

THE
AUTISM PARENT
RESOURCE KIT

TABLE OF CONTENTS

The Autism Parent Resource Kit	3
1.2. Ontario Autism Programs	3
1.3. Regional Offices	5
1.4. How this kit is Organized	6
1.6. Commonly Cited Organizations	6
1.7. Creating a Binder to Stay Organized	7

PARENT RESOURCES

<u>ASD Diagnosis and Treatment</u>	8	<u>Social Development</u>	70
Introduction	8	Introduction	70
Topics Covered	9	Topics Covered	71
Individual Topics	9	Individual Topics	71
Learn More	17	Learn More	76
<u>Everyday Living</u>	20	<u>Emotional and Mental Health</u>	79
Introduction	20	Introduction	79
Topics Covered	21	Topics Covered	80
Individual Topics	21	Individual Topics	80
Learn More	27	Learn More	84
<u>Common Transitions</u>	29	<u>Encouraging Your Child</u>	85
Introduction	29	Introduction	85
Topics Covered	30	Topics Covered	86
Individual Topics	30	Individual Topics	86
Learn More	35	Learn More	87
<u>Educational Transitions</u>	36	<u>Health Care</u>	88
Introduction	36	Introduction	88
Topics Covered	37	Topics Covered	89
Topics Top	37	Individual Topics	89
Learn More	47	Learn More	91
<u>Family Transitions</u>	51	<u>Family Support</u>	92
Introduction	51	Introduction	92
Topics Covered	52	Topics Covered	93
Individual Topics	52	Individual Topics	93
Learn More	56	Learn More	98
<u>Sensory Development</u>	57	<u>ASD Research</u>	100
Introduction	57	Introduction	100
Topics Covered	58	Topics Covered	101
Individual Topics	58	Individual Topics	101
Learn More	62	Learn More	103
<u>Physiological Development</u>	63	<u>Glossary of Terms and Organizations</u>	104
Introduction	63	<u>References Organizations</u>	106
Topics Covered	64		
Individual Topics	64		
Learn More	68		

THE AUTISM PARENT RESOURCE KIT

The goals for this Parent Resource Kit are:

- 1) To increase the understanding of parents and caregivers of children with autism spectrum disorder (ASD) and the range of programs and supports available across Ontario.
- 2) To increase the capacities of parents and families to support their child's development by helping them plan for and access needed programs and supports by directing them to useful and credible resources, information, and supports across the province.
- 3) To provide the above assistance through a parent-centered perspective and help parents know they are not alone, through the voices of other parents, autism service providers, educators, health care providers, researchers, and other professionals.

No kit will ever be a completely exhaustive resource, and the autism sector in Ontario and around the world has already developed many excellent tools and resources that can be of immediate use to parents of children with ASD. By compiling and directing parents to many of those resources, this Parent Resource Kit will fill a need in the sector that has not yet been met to date. At the same time, this kit is not meant to be the last word on any of the issues or challenges parents may encounter. It is a beginning, not an end.

ONTARIO AUTISM PROGRAMS

The Ministry of Children and Youth Services (MCYS) provides a range of services and supports for children and youth with ASD. These services provide various supports for young people to meet their needs at every stage of development from the time of diagnosis, right through their school years. These programs and services funded and/or provided by the Ministry include:

- **Autism Intervention Program**
- **Applied Behaviour Analysis (ABA)-Based Services and Supports**
- **Connections for Students**
- **School Support Program**
- **ASD Summer Camp**
- **March Break Camp**
- **ASD Respite Services**
- **Potential Programme**
- **Transitions Supports**

Autism Intervention Program (AIP)

The Ministry of Children and Youth provides funding for the Autism Intervention Program (AIP). The Autism Intervention Program provides Intensive Behavioural Intervention (IBI) for children and youth who have a diagnosis (from a physician or psychologist) towards the severe end of the autism spectrum.¹

All families of children who meet the eligibility requirements for the program will be offered support services while waiting for IBI to start. This will focus on preparing the child for IBI, to promoting skill development, and encouraging integration into small groups. Building on the best practices that already exist across the province, these services promote positive outcomes and may include the following:

- **Overview on autism:** providing parents with a general overview of autism and related developmental delays and disorders; helping build an understanding of effective interventions and other approaches;
- **Behavioural principles and techniques:** basic information on theory supporting behavioural techniques; principles of reinforcement; effective reinforcement strategies; strategies for more easily teaching children how to complete tasks; handling problematic behaviour; promoting social interaction and communication.

More information on the Autism Intervention Program is located under the Gaining Access to Services heading in the '[ASD Diagnosis and Treatment](#)' Section of this Parent Resource Kit. You can also visit the Ministry of Children and Youth Services' website. <http://www.children.gov.on.ca>

Applied Behaviour Analysis (ABA)-Based Services and Supports

The Ministry of Children and Youth Services provides funding for Applied Behaviour Analysis (ABA)-based services and supports.

ABA-based services and supports provide time-limited skill building services to all children and youth with ASD to improve communication, social and interpersonal, daily living, and behavioural/ emotional skills, with relevant parent support. Funding is provided to agencies located throughout the province to provide services on behalf of the Ministry.

All children and youth with a diagnosis of ASD are eligible to receive these services up to their 18th birthday, including those who are on the waitlist for the Autism Intervention Program or who have completed Intensive Behavioural Intervention.

More information on ABA-based services and supports is located under the Interventions heading in the '[ASD Diagnosis and Treatment](#)' Section of this kit. You can also visit the Ministry of Children and Youth Services' website. <http://www.children.gov.on.ca>

Connections for Students

Connections for Students supports children leaving the Autism Intervention Program and starting or continuing in the publicly funded school system. A transition team made up of educational and teaching professionals, expert(s) in ABA and ASD, other service providers as needed, and parents is established at least 6 months before the child leaving the Autism Intervention Program. This team continues to support and provide assistance to the child for at least 6 months following their exit from the Autism Intervention Program.

More information on the Connections for Students program is located under the Connections for Students heading in the 'Educational Transitions' Section of this kit.

School Support Program

Through the School Support Program, Autism Spectrum Disorder (ASD) consultants provide a variety of consulting services within school boards and schools that assist educators to better understand how children and youth with ASD learn and how the principles of Applied Behaviour Analysis can be used to help improve their learning. Children and youth with autism can face particular challenges during their school years. Teachers and other educators can play a critical role in helping them succeed at school. This

program connects school boards with Autism Spectrum Disorder consultants to help school staff support the learning and social needs of students with autism.

The Autism Spectrum Disorder consultants:

- Provide training and instructional workshops to principals, teachers, teaching assistants and other educational support staff
- Consult with individual educators regarding student specific outcomes
- Provide in-school consultations
- Attend school team meetings
- Identify other community supports available to teachers, students, and families
- Participate as members of the Connections for Students teams

More information on the School Support Program is located under the School Support Program heading in the [‘Educational Transitions’](#) Section of this kit. You can also talk to your school principal, your school board, regional autism service provider, or visit the Ministry of Children and Youth Services’ website <http://www.children.gov.on.ca>

ASD Summer Camps

Summer camps allow children/youth with ASD to maintain and generalize the skills learned during the school year, promotes social development through peer interaction and provides respite for families. Parents can access Summer Camp programs through contacting their local Ministry of Children and Youth Services regional office or through their local Autism Ontario Chapter.

More information on Summer Camp programs is located under the Camp Programs heading in the [‘Common Transitions’](#) Section of this kit. You can also talk to your school principal, your school board, regional autism service provider or visit the Ministry of Children and Youth Services’ website <http://www.children.gov.on.ca>

March Break Camps

Ontario provides ongoing funding for March Break camps so children and youth with ASD can have the opportunity to benefit from this unique learning experience. This support is available to Ontario families who either retain the services of a one-to-one support worker or pay for a March break camp/program.

More information on March Break Camp programs is located under the Camp Programs heading in the [‘Common Transitions’](#) Section of this Parent Resource Kit. You can also visit Autism Ontario’s website <http://www.autismontario.ca>

ASD Respite Services

ASD Respite Services provide temporary relief for families from the stress of caring for a child or youth with ASD. More information on Respite Services is located under the New Caregiver/Babysitter heading in the [‘Common Transitions’](#) Section and under the Respite Care heading in the [‘Family Support’](#) Section of this Parent Resource Kit. You can also visit Autism Ontario’s website <http://www.autismontario.ca> or <http://www.respiteservices.com>

Potential Programme

Funded by the Ministry of Children and Youth Services and delivered by Autism Ontario to directly support families, parents, and children with ASD. The program works to increase greater access

to ASD experts in their communities, and to provide a supportive community-based learning opportunities for children with ASD.

The Potential Programme can provide families with:

- Assistance to help connect to resources in their community, provide them with support in establishing community partnerships and developing family support plans
- Access to expert speakers and workshops related to Autism Spectrum Disorder
- Social skills groups, family support groups, and community events
- A library of resources, materials and computer software that can be used in chapter offices

More information on the Potential Programme is located under the Post-Diagnosis heading in the [‘ASD Diagnosis and Treatment’](#) Section of this kit. You can also visit Autism Ontario’s website <http://www.autismontario.ca>.

Transition Supports

Transition Supports for Adolescents provide crisis intervention, behavioural supports and skill-based training. These supports are available for all children and youth with ASD across the province.

REGIONAL OFFICES

The Ministry of Children and Youth Services operates in 5 regions. For services and supports available in your area, contact the office nearest you.

CENTRAL

6733 Mississauga Road, Suite 200
Mississauga, Ontario L5N 6J5
Tel.: (905) 567-7177
Fax: (905) 567-3215
Toll Free: 1-877-832-2818

17310 Yonge Street
Newmarket, Ontario L3Y 7R8
Tel.: (905) 868-8900
Fax: (905) 895-4330
Toll Free: 1-877-669-6658
TTY: (905) 715-7759

WEST

217 York Street, Suite 203
P.O. Box 5217
London, Ontario N6A 5R1
Tel.: (519) 438-5111
Fax: (519) 672-9510
Toll Free: 1-800-265-4197
TTY: (519) 663-5276

119 King Street West
Hamilton, Ontario L8P 4Y7
Tel.: (905) 521-7280
Fax: (905) 546-8277
Toll Free: 1-866-221-2229
TTY: (905) 546-8276

EAST

347 Preston Street, 3rd Floor
Ottawa, Ontario K1S 3H8
Tel.: 1-613-234-1188
Fax: 613-783-5958
Toll Free: 1-800-267-5111

11 Beechgrove Lane
Kingston, Ontario K7M 9A6
Tel.: (613) 545-0539
Fax: (613) 536-7272
Toll Free: 1-800-646-3209
TTY: (613) 536-7304

NORTH

199 Larch Street, 10th Floor
Suite 1002
Sudbury, Ontario P3E 5P9
Tel.: (705) 564-6699
Fax: (705) 564-3099
Toll Free: 1-800-265-1222
TTY: (705) 564-3233

621 Main Street West
North Bay, Ontario P1B 2V6
Tel.: (705) 474-3540
Fax: (705) 474-5815
Toll Free: 1-800-461-6977
TTY: (705) 474-7665

TORONTO

375 University Avenue
5th Floor
Toronto, Ontario
M7A 1G1
Tel: (416) 325-0500
Fax: (416) 325-0565
TTY: (416) 325-3600

HOW THE PARENT RESOURCE KIT IS ORGANIZED

Overall

This kit is designed to act as a starting point or gateway to help parents of children with ASD find useful and credible resources. Therefore, this kit is organized according to parents' potential information needs at key phases and transitions of a child's life. Each section of the kit addresses a particular set of issues and transitions parents may encounter. For instance, the first section addresses ASD diagnosis and treatment from the point of a parent's first suspicion onwards. The second section addresses Everyday Living and the transitions that parents of children with ASD often encounter on a day-to-day basis.

Individual Sections

Each section of the kit has the following parts:

- **Introduction** – An introduction to the section, some of the key issues it identifies, and why they are important.
- **Topics Covered** – A list of topics covered in the section.
- **Individual Topics** – A short discussion of each topic.
- **Learn More** – A list of resources and available tools to help you support your child in a variety of contexts.

HOW TO USE THIS KIT

There is no one right way to use the kit as each child is unique and parents/caregivers will have varying information and resource needs at different phases of their child's life. As such, this kit takes the view that, "If you've met one child with autism, you've met one child with autism," and therefore, not everything in this kit will be useful to every parent, or useful in the same way. Depending on your needs, you may wish to:

- **Read the entire document** – To get a broad picture of the issues you may encounter and the programs and supports available to you.
- **Read a section** – If you have encountered a particular issue or set of issues, you may wish to read just that section to learn more and find appropriate resources.
- **Read about a topic** – You may have encountered one very specific issue and want to quickly learn more about it. In this case, you may wish to look for the topic in the index at the back of this document, which will direct you to the relevant page(s).

COMMONLY CITED ORGANIZATIONS

The delivery of programs, services and supports for children with ASD and their parents, and research into new therapies, involves many organizations throughout Ontario. The list below is not an exhaustive list of ASD-related organizations in Ontario, but it contains some of the more frequently cited organizations within this kit. All are accessible to individuals across Ontario, either physically or electronically.

ORGANIZATION	WEBSITE
Ministry of Children and Youth Services	www.children.gov.on.ca
Ministry of Education	www.edu.gov.on.ca
Ministry of Community and Social Services	www.mcscs.gov.on.ca
Ministry of Health and Long-Term Care	www.health.gov.on.ca
Ministry of Training, Colleges and Universities	www.tcu.gov.on.ca
Health Canada	www.hc-sc.gc.ca/
Canada Revenue Agency	www.cra-arc.gc.ca/disability/
Asperger's Society of Ontario	www.aspergers.ca
Autism Ontario	www.autismontario.com
Autism Society of Canada	www.autismsocietycanada.ca
Autism Speaks Canada	www.autismspeaks.ca
Regional Autism Providers of Ontario	www.rapon.ca
ABACUS	www.abacuslist.ca
SPIRALE	www.autismontario.com/spirale
CALYPSO	www.autismontario.com/calypso
The National Autistic Society (UK)	www.autism.org.uk
Monash University	www.med.monash.edu.au
The Geneva Centre for Autism	www.autism.net
Kerry's Place Autism Services	www.kerrysplace.org

CREATING A BINDER TO STAY ORGANIZED

If you're like most parents, staying organized amidst the often chaotic atmosphere of daily family life can be difficult. This can be problematic when you need to find your child's medical or education records, government-issued documents, or simply recall the day's activities and appointments. For the parents of a child with ASD, the pure volume of paperwork and number of appointments and contact information for various specialists can be overwhelming and leave you asking how you will keep everything straight and prevent something from 'slipping through the cracks.'

Throughout this Parent Resource Kit there are multiple suggestions to create a binder to help you stay organized and store critical information. Some parents who use binders to stay organized create a single binder with sections for critical information, others divide information between multiple binders (education, health care, etc.), while others still create binders that contain tools and templates (such as visual schedules) for a wide range of daily activities. How you decide to stay organized will depend on your personality, what works well for you, and the level of planning you need to do for your child's needs.

In general, you may want to start by using a large folder, binder or filing system to store the following types of information as your child grows:

- A critical information section that includes a profile of your child and recent pictures
- Copies of all government-issued identification: birth certificate, Ontario Health Insurance Card (OHIP card), passport, etc.
- Medical information: diagnosis details (including who made a diagnosis and the date it was made), medications (who prescribed them and when, dosages), details on any surgeries or hospitalizations
- Education information: copies of your child's Individual Education Plan (IEP) and any assessments/progress reports
- Contact information for: medical providers, therapy providers, financial planner, lawyer, school principal, and school board
- Your current schedule: therapy appointments, extracurricular activities, etc.
- Financial and legal information: banking and other account information including numbers, records of debts or regular bills, insurance policies, copy of your will, tax returns, and space to store information to claim tax deductions/benefits, passwords associated with online accounts.

For privacy and security reasons, you may wish to store financial and legal information separately in a safe place.

