



*Canadian Psychiatric
Research Foundation*

When Something's Wr ng

0

Ideas for Families

Autism and Autism Spectrum Disorders

A young boy with curly hair is looking directly at the camera. The image is overlaid with a semi-transparent pink filter. The text is centered over the image.

Autism and Autism Spectrum Disorders

Autism or Autism Spectrum Disorders are brain disturbances that are more commonly being diagnosed. They appear about four times more often in boys than girls. They usually show up before the age of three, and, with no known environmental influence, occur throughout the world in families of all ethnic, racial and social backgrounds. There appears to be a genetic component, with about a fourfold increased risk of autism in siblings of children who have the disorder.

Autism is associated with a fault in the way the brain processes information. It regularly leads to an inability to develop normal communication and language skills. So, children with autism often fail to develop useful speech, and those who do develop it have trouble starting and keeping up conversations. Some do have distinct skills in certain areas, such as music or mathematics, but most have substantial difficulties with social interaction, verbal and non-verbal communication, and behaviour.

Autism belongs to a group of related disorders called Autism Spectrum Disorders (ASD), including Asperger Syndrome and the rare

disorders in the group, Rett Syndrome and Childhood Disintegrative Disorder. Asperger Syndrome is characterized by difficulties similar to autism, but children with this disorder are normally higher functioning, and symptoms may not appear until school age or later, although their social impairment may be significant. If a child has symptoms of autism or Asperger Syndrome, but does not meet the specific criteria for either, the diagnosis is called Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS).

Early and accurate screening and diagnosis are extremely important when dealing with all autism spectrum disorders. Many children with autism and disorders in the spectrum are able to learn, especially if early diagnosis and intervention take place during the pre-school years.

Behaviour Characteristics

There are many differences among children with autism and autism spectrum disorders, so the behaviour characteristics vary widely in terms of their degree and frequency. Characteristics include:

- Underdevelopment or lack of communication skills needed for social interaction and learning
- Repetitive or inappropriate use of language
- Lack of interest in activities and relationships with others, including peers; little or no eye contact; and, in extreme cases, complete withdrawal
- Lack of empathy and awareness of the needs and perspectives of others
- Compulsive behaviours, such as fixations or repetitive body movements, and inflexible attachment to rituals or routines
- Short attention span and inability to focus on a task
- Activities and play, if any, are rigid, repetitive, and monotonous; often cannot imitate the play of other children
- Toileting and sleeping difficulties

Coping Strategies

- **Early intervention** is key to managing the disorder and preventing further disability.
- **Get help** from a qualified health practitioner, including a professional diagnosis. An accurate diagnosis will help to prevent any incorrect “labeling” of your child by others.
- **Obtain** a second opinion if possible.
- **Find** a support group for both you and your child, and exchange strategies.
- **Learn** all you can about the disorder and educate your family and your child about the disorder.
- **Don’t compare** your child to siblings or other children. Treat your child as a unique individual.
- **Re-evaluate** and modify strategies as necessary. Work closely with your child’s teacher, doctor, and school team.
- **See** *Managing Problem Behaviour in Children, Working with Your Health Practitioner, and Resources* in this handbook for more information.

Behaviour Characteristics

- Lack of reaction, or over-reaction to things going on around them – children with autism may be so unaware of pain that they can hurt themselves and not respond; they also need more time than others to shift between auditory and visual stimuli
- Excessive anxiety and problems with self-control, which can lead to temper tantrums, or possibly even aggression or self-injury
- Seizures, which may sometimes develop in late childhood or adolescence
- Possibly, the presence of special abilities

Coping Strategies

- Reviewing family videotapes, photos, and baby albums can help you remember when each behaviour was first noticed, and can help your health practitioner(s) (e.g., psychologist, neurologist, psychiatrist, physiotherapist, and speech-language pathologist) in the screening and diagnosis of your child.
- It is going to be difficult to learn and remember everything you need to know about the resources that will be most helpful. Write down everything. If you keep a notebook, you will have a way of recalling information. Keep a record of all health practitioner reports and evaluations your child has been given so that his/her eligibility for special programs will be documented.
- Research and understand what services are offered in your province and community for children diagnosed with an autism spectrum disorder. Services will vary, so don't be afraid to ask lots of questions.

