not Otherwise Specified (PDD NOS), please see our separate handout on those topics.

Introduction

A young boy plays hours on end busily lining up cars in perfect rows. A girl at school flaps her arms wildly whenever she gets excited. Another student constantly rocks back and forth. All of these children and youth have Autistic Disorder.

Autistic Disorder is a complex developmental condition that typically becomes apparent during the first few years of life, and affects a person's behaviour and ability to relate and socialize with other people.

Due to differences in how their brains develop, people with Autistic Disorder typically have:

- Problems with communication, such as significant delays in the developmment of speech, language and troubles understanding and using non-verbal communication. Problems with verbal communication may include the absence of speech. Problems with non-verbal communication include troubles understanding social cues, making eye contact, understanding gestures or tone of voice.

- Problems understanding social meaning and behaviours, which makes it very difficult for them to interact with other people. For example, troubles with perspective taking make it hard for them to see things from another person's perspective. On the severe end, many children with autism have no interest in other people. However, on the less severe end, a high functioning child with autism may be interested in peers, but simply not know how to relate to them.

- Repetitive motor movements such as hand flapping, rocking, or a limited range of interests, such as interest in parts of objects.

- Problems with change or transitions, which may lead them to become easily upset, overwhelmed or have tantrums with the smallest situations that don't go as they expect.

- Sensory processing problems, which are problems processing normal sensory input such as :
    - Sound (auditory) hypersensitivity, whereby they are easily upset or overwhelmed by noise
    - Touch (tactile) hypersensitivity, whereby they are easily upset by touch, e.g. food textures, tags or seams in clothing.

Terms

Commonly used terms include:

- Autistic Disorder or Autism or Pervasive Developmental Disorder (PDD): these terms are generally used interchangeably. Autistic Disorder is the official diagnostic term in the classification system known as the DSM-IV, widely used in North America.

- Autism spectrum disorder (ASD): refers to all of the autistic disorders including Autistic Disorder, Asperger's and Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS).

- High functioning autism: usually refers to Asperger's or PDD-NOS, because they are milder forms of autism spectrum disorders (ASD).

How Common is Autistic Disorder?

Autism Spectrum Disorder (including Autistic Disorder, along with Asperger's and PDD NOS and others) is one of the most common developmental disabilities with studies showing that it occurs in about 0.6% or approximately 1 in 165 children (Fombonne, 2006).

Of the Autism Spectrum Disorders, Autistic Disorder is the most common of all ASDs, followed by PDD-NOS, Asperger's, Rett's (extremely rare) and Childhood Disintegrative Disorder (extremely rare) (Fombonne, 2003).

What Causes Autistic Disorder?

It is felt that autistic spectrum disorders are due to a variety of numerous complex factors (including genetic and environmental causes), and not to any single one cause. It is generally accepted that ASD is a neurodevelopmental condition due to the child's brain functioning and being wired differently.

There is excellent evidence that ASDs are NOT caused by vaccines or mercury.

Interestingly, there appears be a significantly increased risk of having a child with autism if both parents are in a technical field such as engineering. There is a theory that having "just enough" autism traits may be helpful in our society, because it helps with technical fields such as engineering (Baron-Cohen, 2002). Such individuals are better able to deal with technology and objects, areas that have contributed greatly to our modern age.

Signs and Symptoms of Autistic Disorder

Children with autism may appear relatively normal early on, but usually by age 24-30 months, parents may notice differences or delays in various areas such as language, play or social interaction:

- Differences in language: Problems communicating may include no speech, or ability to make sounds, but no meaningful or intelligible speech.

- Differences in play: Lack of spontaneous or imaginative play; may not imitate others' actions; may not initiate pretend games.

- Differences in social interaction: Ranging from mild to severe abnormalities relating to people (e.g. showing no interest or awareness in other people).

- Adaptation to change: Ranging from mild to severe problems with change (having anger or tantrums with even the slightest changes in the routine or the environment)

Lack of eye contact and use of gestures such as pointing at objects are particularly important early signs for parents to be aware of.

Overall, people with autism tend to have difficulties in these following areas:

- Theory of Mind: People with autistic disorder have difficulties seeing things from other people's perspectives.

- Communication skills:
    - Troubles communicating with others and relating to the outside world
    - Language develops slowly or not at all
    - May use words, but without attaching the usual meaning to them
    - Social interaction and communication:
    - With more severe autism: may have no interest at all in other people, preferring to spend time with objects.
    - With more higher functioning autism, may be interested in people, but does not know how to talk, play with, or relate to them. Initiating and maintaining a conversation is usually difficult.