There are a number of websites and parenting magazines that can be helpful for creating a parenting "binder." Autism Ontario's Knowledge Base website also contains some suggestions on what you may want to include in the file, folder or binder. Finally, you can also speak with other parents of children with ASD to help you make sure you don't miss anything.



ASD DIAGNOSIS AND TREATMENT

Introduction

Suspecting or learning that your child has ASD or another developmental disability can be a difficult, unsettling, and sad experience. It is common for concerns and questions to race through your mind, and parents can struggle to find accurate information and supportive resources at this critical time. There is so much to learn, and it can be hard to know whether you can trust certain sources of information, what the terminology you encounter means, and who you can turn to for help.

THIS SECTION PROVIDES AN OVERVIEW OF ASD AND WILL HELP YOU to discover some of the resources and supports available in Ontario. At this stage, it is important to recognize that you

♥ *do not* need to become an expert on ASD

but you will find it helpful if you

♥ begin to develop expertise about your own child's specific diagnosis, circumstances, and needs.

Why is it important that you become an expert on your own child? Because you know your child best, and you will be your child's voice, advocate, and kit in the years to come.

Topics Covered

This section contains information you may find useful if you suspect your child may have ASD, or if your child has been recently diagnosed with ASD. Depending on whether you are concerned about certain aspects of your child's development, are awaiting a diagnosis or have recently received an ASD diagnosis for your child, you will have very specific information needs. This section is an entry point to the available information on ASD and includes the following topics:

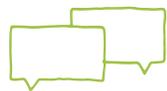
- ♥ What is ASD?
- ♥ Pre-diagnosis
- ♥ Diagnosis
- ♥ Post-diagnosis
- ♥ Determining services needed/navigating multiple systems
- ♥ Dual diagnosis
- ♥ Medications and responses
- ♥ Learning about ASD and your own child's specific characteristics
- ♥ Interventions
- ♥ Gaining access to services

WHAT IS ASD?

Autism Spectrum Disorder (ASD) refers to a group of complex developmental brain disorders that affect the way the brain works. People with ASD experience difficulties in three areas:²



SOCIAL INTERACTION



LANGUAGE AND COMMUNICATION



STRONG INTERESTS AND REPETITIVE BEHAVIOURS

ASD is a lifelong disability, with symptoms usually appearing at an early age. While there is no cure for ASD, people's symptoms, abilities, and experiences can improve over time with the help of evidence-based therapies and interventions.³

What causes ASD?

While the exact cause of ASD is still unknown, researchers have linked ASD to biological or neurological differences in the brain.⁴ There may be a physical cause that affects the development of parts of the brain.

There are many theories as to why this might happen. Theories include genetics, viruses, poor immune system, chromosome abnormalities, and pollutants.

We do know that autism is not caused by the way a child is raised. The best evidence to date also indicates that ASD is not the result of infections, contagions, or vaccines.⁵ Misconceptions exist about a link between vaccines and ASD. The reality is that vaccines are among the safest medical products available and no vaccine, including the MMR (measles, mumps and rubella) vaccine, is responsible for causing ASD.⁶ Nor is thimerosal (a preservative used in some vaccines) linked to autism or any other neurodevelopmental disorder. This is a finding supported by the Canadian National Advisory Committee on Immunization and shared by international bodies including the World Health Organization, US Food and Drug Administration and Institute of Medicine in the US.⁷

How common is ASD?

As the parent or primary caregiver of a young child or adolescent with ASD, you are not alone in your search for information and answers. ASD is one of the most common developmental disabilities.⁸ Previously, it was estimated that 1 in 150 children were affected by ASD, with the majority being boys. This rate is an estimate of the prevalence of children with Autism Spectrum Disorder (ASD) based on American research published by the Centers for Disease Control and Prevention (CDC) in 2007. Recent research by the CDC suggests that the prevalence of autism is increasing. Please refer to the following link for more information about the prevalence of autism: <http://www.cdc.gov/ncbddd/autism/data.html>⁹

Are there different kinds of autism?

The term "spectrum" is used to highlight how individual experiences with the social, communication, and behavioural challenges of autism can be very different. Individuals with ASD will experience differences related to:¹⁰

- ♥ The number of, types, and severity of symptoms
- ♥ Levels of functioning
- ♥ Age of diagnosis
- ♥ Challenges associated with social situations

Until recently, children with ASD were typically (though not exclusively) diagnosed with one of three types of ASD:

- ♥ Autistic Disorder (usually referred to as autism and considered to be at the more severe end of the spectrum)
- ♥ Asperger's Syndrome
- ♥ Pervasive Development Disorder – Not Otherwise Specified (PDD-NOS)

These categories come from a manual produced by the American Psychiatric Association called the *Diagnostic and Statistical Manual of Mental Disorders IV (DSM-IV)*, a tool used by mental health professionals, service providers, and others to classify mental health, intellectual and developmental disorders. The *Diagnostic and Statistical Manual of Mental Disorders V (DSM-V)*, which was released in May 2013,¹¹ has a new definition of autism. This definition eliminates these subcategories and includes them all under the broad term Autism Spectrum Disorder.

There is an increasingly large volume of reference materials on the subject of ASD, and it can be very difficult to find "my child" and

your specific needs, in all the information. The [“Learn More”](#) at the end of this section highlights some credible sources that can help explain the differences among specific diagnoses of ASD and characteristics of the condition.

PRE-DIAGNOSIS

Early intervention is critical

Although the actual diagnosis of ASD usually doesn't take place until around age four for autistic disorder (and around age six for Asperger's disorder)^{12 13 14}, the first signs that a child is at risk for ASD are often noticeable in early childhood, and parents are often the first to notice these signs.¹⁵

“ Do not delay getting a referral to a professional capable of giving the diagnosis. While you wait for a diagnostic appointment or its results, get to work addressing whatever deficits have raised your concerns with whatever energies and other resources (including the support of extended family and friends) you have at your disposal. If the diagnosis is not given, those early parental attempts to alleviate deficits will do no harm as long as patience in all interactions remains paramount. Also, remember that the imagination is both a wonderful and terrible thing. Do not allow fear of imagined scenarios to discourage you. Those scenarios may be nothing but conjured images that never materialize.

- PARENT FROM THE HAMILTON-NIAGARA REGION

If you suspect that your child may have ASD it is very important to identify and address developmental concerns associated with ASD early in life. If you do have concerns or suspect that something is wrong in the way your child is developing, it is best to make an appointment with your child's doctor as soon as possible.

Knowing the symptoms of ASD

Every individual with ASD is different, and symptoms vary among children in both type and severity. Generally speaking, early warning signs for ASD in early childhood can be grouped into three categories: communication concerns, behavioural concerns, and social concerns. Health Canada highlights:

Possible signs of Autism Spectrum Disorders:

- ♥ Trouble with pointing or making meaningful gestures by 1 year
- ♥ Cannot speak one word by 16 months
- ♥ Cannot combine two words by 2 years
- ♥ Doesn't smile
- ♥ Does not respond to their name
- ♥ Noticeable delays in language or social skills
- ♥ Avoids making eye contact
- ♥ Strongly resists changes in routines
- ♥ Has problems with, or is not interested in playing with toys
- ♥ At times seems to be hearing impaired
- ♥ Has problems interacting with other children or adults¹⁶

Autism Ontario has developed a [“Red Flags for Autism”](#) factsheet included at the end of this section. If you feel concerned that your child may show some of these signs, you should consult with your child's doctor and ask for a referral to a developmental paediatrician, or other professional in your area experienced in ASD diagnosis. Your

local Autism Ontario chapter can provide you with information on skilled professionals/multi-disciplinary teams in your area.

DIAGNOSIS

How is ASD diagnosed?

Getting your child evaluated for ASD is worrying for parents, particularly because there is no simple medical test for diagnosing ASD. ASD is diagnosed based on observation of a child's communication, behavioural, and developmental levels.¹⁷

ASD is not diagnosed based on a single factor or symptom. Rather it is diagnosed after a confirmation of:¹⁸

- ♥ specific behaviours,
- ♥ communication delays and/or
- ♥ developmental disabilities

The Diagnostic and Statistical Manual for Mental Disorders is used as the kitline for defining the above criteria.

To assist with the diagnosis process, there are a number of diagnostic tools that a qualified professional may use. These could include: the Autism Diagnostic Observation Schedule, the Childhood Autism Rating Scale, and/or the Autism Diagnostic Interview – Revised.¹⁹ Regardless of the specific method used during the diagnosis process, observation is critical.

“ It was an extremely emotional time for us. But, when it was confirmed, it was in many ways a relief. At least we knew. At least we had something to tell people. At least we could begin.

- PARENT OF 9-YEAR-OLD WITH ASD

Who can make an ASD diagnosis?

A diagnosis of ASD can be made by a:²⁰

- ♥ family physician
- ♥ paediatrician
- ♥ psychiatrist
- ♥ psychologist and/or
- ♥ psychological associate

Please refer to The Ministry of Children and Youth Services's website for information on the [Autism Intervention Program](#) and the Applied Behaviour Analysis-based services and supports guidelines for more details on who can make a diagnosis. If your family physician or paediatrician has only limited experience with ASD they may refer you to one of these other professionals. Once referred, the process of obtaining a diagnosis may take some time.

How to prepare for the diagnostic appointment

Many parents are unsure of what to expect or how to prepare for their child's appointment. Prior to your appointment there are some things you can take note of to reduce your anxiety and assist your doctor.

Before the appointment it may be helpful to:²¹

- ♥ List all medications your child is taking (including vitamins, herbs or supplements, or any other over-the-counter medication).

- ♥ List any changes that you or anyone else has noticed in your child's behaviour. If your child has been evaluated by a pre-school or any other early childhood educator, bring their notes.
- ♥ Bring a video or photograph of behaviour, rituals, or routines displayed by your child. Many cell phones or digital cameras can be used to assist with this.
- ♥ If your child has siblings, try to make note of their siblings major developmental milestones to help spot differences and signs of development, which may indicate an ASD (such as the age they began talking).
- ♥ Make some notes about and be prepared to discuss how your child plays with other children, siblings, and parents.

You should expect your doctor to ask a few questions that will lead to a discussion on your child's development and behaviour. These may be related to the frequency of behaviours, when symptoms were first noticed, the timing of developmental milestones, your family's medical history, and what prompted your visit.²²

During the appointment you may also want to ask the doctor some questions about ASD and their evaluation of your child. Some of these could include:^{23 24}

- ? How familiar are they with ASD, and have they worked directly with children or adults with ASD?
- ? Do they have any information you could take with you (brochures, internet resources, etc.)?
- ? How can they confirm the diagnosis?
- ? What kind of regular medical care will your child need?
- ? What kind of therapies or interventions could benefit your child?
- ? Have they identified any other medical conditions (such as gastrointestinal [GI] problems or epilepsy) that can occur more often among individuals with ASD?
- ? How can you get in contact with your doctor over the next month should you have any questions? Can you book a follow-up appointment in two weeks to discuss any questions at that time?

Finally, you may want to consider bringing another family member or friend with you to the appointment. They can help provide additional information on your child's development and offer emotional support.

POST-DIAGNOSIS

Shock and grief are normal reactions

No parent can ever be prepared for a diagnosis of ASD. The diagnosis is often associated with aspects of grieving, such as shock, sadness or grief, anger, denial, loneliness, and finally acceptance.

“ Yes, a diagnosis can be overwhelming, but it doesn't change who your child is. They are the same child that you loved yesterday. It is just a label and does not define your child. ”

- PARENT FROM CENTRAL EAST ONTARIO

You may ask what causes ASD or why your child has ASD and what you need to do next. One helpful source of information is Autism Speaks' 100 Day Kit (see "[Learn More](#)" at the end of this section). This kit helps families understand the critical information they need in the first 100 days after an ASD diagnosis. It contains parent-focused information about ASD, the impact of ASD on you and your family, services your child may need, and treatments. While this kit can be very useful in helping you understand ASD and topics you may want

to learn about it should be noted that it is as an American resource. As a result the kit also contains some information that does not apply to Ontario. Specifically, sections and references to American laws and educational requirements will differ from those in Ontario. The chapter on [Educational Transitions](#) in this Parent Resource Kit provides information and resources on Ontario specific educational requirements and supportive programs.

How can I help and support my child?

Research shows that certain early intervention and treatment programs can benefit children with ASD.²⁵ The Therapies and Interventions section contains information on many of these treatment options and their availability within Ontario.

One of the first things you can do is to become generally familiar with ASD and your child's specific diagnosis. You do not have to become an expert about ASD, but you do need to become an expert about where your child fits into the ASD spectrum. Parents sometimes find that "bits and pieces" of their child's behaviour are associated with different parts of the autism spectrum.

Parents consistently say that the best way to prepare for the challenges ahead is to find the right help, support, and information sources. Some good starting points include:

- ♥ Learning from reliable sources for information. At the end of this section, you can find a [sample of such resources](#).
- ♥ Talking to your health care provider about support groups in your community. These can be especially useful for learning from other families about resources and supports in your particular community. Your local Autism Ontario chapter is often a good starting point.

“ The diagnosis can be seemingly devastating, but as time goes on you become stronger. ”

- PARENT FROM SAULT STE. MARIE

Immediate services and supports for your child

The "[Therapies and Intervention](#)" and "[Gaining Access to Services](#)" parts of this section provide information on the types of services available for children with ASD and how you can work with service provider organizations to access them.

While the Ontario Government funds services and supports for children with ASD and their parents through a variety of organizations, you may find yourself waiting for a period of weeks or months to get access to some of those services and therapies, particularly those based on Applied Behaviour Analysis (ABA) and Intensive Behavioural Intervention (IBI). This is understandably a point of frustration and anxiety among parents who want to access those services for their child immediately.

At the same time, it is important to recognize that there are a variety of helpful therapies, services, and supports available to families dealing with ASD. It is important to take a "whole person" and "whole family" approach. While ABA and IBI are important, they are not the only things that will help you and your child.

Whether or not you are waiting for certain services or therapies, there are a number of steps you can take to help you and your child receive the support needed, including:

- ♥ Joining support groups, counselling sessions and other organizations in your community
- ♥ Enrolling in parent training courses that provide an overview of ASD and can also provide insights into the basic principles ABA. This can help parents practice the principles of ABA at home.

Connecting with other parents is an important step to building your support network. [The Geneva Centre for Autism](#) and [Kerry's Place Autism Services](#) both offer frequent Parent Training Courses over the internet in webinar format allowing them to be accessible across the province.

[Autism Ontario's Potential Programme](#) also provides workshops to parents on topics deemed to be of interest to families, agencies, and other professionals within the community. The Potential Programme aims to connect families throughout Ontario by supporting greater access to ASD experts in local communities and opportunities for children to engage in community-based learning. Through expert speakers, workshops, and social events the Potential Programme can provide you with:²⁶

- ♥ ASD information from qualified Autism Ontario staff
- ♥ Access to ASD experts
- ♥ Family support groups
- ♥ Social learning opportunities for your child
- ♥ Community events
- ♥ Access to resources in your community

Your local Autism Ontario chapter can direct you to a representative for the Potential Programme.

DETERMINING SERVICES NEEDED/NAVIGATING MULTIPLE SYSTEMS

As you learn about and access supports, services, and resources for your child, you will find that they are provided by a variety of government ministries and agencies, as well as other agencies and professionals who provide health, educational, and child and youth services to Ontario's families.

“ Having a social worker helps a lot directing parents to the services already existing in the community. ”

- PARENT FROM EASTERN ONTARIO

While social workers and others will certainly assist you, parents and professionals emphasize that you will need to become your child's advocate and “case manager” as you access these supports and interact with different organizations.

While daunting at first, this is something you will get better at over time. It does require a lot of time, persistence, and especially planning. Many transitions and activities for children with ASD require planning weeks, months, and even years in advance. One of the goals of this Parent Resource Kit is to help you find both supports and people who will help you as you act on your child's behalf. At the same time, you will need to step back on occasion and remember that you are wearing “two hats”: one as your child's parent, and another as their “case manager.” As difficult as it is, sometimes it is better to be just one at a time.