Coping Strategies

- Provide as much structure as possible for your child. Try to tailor your child's structured activities to the development of the skills they need most, such as language and social skills. Work closely with your child's teacher(s) and the health practitioners on your team. Consistency is important.
- Whenever you ask your child to do anything, give clear, concrete instructions, repeat them often, and use visual cues (e.g., show pictures of what you want him/her to do).
- Break each activity into units and allow your child to practice it over and over until he/she has mastered it in a variety of meaningful situations (e.g., calling a close relative/friend on the phone, role-playing an activity, watching a whole TV program and then discussing it, putting a puzzle together, threading beads on a string).
- Reward and praise your child for each small step or effort that he/she makes to master a skill or activity (e.g., child points to a cookie jar and says "cookie" and then is rewarded with the cookie – best if the reward is directly related to the behaviour).

Coping Strategies

- Look for activities your child is good at and encourage these activities. Try not to always focus on those activities that are difficult for your child.
- Write “social stories” from the point of view of your child, to help him/her cope with social, learning and behavioural challenges. In these stories, include a description of the situation (e.g., riding on the bus, waiting in the lunch line in school, greeting unfamiliar people) and the desired positive response (e.g., “I can try___,” “I will try to remember to ___,” “I am proud of myself when ___”).
- Involve your child in all the normal routines of life wherever possible. Routine and structure can help reduce your child’s anxiety and behaviour problems. Prepare your child ahead of time if any routine is going to change.
- Create “Things To Do” lists or charts for daily or weekly routines so your child can see his/her progress visually.
- Prepare your child for each transition (e.g., “We are going to be doing this activity for another five minutes, and then we are going to put the ball away.”).

Coping Strategies

- Ensure your child has appropriate supervision for transitions (e.g., recess, lunch, to and from school, other outings).
- Be aware of your child's safety. Children with autism may hurt themselves, especially when they are more anxious (e.g., during transitions).
- Collaborate with your child's teacher to develop a behaviour management program.
- Be aware that controversial or non-traditional interventions are often suggested for children with autism. Speak to your child's health care team about the relevance of any intervention recommended.
- Children with autism often suffer the added stress of teasing, rejection, and even bullying from peers. Encourage your child to talk about the disorder with classmates, friends and family, and thereby increase acceptance of it. If your child agrees, even a presentation to his/her class or school might help. Determine the best approach with the teacher and with your child to create awareness and understanding of your child's disorder.

Coping Strategies

- Research has shown that parent involvement in treatment is a major factor in treatment success. More and more programs are beginning to train parents to continue therapy at home. Ask about programs in your area.

Autism and Autism
Spectrum Disorders

Autism and Autism Spectrum Disorders: Treatment and Resources

TREATMENT

Although in many cases symptoms of autism and other autism spectrum disorders may decrease or change, they tend to be chronic over the child's life. Therefore, the focus needs to be on encouraging the highest level of development possible, given the limitations, and on preparing for and facilitating as much independence as possible for adulthood.

A supportive environment and a multi-faceted educational and behavioural approach that is tailored to the needs and abilities of the individual seem to produce the best results. Your own observations and concerns about your child's development will be essential in supporting the treatment of your child. An effective treatment program will build on your child's interests, offer a predictable schedule, teach tasks as a series of simple steps, actively engage your child's attention in highly structured activities, and provide regular reinforcement of behaviour. In some cases, carefully monitored medication – to alleviate specific symptoms only – can be helpful.

More specifically, language and social skills may, in some children with autism spectrum disorders, be greatly improved through early intensive speech language therapy and behavioural intervention – about 20 to 40 hours a week for two years, prior to age six. Research over the last 15 years indicates that such intensive early intervention has improved outcomes in most young children with an autism spectrum disorder.

Supportive counselling often helps families to cope with the physical and emotional demands of caring for a child with this disorder.

RESOURCES

Autism Society Canada

P.O. Box 65

Orangeville, ON L9W 2Z5

Phone: (519) 942-8720

Toll Free: 1-866-874-3334

Web: www.autismsocietycanada.ca

(See the “Other Resources” section of the Web site for a good list of additional information sources)

Canadian Autism Intervention Research Network

The Offord Centre for Child Studies, Faculty of Health Sciences, McMaster University, 107 Patterson Building, Chedoke Site

1200 Main Street West

Hamilton, ON L8N 3Z5

Web: www.cairn-site.com

Center for the Study of Autism

Informational Web Site: www.autism.org

The Gray Center for Social Learning and Understanding

2020 Raybrook S.E., Suite 302

Grand Rapids, MI 49546

Phone: (616) 954-9747

E-mail: info@thegraycenter.org

Web: www.thegraycenter.org

(Good “social stories” section)

Yale Child Study Center

Developmental Disabilities Clinic

Web: info.med.yale.edu/chldstudy/autism

(Good list of additional information sources and answers to frequently asked questions)

Please also see *Resources* in the back of this handbook.



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ISBN 0-9734947-1-9