- Social interaction:
    - Including difficulties playing or interacting with others, and may have unusual responses to people, or attachments to objects
    - Troubles interpreting non-verbal communication such as social cues, respecting other people's personal space, or the use of gestures and facial cues, like smiles, that most of us take for granted.

- Rigidity and inflexibility: Extreme difficulties with transitions or changes in routines, to the point where it may appear the child has an obsessive need to keep everything the same.

- Restricted interests: may focus obsessively on only one thing, idea, or activity.

- Sensory Impairment: may be easily overwhelmed by senses such as sound, touch, and smells due to having ‘sensory hypersensitivities'.
    - Examples include:
        - Visual hypersensitivity: difficulties with eye contact, and may use peripheral vision rather than looking directly at other people.
        - Touch hypersensitivity: become distressed with tags on their clothes, having their face or hair washed.
        - Food/texture sensitivity: this is a type of touch hypersensitivity, where they may have troubles with soft, mushy foods or foods with mixtures of things such as stews. Conversely, they may prefer crunchy, chewy foods.
        - Sound hypersensitivity: become extremely distressed when there is a lot of noise, e.g. classrooms, school buses, parties, shopping malls, movie theatres.
    - On the other hand, they may seek out sensory stimulation, e.g. flapping their hands or rocking back and forth, spinning, hitting oneself or head banging.

- Autism may affect their range of responses and make it more difficult to control how their bodies and minds react.

- Difficult behaviours such as aggressive and/or self-injurious behaviour may be present.

How is Autistic Disorder Diagnosed?

Autism is diagnosed by seeing a professional such as a psychiatrist or psychologist with expertise in this area. There is no blood test or lab test that can be done to see if someone has autism or not.

Official Diagnostic Criteria

The following are the official diagnostic criteria for Autistic Disorder from the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV):

A. A total of six (or more) items from (1), (2), and (3), with at least two from (1), and one each from (2) and (3)

1. Qualitative impairment in social interaction, as manifested by at least two of the following:

   a) marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction
   b) failure to develop peer relationships appropriate to developmental level
   c) a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest)
   d) lack of social or emotional reciprocity

2. Qualitative impairments in communication as manifested by at least one of the following:

   a) delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime)
   b) in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others
   c) stereotyped and repetitive use of language or idiosyncratic language
   d) lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level

3. Restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:

   a) encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
   b) apparently inflexible adherence to specific, nonfunctional routines or rituals stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements)
   c) persistent preoccupation with parts of objects

B. Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years: (1) social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play.

C. The disturbance is not better accounted for by Rett's Disorder or Childhood Disintegrative Disorder.

Other Conditions that May Occur Along with Autistic Disorder

Individuals with autism may have other brain conditions as well, such as mental retardation, seizure disorders, Down Syndrome and Tourette's Disorder. Many of those diagnosed with autism will test in the range of mental retardation.

Strengths of Autism

Despite the difficulties, there are many notable examples of people with autism being geniuses in specific areas, such as: having a photographic memory for anything that see or read; being ‘human calculators' with the ability to solve complex mathematical problems as well as skills at music and art/drawing.

Although the typical person with autism does not have such extraordinary talents, they nonetheless often have abilities such as:

- Be very good with mechnical objects and technology.
- Ability to think visually and in pictures
- Easily memorize facts
- Have extraordinarily good long-term memory
- Exceptional attention to detail
- Being perfectionistic
- Being very focused on tasks
- Being very good at understanding rules / sequences

Finally, perhaps one of the biggest strengths of individuals with autism disorders is their tendency to be always honest and genuine. Whereas a neurotypical child will often tell a lie to avoid getting into trouble, parents of children with autism will talk about how these children always tell the truth, even if it means they will get into trouble. Indeed, in the modern world we live in, the world would be a better place if more people could share the same sense of honesty.

Prognosis

Early intervention is key, meaning that the earlier the interventions are started, the more effective they will be. If you suspect that your child may have Autistic Disorder, do not delay; have your child seen by a family physician or paediatrician.

Treatments for Autistic Disorder

There is no one single treatment for Autistic Disorder. A comprehensive treatment plan may include some combination of the following:

Various types of therapies are available, including (but not limited to):

- Medications: Although medications do not "cure" autism, medications can be useful for specific issues such as sleep, anxiety, depression, attention problems, and impulsivity. Medications are prescribed by seeing a family physician, paediatrician or psychiatrist.