“ I wished I had a step-by-step guide on who to call when, in terms of navigating the maze of social services. The tax credit certificate, the worker with MCYS, Assistance for Children with Severe Disabilities, etc. That was a veritable nightmare for me. All that, laid out in a clear format, would be so welcome to anyone trying to navigate these waters. I felt so lost and so alone. This should not be the case. ”

- PARENT FROM EASTERN ONTARIO

DUAL DIAGNOSIS

In some cases a diagnosis of ASD is not the only diagnosis a child may receive. In some cases, families may receive what is called a “dual diagnosis”. Dual Diagnosis in Ontario refers to individuals “with both a developmental disability and mental health needs.”²⁷ It is sometimes difficult to distinguish between developmental disabilities and mental health needs.²⁸ Many parents are curious about the differences between these conditions.



DEVELOPMENTAL
DISABILITY

“A condition of mental impairment, present or occurring during a person's formative years, that is associated with limitations in adaptive behaviour.”²⁹



MENTAL HEALTH
NEEDS

Defined as “diagnosed mental illness or symptoms consistent with mental illness.”³⁰ Examples include: schizophrenia, mood and anxiety disorders, and behavioural challenges.³¹

“ If a child has one diagnosis (e.g., ADHD), don't assume that this is all there is. Many children have multiple diagnoses, which I was not told about. Our child was diagnosed with ASD later. ”

- PARENT FROM PICKERING

If your child has received a dual diagnosis or you are concerned that your child may have more than one disability or disorder, the [Centre for Addition and Mental Health](#) (CAMH) is an excellent starting point for comprehensive information. Their resource database provides recommendations and guides (many of which are in video format) on topics relating to dual diagnoses.

MEDICATIONS AND RESPONSES

Medication: a difficult decision

As a parent of a child with ASD, there may be decisions that you will need to make regarding interventions and treatments for your child. While no decision is simple, decisions about whether or not to use medications can be among the most difficult. You should carefully consider medication decisions with your child's health care provider. It is critical that you are and remain comfortable with the decision and fully understand the possible risks and benefits of different medications.

Common medicines, their side effects, and when they are used

You should be aware that no medication treats or cures ASD—they can only treat the symptoms. For some individuals, medication can help with issues such as hyperactivity, anxiety, and irritability. Medicines do not help every child with ASD, and it is important to understand the symptoms that are causing problems and whether medicines will help, if at all. Medicines are most commonly recommended when:³²

- ♥ Your child's behaviours are putting them at risk of harming themselves or others;
- ♥ There is considerable difficulty or stress placed on the family because of behaviours;
- ♥ Behaviours are causing learning problems or making it difficult for a school to work with your child;
- ♥ It is not possible for your child to participate in community activities because of behaviour issues.

Like any medication, those prescribed for ASD may have side effects ranging from mild to more severe. Health Canada maintains a database of advisories and warnings associated with approved products where you can find additional information. Also, monitoring your child and scheduling regular checkups with your physician is important to track and understand the impact of medicines on your child.

Tools for helping you understand your choices

Decisions about whether to give your child medication are difficult. In general, you should ask yourself:

- ? What is the symptom I am trying to treat?
- ? Is it so severe that it is worth trying to treat with medicine?
- ? What are the potential side effects of a given medicine? How do they compare to the symptom I am trying to treat?
- ? Are the side effects of the medicine worse than the symptom I am trying to treat?

Of course, you should consult your child's physician regarding any medication decisions. Finally, you should always know what medications your child is taking and why.

LEARNING ABOUT ASD AND YOUR OWN CHILD'S SPECIFIC CHARACTERISTICS

What will my child be like?

The behaviour of each individual with ASD will differ. However, there are three core features that individuals with ASD tend to share:³³

DIFFICULTY WITH RECIPROCAL SOCIAL INTERACTION

Individuals with ASD often have difficulty interacting or engaging with others. They are often unable to read the social signals of others such as gestures and facial expressions, making the social world confusing to them. Some children with ASD do not understand that other people have different and independent thoughts, feelings, and desires from their own.

COMMUNICATION CHALLENGES

In individuals with ASD, language can develop slowly or not at all. They tend to use words without attaching the usual meaning to them and sometimes communicate in gestures instead of words.

REPETITIVE BEHAVIOURS AND NARROW INTERESTS

Individuals with ASD often engage in repetitive behaviours and have specific interests and needs. These include things like lining up toys and objects in certain ways rather than engaging in pretend play, the need for absolute consistency and structured routines in their environment, and strong interests.

What are the common characteristics?

Every child is different and it is impossible to say exactly how your child will develop. They can show a wide variety of symptoms and characteristics, from mild to severe. Even if they have the same diagnosis, they can act very differently from one another and have very different skills. Some of the characteristics of ASD include:

- ✔ Insisting on sameness, resists change
- ✔ Having difficulty in expressing needs, gestures or pointing instead of using words
- ✔ Repeating words or phrases instead of typical, responsive language
- ✔ Laughing, crying, and showing distress for reasons that are not apparent to others
- ✔ Tantrums
- ✔ Difficulty interacting with others
- ✔ Not wanting to cuddle or be cuddled
- ✔ Making little or no eye contact
- ✔ Not responding to normal teaching methods
- ✔ Playing in a restrictive or repetitive manner
- ✔ Spinning objects
- ✔ Becoming inappropriately attached to objects
- ✔ Being overly sensitive or under-sensitive to pain or other sensations
- ✔ Having no real fear of danger
- ✔ Being physically overactive or under active
- ✔ Having an uneven profile of gross/fine motor skill development
- ✔ Not responding to verbal cues, acting as if deaf although tests indicate that hearing is within the normal range

ASD is a lifelong condition and not something your child will outgrow. However, it is possible that your child's condition and characteristics may change over time. For example, with the help of intervention and therapies, individuals may further overcome challenges.³⁴

Where can I find out more?

One helpful way to learn about your child is to develop a better understanding of what it is like to have ASD. Temple Grandin is among the more well-known authors with ASD who has written extensively about her experiences with Asperger's Syndrome. Some of her books are included in the "[Learn More](#)" section as is a link to one of her many video-lectures available online. Taking some time to understand the world from the perspective of an individual with ASD can help you understand why your child acts in certain ways or is interested in different objects or activities.

INTERVENTIONS (E.G., IBI, ABA)

Interventions are not a cure

While there is no cure for ASD, there are a number of intervention approaches to address ASD symptoms. ASD treatments are intensive programs and may require participation from the entire family. Some therapies are delivered at home, while others are delivered in specialized centres, classrooms, or educational settings. Services can be provided by professional specialists and trained therapists or by parents who have received specialized training.

“ Know your child, and do not accept a therapy that you truly are not comfortable with. Just because it works for some, does not mean it will work for your child. They are truly unique. ”

- PARENT OF TWO CHILDREN WITH ASD

Applied Behaviour Analysis (ABA) and Intensive Behavioural Intervention (IBI)

ABA and IBI are terms you will hear often when exploring treatments, therapies, and interventions.

♥ **Applied Behaviour Analysis (ABA)** – ABA is a set of methods based scientific principles of learning that act as the foundation for various ASD-related interventions and therapies. ABA methods build useful behaviours and skills while reducing problematic ones by focusing on understanding the underlying reasons for behaviours, the context in which they occur, and the “triggers” of the behaviour.³⁵ ABA methods can be used at home, at school, and in the community. ABA methods can help individuals of any age and of varying degrees of intensity of ASD. Ontario’s publically funded school boards are required to provide ABA methods as a component of special education services where appropriate.³⁶

♥ **Intensive Behavioural Intervention (IBI)** – IBI is a specific application of ABA methods used by the Ministry of Children and Youth Services’ Autism Intervention Program. IBI is delivered by a qualified therapist with the program customized based on the needs of each child.³⁷ The therapist will “work one-on-one with the child or in a small group. The intervention is delivered with the goal of increasing the child’s developmental trajectory or rate of learning.

“ It is very confusing to know the difference between the Children’s Hospital of Eastern Ontario, Ottawa Children’s Treatment Centre, Children’s Integration Support Services, etc. And confusion between ABA and IBI lists, etc. Parents often think they are on a wait list for services and find they are only on some lists and not others. ”

- PARENT FROM OTTAWA

What is the difference between ABA and IBI?

ABA uses methods based on scientific principles of learning and behaviour to build useful modes of behaviour while reducing problematic ones.

IBI is an application of ABA to teach new skills in an intensive format (approximately 20 or more hours per week). Primarily, a one to one teaching ratio is required.

Additional types of therapies and interventions

In Ontario there are waitlists for these services and many parents will look for other services or activities to help their child while they are waiting. You may want to talk to your child’s paediatrician or other health care provider to discuss other therapies and interventions.

“ Try to align your immediate needs with your therapy path. For example, my son’s behaviour at daycare resulted in phone calls for pick-up on a daily basis. While my son has many needs it was more important to focus on the behaviour concerns as they were the most concerning. You’re not forgetting about other needs, just prioritizing. Assistance in determining what needs are a priority would be helpful to many parents as you have NO idea where to start. ”

- PARENT FROM TORONTO

Also, you may find that your child needs additional treatments for medical conditions or disorders that sometimes accompany ASD, such as articulation disorder, apraxia, seizures, and/or gastrointestinal (GI) problems.

Before starting with a new therapy many parents want to ask the provider questions to fully understand the therapy. These may include:³⁸

- ? Why do you think this therapy could help my son/daughter and what do you expect the outcomes to be?
- ? Is there any independent and scientific research that evaluates the results of this therapy?
- ? What are the potential side effects?
- ? How will it integrate with other therapies my son/daughter is participating in?
- ? If I am seeking private therapy for my child, how much does it cost?
- ? Is there a waitlist for services?
- ? Can you provide references from other parents who you provide this service to?

[The Geneva Centre for Autism](#) has posted a number of questions on its website that parents may want to consider asking any new service provider.

GAINING ACCESS TO SERVICES

Accessing services can be confusing

How to access services is among the most frequently asked question by parents of children with ASD. Understanding or accessing the network of services can be a source of frustration for many parents. Below is a description of some of the major programs funded by the Ministry of Children and Youth Services.

Autism Intervention Program (AIP)

If your child’s condition is considered to be towards the severe end of the autism spectrum your doctor may refer you to the Autism Intervention Program, which is funded by the Ontario Government.³⁹

The Autism Intervention Program is delivered by [nine regional programs](#). Your local regional program will review referrals for children who have a diagnosis of ASD towards the severe end of the autism spectrum. The regional program will conduct an assessment to determine eligibility. The assessment by the regional program should not duplicate diagnostic tests conducted by a physician or psychologist and should occur within 4 to 6 weeks of referral. The outcome of the assessment will determine the child's eligibility for IBI services, including the intensity, setting/location, and duration. Children who are not eligible for the Autism Intervention Program and IBI services will be referred to other appropriate services.⁴⁰

THE AUTISM INTERVENTION PROGRAM INCLUDES:

- ♥ *Support Services*, including advice, information, materials, consultation, and training for families to get their child ready for Intensive Behavioural Intervention.
- ♥ *Intensive Behavioural Intervention (IBI)* from a trained professional to focus on developing the skills children need to function in school and gain independence.

YOU WILL HAVE TWO CHOICES FOR RECEIVING SERVICES:⁴¹

- ♥ The Direct Service Option, where the child receives services directly from one of Ontario's nine regional programs; or
- ♥ The Direct Funding Option, where parents receive funding from one of Ontario's nine regional programs to directly arrange services (based on assessment completed by the regional program) from a private service provider.

Your choice will not affect your position on a waitlist. Parents on a waitlist may have a preference for one of these options. However, many parents will choose to receive the option that is available first even if it is not their first choice. One of the ways you can find out information on private service providers is through Autism Ontario's ABACUS registry, listed in ["Learn More."](#)

Independent Review Mechanism

Parents or caregivers who receive notice that their child is ineligible for or is being discharged from the IBI services under the AIP may request an independent review of that decision.

The Independent Review Mechanism (IRM) for the AIP is coordinated by Contact Niagara. To learn more about the Independent Review Mechanism see the Program Guidelines listed in the "Learn More" section. Contact Niagara's website which also contains information on the Independent Review Mechanism process. To learn more about the process visit <http://www.contactniagara.org/en/welcome>.

The ["Learn More"](#) section provides a link to a directory of service providers across Ontario and Program Guidelines for the Autism Intervention Program.

⁴¹ Diagnoses may be made by family physicians, paediatricians, psychiatrists, psychologists and psychological associates

⁴² The individuals listed on SPIRALE are self-described. Neither Autism Ontario nor the Ministry of Children and Youth Services endorses or checks the credentials of these individuals.

Applied Behaviour Analysis (ABA)-based services and supports

ABA-based services help children and youth with ASD develop skills and reinforce positive behaviour. To access ABA services, parents of a child diagnosed with ASDⁱ can contact an ABA lead agency directly or be referred to one by a health professional. Health care professionals who can refer you to ABA-based services and supports include:⁴²

- ♥ Family physician
- ♥ Psychiatrist
- ♥ Developmental paediatrician
- ♥ Psychologist
- ♥ Psychological associate
- ♥ Speech-language pathologist
- ♥ Occupational therapist
- ♥ Social worker
- ♥ Nurse (includes registered practical nurses, registered nurses and nurse practitioners)

Using an ABA approach, time limited services and supports are provided to children and youth with ASD to help build their skills in four key areas:

1. **Communication:** the ability to use language for social purposes (for example, starting a conversation with another person), understanding language, using gestures, spoken and written language, as well as pictures/symbols and facial expressions.
2. **Social/interpersonal:** including the ability to establish and maintain relationships with other people, skills that serve as building blocks for developing other skills such as joint attention, turn taking, play, and recreation.
3. **Daily Living:** including personal care activities (toileting and hygiene), domestic skills (cleaning, laundry, shopping, food preparation), use of community services (public transportation, banking, restaurants, accessing community services), motor skills, vocational skills in preparation for adulthood, personal safety skills, and skills related to personal boundaries.
4. **Behaviour management/emotional regulation:** to address the aggressive, destructive, and self-injurious behaviours that interfere with the child's learning of positive skills and to focus on difficulties that children and youth may have related to attention, planning, problem solving and memory that may impede their ability to plan and follow through on a course of action.

ABA lead agencies provide coordination for services within the nine regions of Ontario. Links to ABA agencies are provided at the end of this section. These agencies also have additional information on their websites.

Helpful databases to locate service providers

Two helpful databases that are available when searching for private services and service providers in Ontario are ABACUS and SPIRALE.ⁱⁱ

- [ABACUS](#) provides information on Applied Behaviour Analysis (ABA) services and service providers for individuals with ASD in Ontario.
- [SPIRALE](#) provides information to help parents locate regulated professionals and experienced autism workers for individuals with ASD.

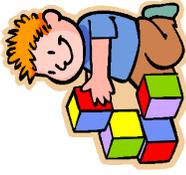
Both of these websites are operated by Autism Ontario with funding support from MCYS.

Red Flags for Autism



If there are concerns with any of the following, parents can:

- Request that their Family Doctor make a referral to a Paediatrician
- Have their child assessed by a Speech-Language Pathologist



Social Red Flags

- Rarely makes eye contact when interacting with people
- Does not play peek-a-boo
- Does not point to show things he/she is interested in
- Rarely smiles socially
- More interested in looking at objects than at people's faces
- Prefers to play alone
- Does not make attempts to get parent's attention; doesn't follow/look when someone is pointing at something
- Seems to be "in his/her own world"
- Does not respond to parent's attempts to play, even if relaxed
- Avoids or ignores other children when they approach



Communication Red Flags

- No babbling by 11 months of age
- No simple gestures by 12 months (e.g., waving bye-bye)
- No single words by 16 months
- No two-word phrases by 24 months (noun + verb - e.g., "baby sleeping")
- No response when name is called, causing concern about hearing
- Loss of any language or social skills at any age

Behavioural Red Flags

- Odd or repetitive ways of moving fingers or hands
- Oversensitive to certain textures, sounds or lights
- Lack of interest in toys, or plays with them in an unusual way (e.g., lining up, spinning, opening/closing parts rather than using the toy as a whole)
- Compulsions or rituals (has to perform activities in a special way or certain sequence; is prone to tantrums if rituals are interrupted)
- Preoccupations with unusual interests, such as light switches, doors, fans, wheels
- Unusual fears

LEARN MORE

USE	RESOURCE TYPE	TITLE	ORGANIZATION OR PUBLISHER	AUTHOR	LINK (IF AVAILABLE ONLINE)
ASD Information	Reference	Autism and Asperger Syndrome	Oxford University Press, 2008	Simon Baron-Cohen	
ASD Information	Reference	Autism: A Very Short Introduction	Oxford University Press, 2008	Uta Frith	
ASD Information	Reference	The Complete Guide to Asperger's Syndrome	Jessica Kingsley Publishers, 2007	Tony Attwood	
Warning Signs	Guide	Your Child Might Have Autism	Autism Ontario		http://www.autismontario.com/client/aso/ao.nsf/Simcoe/Red+Flags+For+Autism
Answers to frequently asked questions	Guide	Autism Spectrum Disorders	Autism Ontario		http://www.autismontario.com/client/aso/ao.nsf/web/ASD+An+Overview?OpenDocument
Warning Signs	Reference	It's Your Health – Autism Spectrum Disorders (ASD)	Health Canada		http://www.hc-sc.gc.ca/hl-vs/iyh-vs/vv/diseases-maladies/asd-ted-eng.php
Diagnosis	Reference	How is Autism Diagnosed	Autism Ontario		http://www.autismontario.com/client/aso/ao.nsf/web/ASD+4?OpenDocument
Post Diagnosis	Tool Kit	Autism Speaks 100 Day Kit	Autism Speaks		http://www.autismspeaks.org/docs/family_services_docs/100day2/100_Day_Kit_Version_2_0.pdf
Post Diagnosis	Tool Kit	Asperger Syndrome and High Functioning Autism Tool Kit	Autism Speaks		http://www.autismspeaks.org/family-services/tool-kits/asperger-syndrome-and-high-functioning-autism-tool-kit
Family Support, Post Diagnosis	Tool Kit	Family Support Tool Kits	Autism Speaks		http://www.autismspeaks.org/family-services/tool-kits/family-support-tool-kits
Post Diagnosis references	Database	Autism Ontario KnowledgeBase	Autism Ontario		http://autismontario.novosolutions.net/default.asp?id=103&Lang=1&SID=
Autism Ontario Potential Programme	Brochure	Potential Programme	Autism Ontario		http://www.autismontario.com/Client/ASO/AO.nsf/object/Flier/\$file/Potential+Programme+Brochure+0812.pdf

USE	RESOURCE TYPE	TITLE	ORGANIZATION OR PUBLISHER	AUTHOR	LINK (IF AVAILABLE ONLINE)
Calendar of upcoming Parent Training Workshops	Directory	Parent Training Calendar	The Geneva Centre for Autism		http://www.autism.net/services/services-for-parentscaregivers/parent-training/parent-training-calendar/cat.listevents/2013/02/12/index.php?option=com_jevents&task=cat.listevents&offset=1&category_fv=0&Itemid=100393
Calendar of upcoming Parent Training Workshops	Directory	Workshops	<i>Kerry's Place Autism Services</i>		https://secure.kerrysplace.org/community/TrainingInfo_camps.aspx?currenttab=Workshops&Type=Workshops&i_loc=
Dual Diagnosis and Mental Health	Reference	Dual diagnosis resources	Centre for Addiction and Mental Health (CAMH)		https://knowledge.camh.net/amhspecialists/specialized_treatment/dual_diagnosis/Pages/default.aspx
Dual Diagnosis	Reference	Dual diagnosis: An information guide	Centre for Addiction and Mental Health (CAMH)		https://knowledge.camh.net/amhspecialists/specialized_treatment/dual_diagnosis/Documents/dual_diagnosis_infoguide.pdf
Medicines/Drugs	Decision Aid	Autism: Should My Child Take Medicine for Challenging Behavior?	Autism Speaks		http://www.autismspeaks.org/sites/default/files/documents/atn/medicine_decision_aid.pdf
Medicines/Drugs and Health Products	Advisories, Warning and Recalls	Drugs and Health Products: Advisories, Warnings and Recalls	Health Canada		http://www.hc-sc.gc.ca/dhp-mps/advisories-avis/index-eng.php
Medicines/Drugs	Database	Drugs and Health Products: Drug Product Database	Health Canada		http://www.hc-sc.gc.ca/dhp-mps/prodpharma/databasdon/index-eng.php
ASD person's perspective	Reference	The Way I See It	Future Horizons, 2011 (2 nd edition)	Temple Grandin	
ASD person's perspective	Reference	Thinking in Pictures	Vintage, 2006 (Reissue)	Temple Grandin	
Building on strengths	Web-based Video	Temple Grandin: The World Needs All Kinds of Minds	TED	Temple Grandin	http://www.ted.com/talks/temple_grandin_the_world_needs_all_kinds_of_minds.html
Information guide to Applied Behaviour Analysis (ABA)	Guide	Applied Behavior Analysis: A Parent's Guide	Autism Speaks		http://www.autismspeaks.org/science/resources-programs/autism-treatment-network/atn-air-p-applied-behavior-analysis

USE	RESOURCE TYPE	TITLE	ORGANIZATION OR PUBLISHER	AUTHOR	LINK (IF AVAILABLE ONLINE)
Manual developed to help parents learn about evidence-based practices	Reference	A Parent's Guide to Evidence-Based Practice and Autism	National Autism Centre		http://www.nationalautismcenter.org/pdf/nac_parent_manual.pdf
Autism Intervention Program Guidelines	Reference, program eligibility	Autism Intervention Program: Program Guidelines	Ministry of Children and Youth Services		http://www.children.gov.on.ca/htdocs/English/topics/specialneeds/autism/aip_guidelines.aspx#2.1
Autism Intervention Program Guidelines – Independent Review Mechanism	Reference, Independent Review Mechanism	Guidelines: Independent Review Mechanism (Appendix to AIP Guidelines)	Ministry of Children and Youth Services		http://www.children.gov.on.ca/htdocs/English/topics/specialneeds/autism/aip_guidelines.aspx#IRM
Autism Intervention Program Guidelines – Independent Review Mechanism	Reference, Independent Review Mechanism	Independent Review Mechanism	Contact Niagara		http://irm.contactniagara.org/en/home
Applied Behaviour Analysis-based Services and Supports	Reference, program eligibility	Applied Behaviour Analysis-based Services and Supports Guidelines	Ministry of Children and Youth Services		http://www.children.gov.on.ca/htdocs/English/topics/specialneeds/autism/guidelines/guidelines-2011.aspx
Information on ABA treatment and directory of service providers	Reference, Service Provider Directory		ABACUS (Autism Ontario)		www.abacuslist.ca
Directory of experienced ASD service providers	Reference, Service Provider Directory		SPIRALE (Autism Ontario)		www.autismontario.com/spirale
Directory of camps	Reference, Service Provider Directory		CALYPSO (Autism Ontario)		www.autismontario.com/calypso
Searchable resource database – Asperger's	Reference, Service Provider Directory		Asperger's Society of Ontario		http://www.aspergers.ca/aso-searchable-resource-database/
Autism Intervention Program, School Support Program and ABA-based Services	Reference, Service Provider Directory		RAPON (Regional Autism Providers of Ontario)		http://www.rapon.ca/Providers.htm
Directory for Regional ABA-based Lead Agencies	Reference, Service Provider Directory		Ministry of Children and Youth Services		http://www.children.gov.on.ca/htdocs/English/topics/specialneeds/autism/agencies.aspx



EVERYDAY LIVING

Introduction

Having a child with ASD presents unique challenges every day. Parents often feel there are no “trivial” parts to their day. Everyday experiences that are easy and straightforward for most parents may be sources of effort and stress for you.

THE FOLLOWING SECTION PROVIDES TIPS AND RESOURCES TO HELP you manage your everyday life. All children and youth with ASD have unique needs. This section is a guide. Not all the information in this section will be useful or applicable to every parent. If you have any questions or concerns about the individual needs of your child, speak to your doctor or service provider.

Topics Covered

Parents and professionals have identified the topics covered in this section as key priorities and concerns. They include:

- Assessing and managing the environment
- Emergency contacts
- Preparations to go out
- Getting to and from school
- Preparing others for sudden changes to plans
- Managing behaviours/ tantrums
- Travel
- Restaurants

ASSESSING AND MANAGING THE ENVIRONMENT

All parents worry about the safety of their child

Safety around the home is something every parent thinks about. This usually involves “childproofing” household areas such as drawers, cupboards, and stairs. However, parents of children with ASD often have additional concerns when assessing the safety of their home and environment.

In households with neurotypical children safety modifications generally last for the first few years of childhood. However, children with ASD do not always understand the consequences of their actions, leading to potentially unsafe behaviours or situations. Parents of children with ASD usually undertake a number of safety modifications over and above those completed in households with neurotypical children, and these modifications often remain in the home for a much longer duration.

Prioritize safety concerns

The task of providing a safe environment can feel overwhelming. However, by prioritizing areas of your home for modification, and following the tips and suggestions of fellow parents, you can find ways to make your home environment safe.

Start with the areas of your home where your child spends the most time—likely their bedroom, bathroom, leisure area, and perhaps kitchen and backyard. Some key things to consider when assessing home safety include:⁴³



Use locks and alarms that notify you when your child attempts to open an exit route (doors, windows, bedroom entrance).



Safeguard windows by locking them and, if your child is prone to breaking glass or pounding on windows, replacing glass panes with Plexiglas.



Make electrical outlets and appliances safe by using plastic knob covers, concealing wiring, and preventing access to electronics your child may want to explore.



Label (with symbols, photos, textures or words) everyday items to help your child understand what they are for and learn how to safely use them over time.



Practice fire safety through social stories (using photos, pictures, and words) about smoke detectors, fire drills and alarms, touching fire, and emergency responders.

For more information, see the Autism Society’s “Safety in the Home” in [“Learn More.”](#)

EMERGENCY CONTACTS

One of the biggest fears for parents of children with ASD is that their child will run off or become lost. To prepare for this worst-case scenario, you can:



Create an Emergency Information Sheet;



Ensure your child has proper identification at all times.

Both of these approaches can help emergency workers assist you in a crisis.

Create an emergency information sheet

An emergency information sheet is a brief summary of information about your child that can assist emergency workers if they need to search for your child.

- You may want to keep this sheet close to your phone so that you or any caregiver can relay the information verbally if needed.
- Also consider keeping a copy of this sheet in your car and distribute it to your school, family members, neighbours, and anyone else who may assist in a search for your child.

It is also a good idea to provide close neighbours, friends, and relatives with a copy of the emergency information sheet. You may want to let them know:

- What ASD is and that your child may not understand dangers and may wander away from home;
- What to do and who to call first (e.g., home, work, 911) if they see your child outside of your home;
- The best way for them help to get your child back to you;
- How they should approach and communicate with your child (what can they say to calm your child down if needed).

You can find an emergency information sheet template at the end of this section.

Consider identification for your child

Identification (“ID”) bracelets and other forms of identification will enable neighbours or emergency workers to quickly identify your child if he or she becomes lost. This is especially important for children who are non-verbal.

Every child with ASD is different, so you will need to determine what type of identification your child can or is willing to wear or carry. Some examples include: cards, temporary tattoos, shoe and clothing tags, bracelets, necklaces, and personal tracking devices.

For more information, see the resources and organizations listed at the end of this section under [“Learn More.”](#)

Talk to your local police force about an Autism Registry

Depending on where you live, your local police force may have specific training on how to approach children and adolescents with ASD during stressful situations. Some police forces may also operate an Autism Registry. These registries provide police with critical details on your child that may help them defuse crisis situations. You can contact your local police force or your local Autism Ontario Chapter for more information on the availability of this service in your area.

Minimizing the risk of children with ASD running off

Beyond taking the steps outlined above, you can:⁴⁴

- ✔ ensure your child always carries identification;
- ✔ use a Velcro wrist strap and coiled cord to keep your child with you when out shopping or walking. This may prevent children from dashing into traffic, falling into water, running away at shopping malls, etc.
- ✔ get to know your neighbours and let those neighbours you trust know in advance that your child with ASD might wander off.

PREPARATIONS TO GO OUT

“Structure and predictability are key. Children’s need for this is universal, but especially the ASD child. Have appropriate expectations. Stop and smell the roses often, step back from the rat race of the neurotypical world and enjoy living in the ASD-friendly world your child needs. Slow down and embrace your child’s uniqueness.”

– PARENT OF TWO CHILDREN WITH ASD

The steps you need to take before leaving the house with your child will depend on your individual child, and what you have learned, usually through trial and error, about how to help your child with change and transitions. Some tips that can be applied to a wide range of outings (e.g., shopping mall, school, movies, restaurants, playground) include:

- ✔ pictures and visual schedules (e.g., of a car, a shopping mall) to help your child understand where you are going and what you will be doing
- ✔ attention to specific routines they like to keep
- ✔ specific clothes they like to wear
- ✔ technological devices (e.g., headphones) they like to take with them

It’s also important to consider the type of environment you are travelling to and whether it will disrupt your child’s routines or trigger sensory overloads or tantrums. If your destination is noisy or unpredictable, think about what you can do to help your child cope with it.

When visiting family and friends, you may want to ask them to alter certain aspects of their homes or a certain room to accommodate your child. You may find that some people’s houses are easier to visit than others. It may be preferable to have certain people visit you at your home instead of you visiting them at their home.

GETTING TO AND FROM SCHOOL

Getting to and from school is a common transition

Transportation to and from school is a major concern for many parents. Individuals with ASD can experience significant difficulty riding a school bus to and from school each day. School boards vary in how they deliver transportation services. Talking to your child’s principal or school board is a good starting point for understanding what supports are available to help your child get to and from school.

Try to help the bus driver get to know your child

Your child’s school board may be able to provide bus drivers with information on ASD. You may want to consider asking the principal of your child’s school or their school board what support they can offer the bus driver. However, they will not know your child. By providing the bus driver with a little bit of information you can make their job easier and help put your mind at ease. Working with the school board, you may wish to provide the bus driver with:

- A summary of general information about your child’s condition and behaviour. This helps to prevent frustration or anger over potential behaviour issues, especially if you can also offer the bus driver tips on dealing with challenging behaviours.
- Information about your child that could help the bus driver. This can be a summary from an “About Me” profile provided to your child’s teachers (find out more about this in the [“Education”](#) Section of this Parent Resource Kit). Include possible behavioural triggers and how to deal with them.

Ideally, you will want the bus driver to keep the information on the bus, so try to keep any printouts small (the size of an index card). Laminating the card can also be a good idea. This can be done at most office supply stores or print shops. A template for general information about ASD is provided in the [“Learn More”](#) section.

Helping your child and next steps

In addition to helping the bus driver understand children with ASD, there are a few activities you can do with your child to help make getting to school a smoother process:

- Establish a morning and bus routine with your child. Use visual aids if this helps to communicate the process of getting ready for school and taking the bus (an example is included in the [“Learn More”](#) section).
- Explain the bus rules to your child. Make sure these are communicated in a way your child understands, such as in a story or visually.
- Provide your child with a tangible activity that can occupy them on the bus.

“Visual schedules for transition and explanation of routines are so helpful! Predesigned home and school magnetic kits are extremely helpful!”

– PARENT OF THREE CHILDREN WITH ASD

Two additional items you may want to discuss with your school board are the possibility of establishing a consistent seat for your child on the bus and pairing them with a “bus buddy.” Both of these methods can ease daily trips to school.

PREPARING OTHERS FOR SUDDEN CHANGES TO PLANS

Enlist family, friends, and parents to help

When a family member or friend changes plans suddenly, people can often get annoyed. Unfortunately, you may find yourself doing this frequently, even when significant plans have been made well in advance. You may need to explain to family and friends that you will often need to change plans suddenly to help your child, for reasons that will not be obvious to them. You may need to explain to them that seemingly simple tasks like leaving the house, visiting friends, or running errands, are often challenging for your child and may sometimes force you to change your plans.