- Applied behaviour analysis (ABA): ABA is a well researched intervention that appears to help many individuals with autism. 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, improve and retain others. Using a process called "discrete trials," each skill is broken down into manageable steps and each step is taught using positive reinforcement and then chained with the other steps until an entire skill is learned. After some time, opportunities are provided to apply learned skills to more complex situations and in new settings and environments. In this way, basic skills such as learning to point at a picture and say a word, or more complex skills such as interacting with others, can be mastered.

There are many other methods and interventions for autism, though few with the same level of evidence that ABA has. Components of many of these methods are integrated into some ABA programs. These other methods and interventions include:

- Treatment and Education of Autistic and Related Communication Handicapped Children (TEACCH), which tries to structure the learning environment to the child with autism, as opposed to the other way around.

- Floor Time/Developmental, Individual Difference, Relationship (DIR) model, which targets the core problem with social relatedness through a variety of interventions such as floor-time play sessions to address sensory-motor, language and social problems.

- Visual supports (such as Picture Exchange Communication Systems (PECS)), which is a way of using pictures to communicate concepts with an autistic child.

- Social stories, which is a way of teaching social skills through the use of stories.

- Sensory processing interventions, which addresses sensory issues such as sensitivities to sound and touch, ideally through working with an occupational therapist.

- Speech/language therapy to improve speech and language skills, ideally working with a speech-language therapist.

Because there are constant innovations in the field of autism, readers are advised to consult websites such as the Canadian Autism Intervention Research Network (CAIRN) [link: www.cairn-site.com] for the most up-to-date information about treatment.

School Intervention

Most children with autistic disorder cannot be simply placed in the regular class and school environment like other children. Making the school aware of the diagnosis of Autistic Disorder so that the school can implement an individualized education plan (IEP).

Individuals with autism respond well to a highly structured, individually tailored specialized education program that includes:

- Social skill development,
- Communication therapy: professionals like speech-language pathologists (SLP) may help with this.
- Strategies for dealing with sensory processing issues: Occupational Therapists (OT) can help the child deal with sensory processing problems.
- Use of visual supports, such as visual schedules
- Having a highly structured schedule of activities
- Parent and staff training in how to work with students with autism

Educational support may range from least intensive to more intensive services:

- Regular classroom placement (Inclusion)
    - A child stays in a regular classroom, but has an individualized education plan (IEP) to meet the ocial, academic and behavioural needs of the child.
    - Adding additional in-classroom support such as an educational assistant (EA) or student support worker (SSW) to work with the student
    - Involving the child in specialized social skills classes or other skills learning

- Special education placement (Non-inclusion)
    - With a more severely challenged student with Autistic Disorder that cannot function in a regular classroom, it is best to place the student in a more structured education and behaviour program (such as an autism class if available).

In addition to help with academics and the standard school curriculum, students with autism should also have explicit training in the "hidden curriculum" such as social interactions and social cues, as well as functional living skills.

Children with autism need to be explicitly taught life skills. For example: learning to cross a street safely; how to make a simple purchase; asking for help when needed. Skills that can help the student be more independent and have more personal choice and freedom in the community are important.

To be effective, any approach should:

- Be flexible in nature
- Rely on positive (rather than negative) reinforcement
- Be regularly evaluated on a regular basis and provide a smooth transition from home to school to community environments

- Provide training and support systems for parents and caregivers, with generalization of skills to all settings.

Housing/Living Situation

A generation ago, most people with Autistic Disorder were eventually placed in institutions. Nowadays, the situation is improved. With appropriate services, such as day programs and special needs workers and other supports, many families are able to support their child with autistic disorder at home. Other options include specialized group homes, and assisted living arrangements.

Is there a Cure?

Autism is lifelong. Unlike other conditions like having an infection (for which you can simply take an antibiotic and get cured), there is no "cure" for autism spectrum disorders, as there is no way of "fixing" the brain differences which result in autism. However, finding out early that a child has autism does allow for families and schools to better help the child, as opposed to simply ‘blaming the child' (or family) for the problems, as happened in the past. With early, intensive supports, many symptoms may lessen as the child grows, and some may even disappear entirely. Nonetheless, most children and adults with autism will continue to have some degree of autism throughout their lives.

References

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For More Information

Canadian Autism Intervention Research Network (CAIRN), www.cairn-site.com

Autism Society Canada, www.autismsocietycanada.ca

About this Document

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