“ We have let friends go that just can’t manage to witness his meltdowns. If you want to see us, then his meltdowns come too.

– PARENT FROM PETERBOROUGH

Parents of all types of children often find themselves with too many things to do, conflicting schedules and needs, and other challenges. As a parent of a child with ASD, you share these “normal” challenges on top of the unique demands of life with ASD. You may be able to lighten this burden by:

- Assessing your own social network—family, relatives, friends, etc.—and identifying people who might be able to help in specific situations or at certain times;
- Bringing members of your social network—perhaps an aunt, uncle or grandparent—to a parent support group or training session that may help them care for your child for a few hours or a day at some time in the future.

MANAGING BEHAVIOURS/TANTRUMS

Tantrums and behaviour issues can stretch the patience of any parent. They may often be a source of stress, anger, and depression, especially if you find it hard to understand or address your child’s behaviour. The following tips and guides may help you understand why your child may act in certain ways, how to manage difficult behaviours, and what you can do in a crisis situation.

Understanding behaviour

If you understand the causes of your child’s challenging behaviour, it can become easier to prevent some behaviour problems and to identify solutions when they do occur. Any given behaviour can occur for a number of very different reasons. In general, behaviours tend to serve one of several functions:⁴⁵

- Obtaining a desired object or outcome
- Escaping a task or situation
- Getting attention, either positive (praise) or negative (yelling)
- Trying to self-calm, self-regulate, or feel good (sensory input)

- Blocking or staying away from something painful or bothersome (sensory avoidance)
- Attempting to gain control over an environment or situation

Questions you could ask yourself to understand why your child is behaving in a certain way include:⁴⁶

- Did this behaviour start suddenly? If so, is there an underlying medical reason? Pain? Stress?
- Is my child trying to tell me something?
- Do certain locations, people, or times of day trigger behaviours?
- What occurred leading up to the behaviour? What were the triggers?
- After the behaviour, is something occurring that is accidentally reinforcing the behaviour?

If you do not know the answer to some of these questions, it may be worthwhile discussing them with your child’s physician or service providers.

Developing an understanding of what causes your child to behave in certain ways, and what works in calming them, will make it easier to control the environment in ways that make problems less likely to occur and more manageable.

How to manage behaviour over time

As you start to understand causes of challenging behaviours, you may be able to develop a plan to address them. Effective approaches to managing behaviours are typically based on positive behaviour supports and address both physical and mental health concerns. Positive behaviour supports is a method to promote functional skill development customized to individual needs of a child by teaching new skills and making changes to the child’s surroundings. While punishment may be an immediate fix to problem behaviours, research tends to show that it is ineffective over time and can actually increase aggressive behaviour, compared to supporting positive behaviours.⁴⁷

Improvements in challenging behaviours will not occur overnight. As a parent you need to keep “the whole child” in mind when working on your child’s behaviours. A holistic behaviour plan, that addresses your child’s health and happiness as well as strategies for improving behaviours, can help you balance all these needs. Try to make the plan:⁴⁸

- Clear, with the expectations and roles of your child, family, teachers, health care professionals, and anyone else involved as clearly understood as possible;
- Consistent in its interventions and approaches, ensuring that all individuals involved in the plan are on the same page with the same expectations;
- Simple, practical, and accessible so that everyone can be involved;
- Continuous, to reinforce good habits and adaptive skills as behaviour improves.

Planning for a crisis situation is critical

When a child is in the full swing of a tantrum, the focus should be on the safety of the child and of anyone nearby. Having a crisis plan for these situations will help you keep everyone safe and de-escalate the situation. In general, a crisis plan should include:⁴⁹

- Settings, events, triggers or signs that a crisis situation might develop

- Intervention steps and procedures promoting de-escalation
- Lists of things to do and NOT to do based on the fears and needs of the individual
- Knowledge of the most appropriate facility if hospitalization or an Emergency Room visit becomes necessary
- A diary or log to document and record effective intervention techniques for future reference

What to do in a crisis situation

A crisis situation is not the time to shape behaviour. If you begin to feel that a situation is escalating and a tantrum is likely, it is best to try and calm your child by:

- ✓ Following the crisis plan you have developed, using the activities and de-escalation processes within it;
- ✓ Trying to reduce stressors by removing distracting elements, going to a less stressful place or providing a calming activity or object;
- ✓ Remaining calm and controlling the emotions your child's behaviour is likely to trigger;
- ✓ Providing clear directions and using simple language;
- ✓ Focusing on returning to a calm, ready state by allowing time in a quiet, relaxation-promoting activity;
- ✓ Praising attempts to self-regulate and the use of strategies such as deep breathing.

When you need outside help

One of the most difficult decisions parents may need to make is when to get more help to manage a situation that has grown out of your control. While this often involves an uncomfortable decision about calling police or other emergency services, the safety of you and your child must be placed above all else. In general, it is important to seek help when:⁵⁰

- Aggression or self-injury become recurrent risks to the individual, family or educational/health care providers;
- Unsafe behaviours, such as running off and wandering, cannot be contained;
- A threat of suicide is made.

Calling for help is difficult, and it is important to remember that many emergency personnel, including police and paramedics, may not know what it means when you tell them your child has ASD. It will be important for you to help them understand this and communicate clearly during the crisis situation. There doesn't have to be an emergency for you to need professional help. You may come to this decision, for example, when:

- A child exhibits a persistent change in mood or behaviour, such as frequent irritability or anxiety;
- The supports your child requires may be better met through out-of-home care or in a residential setting.

TRAVEL

Traveling with young children can be stressful for any parent, particularly parents of children with ASD. The challenges of traveling can sometimes be enough for parents to consider avoiding it all together, even though it means missing out on vacations, day trips, or visiting friends and family. However, with the right planning and preparation, the potential stress and anxiety of travel can be reduced, making trips more enjoyable for you and your family.

Planning is key

Planning for travel and reducing your child's fear of an unfamiliar situation and destination is critical to managing stress and anxiety levels for everyone on a trip. Autism Ontario suggests some steps you can take in advance of your trip:⁵¹

- Prepare a step-by-step picture book of your trip with a short caption for each picture so that the book reads as a story (where you are going, how you will get there, who is going, when you will be returning).
- In the book, clearly outline the beginning and end of phases of your traveling (e.g., taxis, flights, driving in the car, stopping for meals, etc.). Use methods of illustrating time that your child will understand, such as the length of a television program or movie.
- Review the picture book of your trip every morning for two weeks leading up to the trip. Allow your child to ask questions and understand the order in which events will occur.
- Pack items and food your child likes (favourite snacks, activity books, portable DVD player).
- Maintain the daily routine around activities such as meals, rest, and bedtime as much as possible.

“ For really important events, big changes, or major disruptions, no amount of preparation is wasted. We talk about it ahead of time. We write it down on a calendar. We draw pictures about it together. And, half the time, it sort of works. But, when there is no warning (and sometimes you can't help that), it's always far worse. ”

- PARENT OF 9-YEAR-OLD WITH ASD

Additional help

Your destination and method of transportation (car, bus, plane, etc.) can influence how you prepare for traveling. For example, traveling by plane means using an airport, which will require preparation for security checks. Similarly, the pictures and descriptions in your child's storybook will vary based on the type of trip you are taking (day trip, vacation, family visit, etc.). You can also contact your travel provider ahead of time to ask about any special provisions or assistance they might be able to offer you.

The “[Learn More](#)” at the end of this section includes a number of resources to help you understand how to navigate airport security, sample items to include in a storybook, and other helpful suggestions.

RESTAURANTS

The thought of eating out at a restaurant may be overwhelming for many parents of children with ASD. Many parents avoid eating out because of the fear of what may happen in public and the stress it can cause. Dining out may not be possible for all families, but with planning it can be successful for many. The tips and recommendations below can help make dining out an enjoyable family experience.

“ Air pressure vests and apps with white noise are the only way we can get through a meal at his favourite sushi restaurant. He'll put up with a lot to eat raw fish. Go figure. ”

- PARENT FROM PETERBOROUGH

Things to do before you dine out

Before heading to the restaurant, there are a few things you can do to help your child prepare for the experience and enjoy the time out of the house. Some things to consider include:⁵²

- ✔ Where are you planning on going? Will it be an over-stimulating environment? Does it have a child friendly atmosphere?
- ✔ Do you need to provide your child with a description of the location?
- ✔ Reservations are a lifesaver, allowing you to avoid long waits. Request a table (ideally a booth) in a quiet location, at a time when your child will be hungry.
- ✔ Can you print a menu at home and select a meal ahead of time?
- ✔ Bring along some colouring books or a special toy to keep your child occupied. Also consider bringing earplugs or headphones if you are concerned about your child's reaction to noise.

Finally, keep in mind that your child might need a break from the restaurant environment. If you sense that your child has had enough, you might go for a walk together outside to provide them with the space to relax.

Calling a restaurant ahead of time and speaking with a manager is a good way to assess whether it's a good choice for your child and to arrange the accommodations you might need. You may want to try a rehearsal dinner at a fast-food style restaurant before heading to other establishments.

Although it may require more preparation than for most families, and you may not be able to make a spur-of-the-moment decision to head to your favourite restaurant, it is possible to plan for a special night out with your family.

“ Take it one step at a time celebrate the small achievements. ”

- PARENT FROM TIMISKAMING

TOOLS

Getting to and from school can be a difficult process for parents of children with ASD. Using this template and working with your child's school can help provide your child with the skills they need to complete this task.

Bus to School 

Watch for bus 

Walk to bus 

Get on bus 

Find an empty seat 

Sit down 

Quiet hands 

Quiet voice 

Get off bus 

Go to class 

Bus to Home 

Walk to bus stop 

Line up for bus 

Get on bus 

Find an empty seat 

Sit down 

Quiet hands
Quiet voice 

Watch for stop 

Get off bus 

Go home 

LEARN MORE

USE	RESOURCE TYPE	TITLE	ORGANIZATION OR PUBLISHER	AUTHOR	LINK (IF AVAILABLE ONLINE)
Running Off	Tool kit	Wandering/Running Away	Autism Speaks		http://www.autismspeaks.org/sites/default/files/challenging_behaviors_tool_kit.pdf
Behaviour and Tantrums	Tool kit	Challenging Behaviours Tool Kit	Autism Speaks		http://www.autismspeaks.org/sites/default/files/challenging_behaviors_tool_kit.pdf
Emergency Information Sheet	Tips	Lost Child Prevention Sheet	Autism Speaks		http://www.autismservices.ca/Web%20Pages/publications/Docs/Lost%20Child%20Prevention.pdf
Visual Aids and Templates	Tools and Templates	Effective Educational Practices for Students with Autism Spectrum Disorders	Ministry of Education		http://www.edu.gov.on.ca/eng/general/elemsec/speced/autismspecdis.pdf
Home Safety	Tip Sheet	Safety in the Home	Autism Society		http://www.autism-society.org/living-with-autism/how-we-can-help/safe-and-sound/safety-in-the-home.html
Emergency Contact Information	Website		MedicAlert		http://www.medicalert.ca/en/join/
Emergency Planning	Website	Plan Your Response for an Autism Emergency	Autism Risk & Safety Management		http://www.autismriskmanagement.com/documents/autism_emergency.pdf
Running Off	Website		MissingKids.ca		www.missingkids.ca
Running Off	Website	Registries of children arm police with information	Globe and Mail (News Article)		http://www.theglobeandmail.com/news/national/registries-of-autistic-children-arm-police-with-information/article4085778/
School Day Tips	Tips	Effective Educational Practices for Students with Autism Spectrum Disorders	Ministry of Education		http://www.edu.gov.on.ca/eng/general/elemsec/speced/asdfirst.pdf
School Day Tips	Tool Kit	School and Community Tool Kit	Autism Speaks		http://www.autismspeaks.org/sites/default/files/school_community_tool_kit.pdf

USE	RESOURCE TYPE	TITLE	ORGANIZATION OR PUBLISHER	AUTHOR	LINK (IF AVAILABLE ONLINE)
Travel	Article	Six Tips for Traveling with an Autistic Child	TIME		http://www.time.com/time/specials/packages/article/0,28804,1893554_1893556_1893538,00.html
Travel	Tips	Autism and Airport Travel Safety Tips	Society for Accessible Travel and Hospitality		http://www.sath.org/index.php?sec=768&id=2371
Travel	Tips	Ten Strategies for Traveling with a Child with Autism OR How Do We Survive the Trip?	Autism Speaks (by Ann Schlosser)		http://www.autismspeaks.org/docs/family_services_docs/schlosser.pdf
Travel	Tips	Travelling with a Child with Asperger's Syndrome	Autism Ontario		http://autismontario.novosolutions.net/default.asp?id=74&Lang=1&SID=
Travel	Tips	Air Travel and Asperger Syndrome	Asperger's Society of Ontario		http://www.aspergers.ca/2012/12/1234/
Dining Out	Tips	Dining Out with an Autistic Child	TIME		http://www.time.com/time/health/article/0,8599,1653262,00.html
Dining Out	Tips	Going to Eat Out	Autism Speaks		http://www.autismspeaks.org/family-services/going-out-to-eat



COMMON TRANSITIONS

Introduction

Many of our day-to-day routines change every year. School-aged children experience a major change in routine at the beginning and end of every school year, as well as during seasonal holidays and family vacations. The opportunity to spend vacation time with family members or visit new places is something many parents look forward to. However, holidays and vacations can be difficult for parents, because disrupted routines are difficult for children with ASD. Families' ability to plan for common or annual transitions varies greatly based on their child's diagnosis and symptoms. However, there are techniques you can use to smooth these transitions and make life easier.

Topics Covered

This section of the Parent Resource Kit provides information and tips on transitions and events that occur on an annual or regular basis, including:

- ▣ General planning
- ▣ New babysitters/caregivers
- ▣ Start of the school year
- ▣ Extracurricular activities
- ▣ Holidays
- ▣ Camp Programs
- ▣ Accessing Camp Programs-CALYPSO

GENERAL PLANNING

Whether planning for school, vacations, camps or other transitions, it is important to plan ahead. Here are two things you can do to assist planning for any transition is:

- 1) Develop a “binder” or other book with all of your child’s relevant information, along with a list of questions to ask depending on the setting (e.g., school, camp). It is easy to forget all the questions you may have in a quick meeting, so it helps to write them down in advance (see advice for creating a binder in the front section of the kit).
- 2) Try to ensure you have good access to your child’s family physician, paediatrician and/or their assistant. Many parents and professionals refer to their paediatrician’s receptionist as their “quarterback” for accessing medical records, reports, authorizations, and other documents that various organizations may request.

NEW BABYSITTERS/CAREGIVERS

As any parent knows, finding a good babysitter for your child can make life much easier, and this is even truer for parents of children with ASD. You will likely want to find someone with qualifications or experience in babysitting a child with ASD. And once you find a babysitter, it will be important for you to clearly communicate your child’s unique needs to them.

Here are some ideas that may help you find a babysitter:⁵³

- ✔ Ask other parents who have children on the autism spectrum for a referral.
- ✔ Search for respite care services.
- ✔ If your child goes to preschool, daycare, or any type of speech, occupational, or physical therapy, ask the service provider if they ever babysit or know someone who does.
- ✔ Ask relatives such as an aunt/uncle or older niece/nephew.
- ✔ Ask someone the child already knows.

Respite care services

The Ministry of Community and Social Services and the Ministry of Children and Youth Services jointly fund www.respiteservices.com.

This website can be used by parents to explore respite options, review community partners, and post and review classifieds related to care services including babysitting. The “Family Support” section of this Parent Resource Kit includes more specific information about Respite Care available in Ontario.



What is respite care?

Respite care is a family support service that provides temporary relief from the physical and emotional demands involved in caring for a family member with a developmental disability and/or a child with a physical disability. Respite creates greater opportunities for all family members to live actively and participate in community activities while allowing caregivers time for themselves.

<http://www.respiteservices.com>

Preparing a babysitter/caregiver

Once you have identified a potential babysitter or caregiver, it is important to prepare both your babysitter/caregiver and your child before their first session. Provide the babysitter/caregiver with as much information as possible about your child in advance of their meeting. This will help the babysitter/caregiver get to know your child and also provide information they will need to navigate challenging situations. This can also help to put your mind at ease.

Questions can include:⁵⁴

- ❓ How does your child react to new people? Will they be shy?
- ❓ How do you communicate instructions to your child? Several instructions at once or one at a time?
- ❓ What level of supervision does your child need?
- ❓ Does your child think about the consequences of their actions?
- ❓ What level of language skills does your child have? Can they understand directions? Can the babysitter use or understand their communication method?

Preparing your child

It is also important to prepare your child for a babysitter/caregiver. The more they understand and can prepare for what will be the same and what will be different, the less anxious your child will be and the more likely they will be to enjoy their time with the babysitter/caregiver. For example, you could prepare by:⁵⁵



Outlining what will remain the same and what will be different while you are away;



Planning and reviewing a schedule that involves activities, toys, and games your child enjoys;



Working with your child to develop a list of likes, dislikes, and other information they want the babysitter/caregiver to know;



Explaining how long you will be gone to your child in terms they will understand and trying to remain on time.

It is a good idea to keep the first few babysitting occasions short to prevent either your child or the babysitter from becoming overwhelmed as they get to know one another.

START OF SCHOOL YEAR

Adjusting to a new year

Every year, September brings new teachers, classmates, schedules, and routines. For children with ASD, the new demands, expectations, and physical environment associated with a new school year can be particularly challenging. This section focuses on the yearly transitions between grades, particularly those relating to changing schools. (See

the [“Educational Transitions”](#) Section for more on supporting your child’s school experience.)

“ We found it takes our son 6 to 8 weeks to settle into each school year—so we don’t plan any other activities, and we expect a bumpy ride. A routine helps so much. Do a picture board linear of each step getting ready for school. Send a one page “cheat sheet” of vital info about your child for the teacher (ideally meeting the teacher the week before school starts).

”
- PARENT FROM KINGSTON

Preparing for a new grade

Before your child begins a new grade, you will typically want to have worked with the teachers and administrators at your child’s school to support the transition process.

If the new grade involves a new classroom, “previews” can be helpful.⁵⁶ You can do a preview in a number of ways, including:



Videotaped tours with teacher interviews



Face-to-face meetings with new teachers



School walkthroughs



Listening to siblings, parents, or friends tell your child about the school

A preview should occur before school officially starts, and can be supplemented by letting your child review brochures, newsletters from the previous year, and the school’s website.

“ Visit the school in June and take pictures of the school, classroom, teacher (if known—but be prepared for changes), coatroom, desk, even the toilets. Place these pictures in an album and look at it over the summer. Visit again before school starts, when the teachers are getting ready. Once the daily schedule is known, make a new album with all the activities in a day: hang coat, change shoes, circle time, craft time, snack time...

”
- PARENT FROM EASTERN ONTARIO

Information for the teacher

Critical information sheets or personal portfolios are a useful tool to help support the transition to a new grade through straightforward communication and information sharing. An example of a critical information sheet is provided in the [“Learn More”](#) section. You may also wish to create a personal portfolio for (or with) your child; this can be similar to a scrap book and include photographs, art, sample academic work, lists of likes and dislikes, and anything else that could help introduce your child to their teacher.

EXTRACURRICULAR ACTIVITIES

Some children with ASD can be socially isolated. If they are getting support services or undergoing therapy outside of school hours, they may also get fewer opportunities than other children to interact with their peers. Extracurricular programs can broaden children’s social experience while involving them in an enjoyable activity. You may need to explore several possibilities before finding the activities that best suit your child.

If you do enroll your child in an activity, it is important to tell any instructors, facilitators or other people running the program about your child’s needs and provide them with appropriate information.

HOLIDAYS

Preparing for holidays

Holidays can be a stressful time for the parents of children with ASD, regardless of the traditions they celebrate. Holidays can represent a disruption in normal routines. Children with ASD often have difficulty understanding the meaning or traditions of holidays and may experience sensory overloads caused by the sights, sounds, and extra household visitors that accompany many holidays.

Like parents of neurotypical children, you may be stressed by the desire to make a holiday “just right.” However, it is important to establish realistic expectations about how you can enjoy a holiday. Think about what changes you might make to your family traditions to make them more manageable and fun for you and your child. To start, you might think about what aspects of a holiday (for example, food, activities, people) you have always loved and what changes would allow you to continue enjoying them. Shortening or adjusting some events, breaking them down into small, manageable pieces, or, if necessary, even avoiding certain events can go a long way towards reducing your stress and making your holidays enjoyable.

“ Identify what is causing the behaviour. Don’t just focus on the behaviour itself. For example, for years, every time I put up my Christmas tree, my son with autism would have a huge meltdown and throw the tree over and make me un-decorate it, etc. I had no idea why, so every year I just used non-breakable ornaments/lights and got ready for the meltdown. It was exhausting. Two years ago, I was not in a hurry to put it up so I waited. It was the second week of December, and up went the tree and there was no meltdown. I was happy but shocked...turns out that I was putting it up before December 1st; to him, the meltdown was because it was still November. He did not have the language to tell me that, so a huge meltdown would happen. Now I simply wait until after December 1st to put up my tree and everyone is happy.

”
- PARENT FROM THUNDER BAY

Here are some tips to help parents make holidays more enjoyable for everyone involved:⁵⁷

- ✔ Try to think of activities to keep your child occupied wherever you go, if necessary pack toys, games, or movies for them to enjoy.
- ✔ Create a visual story or guide of upcoming holiday events to help your child prepare.
- ✔ If you need to travel to visit friends or family, ask them to have a quiet place where your child can relax if they need to.
- ✔ If you are giving gifts to your child, take them out of the packaging then wrap the gift so that once your child unwraps it they are able to play right away.
- ✔ Take pictures and help your child remember the good time they had.

Autism Speaks has a number of holiday-related tips and suggestions on their website that may help you in planning. You can visit their website at: <http://www.autismspeaks.org/news/news-item/holiday-tips>

CAMP PROGRAMS

The March Break and summer periods when school is out present a number of challenges for parents of children with ASD. Parents may need to work full-time and the thought of weeks or months of unstructured time often causes them to worry. Many of the suggestions and tips discussed in the babysitter/caregiver section of this kit are useful in finding caregivers to bridge work schedules and other activities during this time.

To help families during these times the Ministry of Children and Youth Services funds two distinct camp programs: March Break Camps and Summer Camp Programs.

March Break camps

The March Break camp opportunities are available to Ontario families who either retain the services of a one-to-one support worker or who pay for a March break camp/program out of their own pockets.⁵⁸

Your local Autism Ontario chapter is a good resource for identifying March Break programs in your area. The application process for the March Break Reimbursement Fund, which is run by Autism Ontario, typically runs from mid-December to mid-January. Information on financial reimbursements and the application process can be found by following the link to Camp Programs located on Autism Ontario's main website (www.autismontario.com). As part of the application process you will need to include evidence of an ASD diagnosis from a professional qualified to make the diagnosis.⁵⁹

Funding for reimbursements will be provided to families through a random lottery of all eligible applications. Autism Ontario will reimburse these families for the cost of hiring a one-to-one worker for the child with ASD or the cost of the March Break camp/program.⁶⁰ The reimbursement process will require you to keep and then submit all receipts that detail these costs.⁶¹

To help parents research and select a camp program, Autism Ontario operates [CALYPSO](http://www.calypso.ca). CALYPSO is a website that provides tips and recommendations to consider when selecting a camp program for your child, as well as a directory of camps throughout the province. More detail on CALYPSO is located in Section 3.3.3.7 – CALYPSO.

Summer camps

Summer camps are supported by all nine regional [Ministry of Children and Youth Services offices](http://www.mycyso.ca). These camps give parents a much-needed break and help children have fun and build new skills. Autism Ontario also administers a reimbursement program funded by the ministry for families hiring one-to-one support workers so that your child can attend summer camp.⁶²

As the Summer Camp Programs offered by Autism Ontario can vary from region to region, it is recommended that you contact your local Autism Ontario Chapter or Ministry of Children and Youth Services' regional offices for additional information. CALYPSO is also a helpful resource that can be used by parents to address questions you may have and search for possible camps within the province.

CALYPSO

[CALYPSO](http://www.calypso.ca) is a website operated by Autism Ontario and a good tool for finding camp programs for your child. It provides:

- A searchable database that groups camps by region, provides contact information, and outlines details on the programs and services offered by each camp;ⁱⁱⁱ
- Camp-oriented templates and factsheets to help prepare your child for a camp experience;
- Resources to use when considering a camp, including suggestions to help you decide whether an integrated camp program or specialized camp program is a better fit for your child.

Integrated Programs

The child/youth with ASD is integrated into a program with similar-aged neurotypical peers or into a general camp program.

Specialized Programs

These camps offer activities/programs within an environment specifically for children with ASD. Examples of these programs are the day camps that Autism Ontario chapters operate.

The [CALYPSO](http://www.calypso.ca) website can help you make a decision about March Break and/or summer camp programs. The website contains a number of questions for parents to consider and tips and recommendations associated with camp programs.

In general, some questions to consider include:⁶³

- ? What percentage of children with special needs makes up the camp population?
- ? Will my child be integrated into a cabin/tent/group or just into the general camp program?
- ? What does this camp do specifically for a child with ASD?
- ? How are the people working directly with my child trained? How old are they?
- ? How are transitions between programs managed?
- ? Are visual reminders available or will I have to send them? Visual reminders can be a collection of graphics and pictures to supplement verbal communication and/or support the user understand a sequence of events.

ⁱⁱⁱ The camps/individuals listed on CALYPSO are self-described. Neither Autism Ontario nor the Ministry of Children and Youth Services endorses or checks the credentials of these individuals.

[CALYPSO](#) has developed tips to help parents make their child's transition to a camp program an enjoyable experience. These include:⁶⁴

- ✔ Tour the camp ahead of time if possible. Take pictures and review them with your child in the days leading up to camp.
- ✔ For non-verbal or low-verbal children, include a small plastic photo album with photos of common items that they will use at camp (e.g., swim area, toilets, showers, change room, dining hall, lunch shelter, playground). They can use this to communicate with staff by pointing.
- ✔ Help the camp staff with “first this, then this” instruction. Create a laminated Velcro board with various words or pictures that staff members can use to communicate schedules and transitions (e.g., first “change room” then “swim”).

Visiting the [CALYPSO](#) website can help you better understand camp programs and find the right one for your child.

Critical information sheet that can be completed and provided to your child's new teacher(s) at the start of a school year.



Critical Information Sheet at a Glance

Student Name: _____ Teacher: _____ Grade: _____

Communication	Reinforcers	Sensitivities	Descriptions of Challenging (Target) Behaviour
How does student communicate? Verbally: Yes _____ No _____ PECS: Yes _____ No _____ Sign language: Yes _____ No _____ Combination of above: Yes _____ No _____ None of above: Yes _____ No _____ How does student let you know: • Wants/Needs _____ • Protest/Refusal _____ • Assistance _____ • To stop _____ • Need for bathroom _____ • Sick _____ Is a visual schedule used? Yes _____ No _____ How do you provide information? Visual references: _____ Pictures: _____ Objects: _____ Signs: _____ Gestures: _____ Strengths of student (list three): _____ _____ _____	List highly preferred/interesting likes/reinforcers. Items: _____ Verbal: _____ Social: _____ Foods: _____ Sounds/Music: _____ Activities: _____ Does student take medication, have allergies, have a special diet? _____ _____ _____	Is change a challenge for student? Yes/No _____ Can student become overwhelmed by noise? Yes/No _____ Does student express emotions? Yes/No _____ If yes, list and describe how: _____ _____ Does student need assistance with bathroom, eating, other? Yes/No _____ If yes, please specify: _____ _____ Does student follow a modified program (academic modification) or are accommodations made to learning (use of computer, class positioning, etc.)? Yes/No _____ If yes, please list: _____ _____ _____	Are specific behaviours observed that would define student's target behaviour? (Describe in detail, as if to a stranger.) _____ _____ _____ _____ _____ What do you do/say/not say to help settle student (re-direct, relaxation, key phrases, etc.)? _____ _____ _____ How do you know behaviour has increased? _____ _____ _____ If student is physically aggressive, what do you do/say/not say? _____ _____ _____ Is there need for a safety plan? Yes No _____



Thames Valley Children's Centre, South West Region

LEARN MORE

USE	RESOURCE TYPE	TITLE	ORGANIZATION OR PUBLISHER	AUTHOR	LINK (IF AVAILABLE ONLINE)
Babysitting	References, Directory		Respite Services (Funded by the Ministry of Community and Social Services and the Ministry of Children and Youth Services)		http://www.respiteservices.com
Respite Services, Babysitting	Tips	Everyday Services	Autism Action Partnership		http://www.autismaction.org/resource-center/everyday-services/babysitting/
Holidays	Tips	Holiday Tips	Autism Speaks		http://www.autismspeaks.org/news/news-item/holiday-tips
Camps/Holidays	Service Listings	Programs and services for children with autism	Ministry of Children and Youth Services		http://www.children.gov.on.ca/htdocs/English/topics/specialneeds/autism/programs.aspx
Camps	Reference, Service Provider Directory		Autism Ontario: CALYPSO		http://www.autismontario.com/client/aso/calypso.nsf/web/Home?OpenDocument
Camps	Guide	Six-Step Guide	Autism Ontario: CALYPSO		http://www.autismontario.com/client/aso/calypso.nsf/web/calypso+six+steps?OpenDocument
New School Year	Tips	Back to School for Children with Autism	Autism Speaks	Dr. Peter Faustino	http://www.autismspeaks.org/sites/default/files/documents/family-services/tips_peter.pdf
New School Year	<i>Educational Best Practices, Tools and Templates</i>	Effective Educational Practices for Students with Autism Spectrum Disorders	Ministry of Education		http://www.edu.gov.on.ca/eng/general/elemsec/speced/autismspecdis.pdf
Babysitting	Article	Finding a Babysitter for your Autistic Child	Autism United		http://www.autismunited.org/blog/finding-a-babysitter-for-your-autistic-child-80323.html



EDUCATIONAL TRANSITIONS

Introduction

A child's first day of school is a momentous occasion for any parent. It is often a day of excitement and anticipation, coupled with feelings of apprehension and concern. For parents of children with ASD, this can be especially true if there is uncertainty about how a child will react to their new environment. The best way to manage these concerns is by preparing and planning for educational transitions. For families of children with ASD, planning and preparation need to begin well in advance to allow for as smooth a transition as possible.

THE GOVERNMENT OF ONTARIO HAS IMPLEMENTED A NUMBER OF services designed to support students with special needs in Ontario's public schools. This includes specific policies to ensure services necessary to support children with ASD are in place across the province. The School Support Program, Connections for Students, Individual Education Plan, and Identification, Placement, and Review Committee are programs and processes that will support your child.

As a parent of a student attending a publicly funded school, remember that you can contact your child's school, principal, school board, or the Ministry of Education at any time. Should you have any concerns or questions about your child's education, you are entitled to speak openly with individuals who are in a position to assist you and your child. A link to the contact information for the publicly funded school boards in Ontario has been provided in the "Learn More" section.

Topics Covered

The first day of school is just one of the many educational transitions that you and your child will go through. Beginning with the transition to daycare, preschool or kindergarten, this process may continue through to college, university, the workplace, or adult supportive housing. Each of these transitions is different and each child will respond differently, so careful planning is required. The common transitions related to education covered in this section include:

- Daycare/preschool
- Kindergarten/primary school
- Special Education and the Individual Education Plan
- Grade 6–7/middle school
- Grade 9/high school
- Work/college/university
- Adult supportive housing

DAYCARE/PRESCHOOL

Can I enroll my child in daycare? Should I enroll my child in daycare, or will it be too upsetting? Should they attend ordinary daycare or a special needs daycare? What are the benefits of daycare? Should I stay home with my child? These are common questions asked by many parents of children with ASD. The most important step in making any decision is to consider all of your options, understand the needs of your child and the rest of your family, and research the resources available in your area.

The Ministry of Education has a number of helpful resources related to child care. These include what child care choices are available, how to find a provider, how you can prepare your child for child care, information on grants and subsidies, how to address concerns about your child's care, and resources available for children with special needs. These can be accessed through the Ministry of Education's website. <http://www.edu.gov.on.ca/childcare/index.html>.

Ontario Early Years Centres

Ontario Early Years Centres offer a range of free programs and services to parents and families of young children and are a good starting point for exploring daycare options. They include services for parents and children with special needs and have the ability to make referrals to additional community-based services. There are over 100 Ontario Early Years Centres across Ontario. Your local centre can be found online at the website listed in the "Learn More" section or by calling 1-866-821-7770, TTY 1-800-387-5559.

If you are considering enrolling your child in daycare, it is important to search for a program that can support existing interventions and therapies. When speaking with daycare program representatives, you may want to ask how their program will support your child with respect to issues such as:



Connections for Students

Some children will transition to school from Individual Behaviour Intervention (IBI) therapies and services offered through the Autism Intervention Program (AIP). If this is the case, Connections for Students can help students move from IBI services offered through the AIP to the Applied Behaviour Analysis (ABA) teaching methods used in public schools. This service is a requirement of all publicly funded school boards in Ontario. You may want to talk to your service provider about supports provided through the Connections for Students initiative.

With your involvement, this transition is supported by a team of educators and community agencies. This team will help to share information about your child as observed during the AIP. Using this information, your child's strengths and needs will be taken into account to develop a transition plan to make the entry into the public education system smoother. The team will be formed approximately six months before your child starts school and will provide ongoing assistance for at least six months after the start of school.

Included in this team will be:

- ✓ The team lead (principal or designate)
- ✓ Parent(s)/guardian(s)
- ✓ Teacher(s)
- ✓ School support program ASD consultant
- ✓ School board professional with ABA expertise (as required)
- ✓ Education assistants (if necessary)
- ✓ Special education resource teachers (if necessary)
- ✓ Other professionals (if necessary) such as mental health service providers, speech-language pathologists, occupational therapists, physiotherapists, etc.

Ontario's factsheet on *Connections for Students* can be found via the link provided to the [Council of Ontario Directors of Education's website](#) in the "Learn More" section.

School Support Program

As parents to a child with ASD, you will naturally want to make sure the support and assistance your child needs to succeed are in place. When children move into the school system, you may worry that some of the individuals responsible for your child's care and education will be unfamiliar with ASD and how to interact with your child. To help ease this concern the Ontario Government has established a province-wide program to provide school boards and educators in publicly funded schools with the information and skills they need to effectively teach students with ASD.

The School Support Program connects school boards with ASD consultants. ASD consultants are professionals who can provide teaching staff with an overview of the learning and social needs of students with ASD, and to help them learn the skills and tools they need to better understand how children and youth with ASD learn.⁶⁵

The Autism Spectrum Disorder consultants:⁶⁶

- ✔ provide training and instructional workshops to principals, teachers, teaching assistants, and other educational support staff
- ✔ consult with individual educators regarding student-specific outcomes
- ✔ provide in-school consultations
- ✔ attend school team meetings
- ✔ identify other community supports available to teachers, students, and families

Also, while School Support Program ASD consultants will not interact directly with your child, they can be involved in the Connections for Students program (if this applies to your child) and/or the development of your child's Individual Education Plan. The School Support Program ASD consultants will be an important resource for school staff regarding your child's educational needs and for issues related to your child's transition to school.

KINDERGARTEN/PRIMARY SCHOOL

Get to know your child's school

“ Approach organizations that help you advocate for the education of your child while you are doing your planning and finding out options...Start planning at least 1 year before your child is ready to enter kindergarten. ”

- PARENT FROM RICHMOND HILL

For parents of children with ASD, it is not uncommon to start planning for the transition to school up to a full year in advance of starting school.⁶⁷ It is extremely helpful to get to know the school and to help the school learn about your child well in advance of your child's first day. You can begin by:

- Visiting the websites of or calling your school and school board to ask about relevant materials and brochures; some have transition-to-school calendars specifically tailored for children with special needs;
- Scheduling a first meeting with your child's teacher, principal, and special education support person.

To prepare for this first meeting, it can be helpful to provide some information about your family and child, and explore some key questions, including:⁶⁸

- ? How can your child's preschool service provider share information, and what can they provide?
- ? What are your before- and after-school needs?
- ? What are your transportation needs and how can the school board accommodate these?
- ? How will your child's therapy services fit into school attendance?
- ? What are your child's strength and needs?
- ? What resources can the school board provide you with to ease the transition (e.g., book for your child, coaching tips, planning calendars)?
- ? What is your child's ability to adjust to change?
- ? What skills has your child developed?
- ? What have you found helpful in teaching your child?
- ? What are your child's favourite activities, likes and dislikes?
- ? How do you calm your child when they are upset, sad, or fearful?
- ? What diagnostic and medical information can you share, including any special equipment your child uses?

“ Make up a 'passport' for the teacher that describes your child's need for certain accommodations...you are the best advocate for your child. Make sure that IEPs are followed. ”

- PARENT OF 17-YEAR-OLD WITH ASD

Before this first meeting ends, ensure that you have a single point of contact at the school who is familiar with your child and their needs. This may be the teacher, the special education support person, or the principal.

The "Learn More" section provides a link to a [Planning Entry to School Kit](#) developed by the Ministry of Education.

“ Sometimes it is good for the teachers to hear how you talk to your child, the tone of voice, the response time, the length of sentences, etc. ”

- PARENT FROM HAMILTON

Helping your child get ready for school

In addition to asking about the supports available for your children, you will also want to ask how you can prepare your child for the school experience. The "Common Transitions" section of this Parent Resource Kit gives some tips for starting new school years. These include:⁶⁹



Creating a photo album of your child's school that includes pictures of the entrances, play areas, classrooms, buses, and any other areas they might use. You can also try to include a picture of your child's teacher. You and your child can review this album together before the start of the school year;



Reading storybooks about school to your child;



Scheduling a short trip to the school so that your child can have a tour in a quiet setting prior to the start of the school year.

Children with ASD often struggle as they transition to school. And no matter how well you plan, you and your child may encounter some frustrations and problems. However, having a transition plan, a single point of contact and maintaining open dialogue and conversations with your child's principal, teacher, and other support workers will help you navigate the challenges you encounter. In fact, the transition to school can provide an opportunity for you to have an early conversation with your child's service providers/health care team about how to teach or increase your child's coping and stress reducing techniques.



ONE YEAR BEFORE SCHOOL

- Introduce yourself and your child to the school.
- Discuss the needs of your child.
- A friend, partner, or advocate may attend for support.



REGISTRATION

- Attend registration clinic for your school and pick up a registration package.
- Create a plan for your child. This should include the various staff members of the school your child will be interacting with, as well as the community services that your child requires.



JANUARY-MARCH

- Continue to build your plan for the child's school year with school staff and community partners.
- Attend school information meetings.
- Plan a time to visit the school with your child.



APRIL-JUNE

- Visit the school to meet the teacher and familiarize your child with the school environment, including the classroom and other spaces your child will access (gym, playground, etc.).
- Practice school routines with your child.

SPECIAL EDUCATION

Identification, Placement, and Review Committee (IPRC)

Students with ASD generally require specific educational supports to thrive and are therefore often involved in special education programs provided by their school boards. To make sure that your child's special education needs are put in place, be sure to ask your child's school for information about special education when registering for kindergarten.

The school principal will refer your child to an Identification, Placement, and Review Committee (IPRC) for identification and placement as an exceptional student. The IPRC will review your child's needs and decide whether your child should be considered an "exceptional pupil." Exceptional pupils are students who would benefit from being placed in a special education program because of behavioural, intellectual, physical, or multiple exceptionalities.⁷⁰ You have the right to attend the IPRC meeting and can request that potential programs, which may meet your child's needs, be discussed. You can also contact the principal to arrange an alternate date or time for the meeting if you are unable to attend the originally scheduled time.

This committee is made up of the principal, school staff, and representatives from the school board. The committee will decide what educational services will be appropriate for your child's needs. This could include placement in a regular class with special education services or placement in a special education class.

Should you disagree with the IPRC decision, you are entitled to appeal the outcome. Parents may appeal a decision based on:⁷¹

- the decision that the student is an exceptional pupil;
- the decision that the student is not an exceptional pupil; and/or
- the placement decision.

To appeal the decision parents must send the appeal to the secretary of the board (who is usually the director of education) and must:

- indicate the decision with which the parent disagrees;
- include a statement that sets out the nature of the disagreement.

Parents may appeal the original and second decision of the IPRC. To do this you must file a notice of appeal with the secretary of the board within 30 days of receipt of the initial IPRC decision. An appeal to the second meeting must be filed within 15 days of the receipt of the decision.

It is important to note that no parent will lose the right to appeal an IPRC or review decision because the notice of appeal is incorrectly written or does not accurately describe the area of disagreement. In most cases, it will likely be sufficient for parents to indicate their reasons for disagreeing and the result they would prefer.



More information on the process of Identification Placement and Review Committees has been provided in the "Learn More" section. This includes information on how to prepare for an appeal process and what to expect during meetings.

Your child's Individual Education Plan (IEP)

It is possible that your child may have an Individual Education Plan (IEP) developed to help them reach their full potential. An IEP is a written plan that describes the special education programs and/or services needed by your child.⁷²



Remember, with the IEP, you can do what's needed for your child. Diapers are fine. Half days are fine. Alternate days are fine. Do what will work and try to be part of the team.



- PARENT OF 15-YEAR-OLD WITH ASD

School boards and principals are required to ensure that special education programs and services for students with ASD are available, including supporting the use of applied behaviour analysis (ABA) as an instructional approach. This requirement is laid out in the Ministry of Education Policy/Program Memorandum No. 140, which is accessible online, and also outlines the principles that underlie ABA programming in the classroom: <http://www.edu.gov.on.ca/extra/eng/ppm/140.html>.⁷³

Your child's IEP will be developed by a team of teachers, other educators, and community agencies. You will also be encouraged to participate in the development of the IEP and share information about your child. Your child's principal will be responsible for approving the IEP and ensuring that it is developed for your child within 30 days of starting school.⁷⁴

Your child's principal will also be responsible for making sure that you are involved in the review of the IEP.⁷⁵ Because of the key role played by your child's principal, many parents recommend getting to know the principal and becoming comfortable with contacting them when you have questions or concerns regarding your child's educational progress or overall school experience.

Many parents also recommend creating a binder dedicated to your child's education and including copies of IEPs, assessments, and other relevant information. This will be useful when you participate in discussions with your child's teacher, principal, or other educator.

“ Before my son first started school, I had training on Individual Education Plans (IEPs), how to create a 'binder' for your child with everything in it, etc. Best training I ever took. ”

- PARENT FROM HAMILTON

The IEP for your child will be reviewed and updated on a regular basis (at least once in every reporting period).⁷⁶ Included in the regular review will be planning for changes. Transitions may be covered in your child's IEP including:⁷⁷

- ✔ Changes between activities and settings or classrooms
- ✔ Transitions between grades
- ✔ Moving from school to school or from an agency to school
- ✔ Transitioning from elementary to secondary school
- ✔ Transitioning from secondary school to postsecondary destinations and/or the workplace

Additional special education resources

The Ontario Ministry of Education has developed a comprehensive summary of special education services for children with ASD, along with a number of helpful toolkits. These are useful in understanding:

-  Provincial guidelines for the education of students with ASD;
-  Information used to determine which educational interventions may be required to support your child;
-  Who is involved in the development of a learning profile/plan for your child;
-  How teachers assess your child's progress on an ongoing basis.

You may want to familiarize yourself with the following Ministry of Education documents:

-  Effective Educational Practices for Students with ASD
-  The Individual Education Plan (IEP): A Resource Kit
-  Transition Planning: A Resource Kit
-  Policy/Program Memorandum No. 140
-  Policy/Program Memorandum No. 156

“ Every parent of a special needs child needs to obtain a copy of the Special Education rules and regulations. ”

- PARENT OF 22-YEAR-OLD WITH ASD

Policy/Program Memorandum No. 140 outlines requirements of school boards to offer students with ASD special education programs and services, including where appropriate special education programs using ABA methods. Policy/Program Memorandum No. 156 sets out requirements associated with transition planning between activities and settings for students with Individual Education Plans.

Links to these documents along with a comprehensive summary of the IEP by Autism Ontario are provided in the [“Learn More”](#) section.

GRADE 6-7/MIDDLE SCHOOL

Many children attend a new middle school beginning in either grade 6 or 7. If possible, you may want to begin preparing for this change in early spring (i.e., March).⁷⁸ It will be important to meet with your child's current teacher/educational team and the individuals who will be primarily responsible for your child at the new school. Here are some ideas on how to promote a smooth transition:⁷⁹

- ✔ Involve your child's new teacher in the planning process and share information about your child's skills, abilities, likes, and dislikes.
- ✔ At the annual education plan conference or at the transition planning meeting, exchange information about effective instructional strategies, needed modifications and adaptations, positive behaviour support strategies, and methods of communication. It is important for your child's new teacher to learn about strategies that have worked in the past.
- ✔ If possible, see if the new teacher can spend time in your child's current classroom to observe your child's behaviour and learning styles.

Ask the new teacher how familiar they are with ASD. If they do not have experience teaching children with ASD you may want to consider asking them and/or the school principal how they could benefit from the School Support Program. As described earlier in this chapter the School Support Program can provide teaching staff with an overview of the learning and social needs of students with ASD. The program can also help educators learn skills and tools to more effectively understand and teach children with ASD.⁸⁰ More information on the School Support Program is available in the [School Support Program](#) section of this Parent Resource Kit.

“ I would make sure the elementary school is involved in the planning to make sure the school's experience with your child, the strategies they've had success with etc. are clearly communicated to the new middle/high school. ”

- PARENT OF TWO CHILDREN WITH ASD

Planning for a new school with your child

The Autism Society has published a helpful guide for school transitions in the elementary grades. This guide discusses a number of practical suggestions for helping your child transition to a new school. Some of these tips include:⁸¹

- ✔ Try to eliminate the uncertainty in your child's mind. Provide them with information about the school. Go over their schedule

along with a map of the school, new rules, and pictures of key people such as their teacher and principal.

- ✔ Arrange a school tour prior to the first day of classes to see their new classroom and meet the teachers and staff.
- ✔ Work with the school to identify a buddy for your child who can act as a mentor and include them in social activities.

GRADE 9/HIGH SCHOOL

“ There are less supports, less supervision, more expectations in secondary school. You need to be more connected to ensure success.

– PARENT FROM NORTHERN ONTARIO

Many children with ASD will attend their local high school. Although they will benefit from the mental stimulation and academic curriculum, they may find the social demands and larger, more chaotic environment very challenging.

For most parents, the transition to high school feels different from previous school transitions. Seeing your child move into the teenage years and closer to adulthood may cause concerns about how they will navigate adolescence generally. The transition to high school is part of the many physical, emotional, and social changes occurring during this period of your child’s life.

In high school youth will start to experience new social situations in a less predictable environment. The tips provided in this Parent Resource Kit on friendship and bullying (“[Social Development](#)” Section) can help with new social situations.

IT IS BEST TO BEGIN THE TRANSITION TO HIGH SCHOOL WHEN THE CHILD IS IN GRADE 7 OR EARLY IN GRADE 8.

This should include both a pre-transition meeting and pre-transition visits to the high school. The pre-transition meeting should include your child’s current educational team and the high school special education team. The pre-transition meeting should provide an opportunity for you to share and learn information about your child, their options, and the supports available.

Many of the issues addressed during your child’s transition to middle school will be relevant to their transition to high school, so their middle school transition plan can provide a starting point for planning their transition to high school. By engaging your child’s middle school education team, you can review the successes and failures of the earlier transition and help your child’s high school team understand what is likely to work well.

“ It won’t be easy...there will be tears...my daughter will be entering high school next year and still has not been to more than one birthday party...they are ‘different’...and may not be accepted by the cool kids...let them find their own friends...sometimes you just have to let them find their own way...it hurts you...and I cry...but I did with my older kids who are considered ‘normal’ as well.

– PARENT FROM SIMCOE COUNTY

As in previous transitions, visits to the high school will be helpful. The first visit is best done during a day or time when students are not in the school, allowing your child to get familiar with the building

in a calm setting. During this visit it is a good idea to introduce your child to individuals they will interact with (e.g., teachers, special education coordinators, principal) and the places they spend time in (e.g., classrooms, locker area, washrooms, cafeteria). If possible, having your child’s middle school teacher attend this visit can aid in the transition. Additional visits should then be scheduled when there are students in the school, but kept short and controlled in a manner appropriate for your child.

Thinking ahead

The section below discusses planning ahead for work, college or university and adulthood. Parents and caregivers are encouraged to begin discussing with your teen plans for the future. This may involve gathering information about the application process for supports and services provided for adults with developmental disabilities through the [Developmental Services Ontario](#) offices (refer to the end of this section for information on this resource).

Developmental Services Ontario is the single point of contact for adult developmental services. Services include:

- ✔ Providing information about adult developmental services and supports
- ✔ Confirming eligibility for services and supports
- ✔ Determining service and support needs
- ✔ Linking people to services and supports
- ✔ Administering direct funding agreements

Note:

Eligibility for adult developmental services and supports is set out in the *Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act, 2008*. Under the Act and its Regulation, a person has a developmental disability if the person has prescribed significant limitations in cognitive functioning and adaptive functioning and those limitations:

- Originated before the individual reached 18-years of age;
- Are likely to be life-long in nature; and
- Affect areas of major life activity such as personal care, language skills, learning abilities, the capacity to live independently as an adults or any other prescribed activity.

WORK/COLLEGE/UNIVERSITY

Developing a transition plan

Many parents report that planning—or even just thinking about—their child’s transition to adulthood is the most stressful task they undertake. It is critical to begin planning as soon as possible, well before age 16. It is also important to understand that many supports present from preschool through high school may not be available in either the same form or at the same level. Finally, as your child transitions to adulthood, your role as a parent and “case manager” will likely change, particularly if they move away from home.

Planning for your child’s transition out of the public education system after high school is supported through the Individual Education Plan (IEP) process. The IEP is used to support students with special education needs or “exceptionalities.” An important component of the IEP process is the development of transition plans. Transition plans are developed in consultation with parent(s), the student (as appropriate), and relevant agencies and/or partners within the community, as necessary. Information on the IEP process and

transition plans can be found on the Ministry of Education's website: <http://www.edu.gov.on.ca/eng/general/elemsec/speced/guide/resource/index.html>

For most students with IEPs, the development of a transition plan begins four to five years before leaving school (grade 8 and 9)⁸². Working with your child and their IEP team, you will begin to explore options such as: work, further education, and independent living in the community. Who is involved in developing the transition plan, and what it focuses on, will vary based on the needs of your child.

The Ministry of Education has developed a Transition Planning Resource Kit that details the transition planning process. It outlines the individuals, activities, and documentation required to develop a transition plan. A link to this document is provided in the [“Learn More”](#) section.

“ Get involved in any quality programs in the community as soon as possible DURING high school. It is better than waiting until high school is finished. Team up with other parents to provide some programs yourselves. I did that and have never regretted it. There is far too little out there for adults with ASD. Parents working together can often fill in some of those gaps. ”

- PARENT FROM HAMILTON

For the student and his/her family and personal support network, the transition plan may identify goals for work, further education, and community living that:

- Reflect actual opportunities and resources that are likely to be available after the student leaves school;
- Are achievable by the student, given appropriate supports;
- Defines the actions that are necessary year by year to help the student achieve his/her goals;
- Clarifies the roles and responsibilities of the student, family, and others carrying out these actions.

The above process discusses transition planning available through the Ministry of Education. In addition to this, the Ministries of Children and Youth Services, Community and Social Services and Education are also working collaboratively to build on and improve the continuum of transitions supports for people with developmental disabilities, which may include ASD. This is done through an integrated transition planning process. The objective is to develop an integrated plan and process that involves parents, service providers, school boards, school authorities, and schools to help make the transition to work, further education, and into the community smoother. The goal is to help your child and your family achieve positive outcomes. The ministries will begin implementing this integrated transition planning process in September 2013.

“THE OBJECTIVE IS TO DEVELOP AN INTEGRATED PLAN AND PROCESS THAT INVOLVES PARENTS, SERVICE PROVIDERS, SCHOOL BOARDS, SCHOOL AUTHORITIES, AND SCHOOLS TO HELP MAKE FURTHERING EDUCATION EASIER AND THE TRANSITION TO WORK, AND INTO THE COMMUNITY SMOOTHER.”

It will be important to involve your child in this planning as much as possible. The transition plan should include helping your child develop self-advocacy skills. These skills will enable them to proactively ask for help or discuss how a postsecondary school or employer can accommodate their needs. You may wish to consult your child's teacher and/or principal on which transition supports are most appropriate for your child.

Considering university or college

Some individuals with ASD can be successful in postsecondary education settings. In fact, universities and colleges in Ontario are reporting that more individuals with ASD are enrolling in their programs than ever before.⁸³ At the same time, like any parent planning for their child's postsecondary education, you should carefully consider whether your child has both the ability and interest required for pursuing postsecondary education.

If your child is considering a transition to postsecondary education, there are a number of issues to consider when developing a transition plan. In particular, it will be helpful to assess what specialised services or supports your child may need and how to access these services at different postsecondary institutions. You may also want to look at:⁸⁴

- Size and location of the university or college (distance from hometown, big or small city, size of the campus and student population)
- Availability of orientation programs for school, community, residences, and on-campus service providers
- Availability of tutoring, counselling, or any other specialized services
- Role of the school's Disabilities or Learning Services Office in arranging needed supports or accommodations (please note selected colleges and universities provide summer transition programs for students with ASD. When contacting the Disabilities Services Offices, you and your child should ask about the availability of these programs).

This information can be obtained by contacting a school's Disability Office, student services, registration or disability department directly. The Ministry of Training, Colleges and Universities' website has information to help students with disabilities transition to postsecondary education. A link has been provided in the [“Learn More”](#) section.

Transition to employment

For students with ASD, high school education and planning should include providing learning opportunities and experiences that will help the child build the skills needed for employment. Each child's plan for transition to adulthood should be based on their abilities and skills. If employment is a possibility, involving your child in this planning will encourage cooperation and ensure that their concerns and ideas are addressed.

“ Getting co-op positions during high school can translate into a more active life after graduation. Emphasize the importance of co-op and suggest locales and positions that would be suitable, if you know of any. ”

- PARENT FROM HAMILTON-NIAGARA REGION

Individuals with ASD sometimes find it difficult to see themselves in an employment situation. Pointing out examples of people doing various jobs in your community, on TV, or in newspapers and

magazines, and having your child perform job-like tasks at home, may help. The Autism Society has published tips for involving your child in the post high school transition process, including:⁸⁵



Be mindful of your child's social and communication skills – Emphasize employment options that do not demand excessive social interactions or the need to interpret interpersonal hints. Jobs that require frequent communication are often more stressful for individuals with ASD when compared to a quieter work setting.



Consider passions and preoccupations – Take advantage of your child's interests and identify realistic goals for employment related to these interests, given their skills and abilities.



Remember to respect the need for routine and predictability – Employment options with clear structure and predictability and minimal surprises tend to be more appealing and lead to greater success for individuals with ASD.



Provide guided choices – When discussing potential employment options try to avoid open-ended questions about what your child would like to do. Instead provide lists of two to four possibilities, or help your child generate their own list.



Work with mentors – Once you have identified some potential employment options, look for a mentor in the field who can provide feedback on the suitability of the options you have chosen and help ease your child into a new environment. This process should begin as early as possible so that the mentor and your child have an opportunity to get to know each other. Provide the mentor with information on your child's communication skills, interests, and behaviour.



Use visual supports – If your child responds well to visual supports, tools such as individualized storybooks can help to explain social expectations or the sequence of events in the new employment environment.

It might be beneficial to encourage your child to visit online blogs written by individuals with ASD who have successfully transitioned to employment. Some more popular blogs are listed in the “Learn More” section although you may want to suggest that your child conducts their own search to find other individuals with similar interests or employment goals.

When your child is ready to begin looking for employment, a number of agencies and organizations can help. Many of these province-wide organizations also provide opportunities for mentoring and/or volunteering programs during the high-school years. They include:

- **Ontario Job Opportunity Information Network (JOIN)** – Provides specialized services to individuals with disabilities to find employment and to employers looking to hire qualified candidates. JOIN also provides professional development services, mentoring connections, and access to additional service providers to find employment.
- **The Hawkins Institute** – A useful resource for families in the Greater Toronto Area. The Hawkins Institute provides employment counselling, training and placement for people with

Asperger's Syndrome and Learning Disabilities. Their services (and online tip sheets) range from assisting job searches, job coaching, and small group training to building work readiness skills, practical tips on what to wear, how to greet people and how to interview successfully.

Autism Speaks has also published an Employment Tool Kit, which can be helpful for individuals with ASD and their parents. The Tool Kit provides tips on finding the right job and employment stories from individuals with ASD. This resource is listed in the “[Learn More](#)” section. It is important to note that while a useful resource, the Autism Speaks Employment Tool Kit is an American document and therefore the employment laws, Social Security references and other American-specific services will differ from those in Ontario. The Ministry of Community and Social Services can provide you with additional information on employment related laws and supports that would apply to individuals with ASD.

ADULT SUPPORTIVE HOUSING

Housing needs

People with ASD vary in their need for supports related to housing and adult living. Some are able to live independently. Others require assistance with some tasks, and some may need 24-hour care. Given these diverse needs, a number of Adult Supportive Housing options are available. The most common are summarized below.

Broadly speaking, there are three factors to consider when helping your child plan for housing and residential supports.⁸⁶



THE HOUSING ITSELF AND THE COSTS ASSOCIATED WITH IT, WHETHER OWNED OR RENTED.



ONGOING EXPENSES SUCH AS UTILITIES, WATER, HEATING, TRASH COLLECTION, CABLE, PHONE, ETC.



SPECIALIZED SERVICES AND SUPPORT.

Planning

Planning for a transition to adult supportive housing takes a number of years. Independent living skills are not typically taught in school, so many parents begin teaching independent living skills while children are in their early teens. This is also a good time to start thinking about potential supports and services they might require in future.

A good starting point when planning housing and residential supports for your child is to ask yourself the questions about their needs, abilities, interests, and preferences. Will they want/need to live alone or with a roommate? Do they need to have easy access to public transit? Are they ready to use skills related to cooking, housekeeping, and self-care? What are the financial considerations?

“ I find this the most difficult, and schools are not preparing the students for this transition, and parents are left on their own. I suggest parents look at what is available and visit the various programs before making any decisions. Sometimes, what a parent feels is good for the individual may not be for the person with autism. The adult with autism needs to feel comfortable in the setting and with the people who work with them. ”

- PARENT FROM OAKVILLE

Models of housing

In Ontario there are a number of resources parents of children with ASD can turn to when considering their child's future living arrangements. One good starting point is Community Living Ontario, a non-profit provincial association representing 117 local associations that advocate for and assist people with intellectual disabilities. Your local Community Living Association will be able to direct you towards ASD-specific supports and help you understand eligibility criteria. A list of local associations can be found online at <http://www.communitylivingontario.ca/find>.

The following table outlines some models for housing. Some combine housing and support services; with others the services are arranged separately.

Ultimately, the most appropriate pathway to adulthood for your child will depend on their own unique abilities and needs.

RESIDENTIAL MODEL CHARACTERISTICS



Custodial Housing

- 24-hour supervision
- Basic assistance with daily living/self-care tasks
- Medication supervision



Supportive Housing

- Focused on community integration
- Personal support provided by staff members
- Usually provided through a group-home setting but can include low-support self-contained apartments



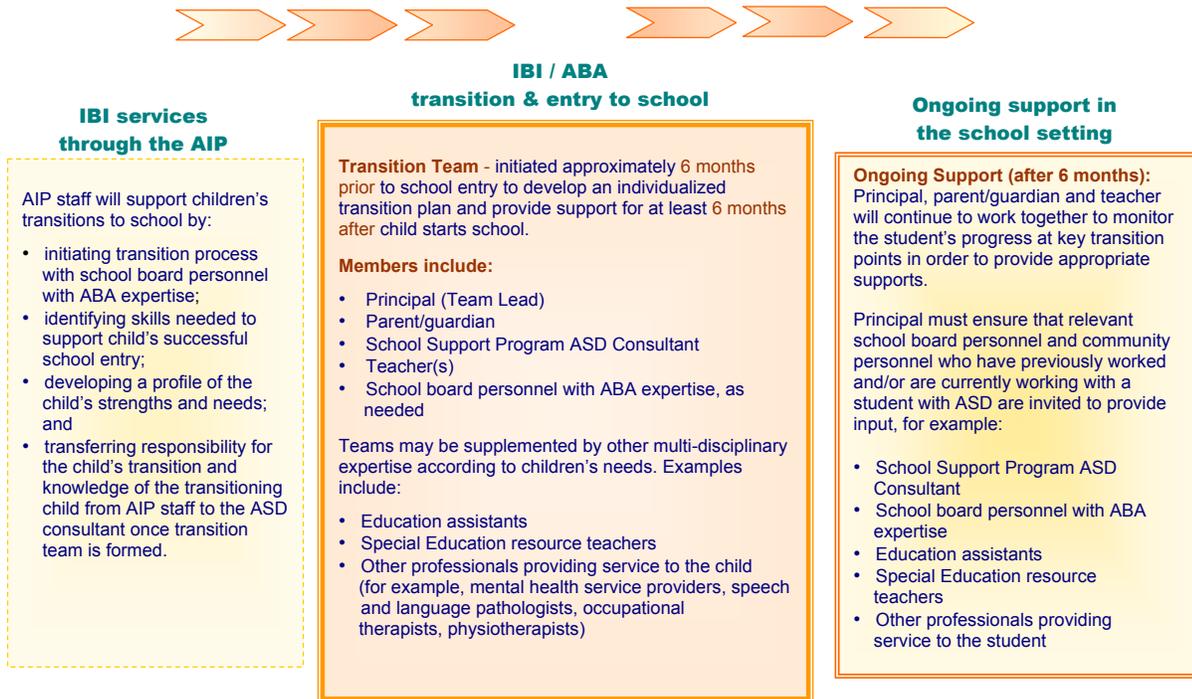
Supported Housing

- Focused on community integration
- Housing and support are separate with support services provided by outside service providers
- Typically consists of independent apartments or housing co-operatives

Source: Adapted from – Canadian Mental Health Association Ontario 'Housing'
http://www.ontario.cmha.ca/services_and_supports.asp?cID=7585

Connections for Students process for transitioning from IBI services offered through the Autism Intervention Program to public school.

CONNECTIONS FOR STUDENTS:
Supporting Seamless Transitions for Students with ASD from the Autism Intervention Program to School



Your regional Ministry of Community and Social Services office can provide you with more information about the ministry's programs and services.

MINISTRY OF COMMUNITY AND SOCIAL SERVICES REGIONAL OFFICE AND CONTACT INFORMATION

Central East Region

17310 Yonge Street
Newmarket ON L3Y 7R8
Phone: 1-877-669-6658, or (905) 868-8900
TTY: (905) 715-7759
Areas served: Durham, Haliburton, Northumberland, Peterborough, Simcoe, Kawartha Lakes, York

Central West Region

6733 Mississauga Road, Suite 200
Mississauga, Ontario L5N 6J5
Phone: 1-877-832-2818, or (905) 567-7177
Areas served: Dufferin, Halton, Peel, Waterloo, Wellington

Eastern Region

347 Preston Street 3rd floor
Ottawa, Ontario K1S 2T7
Phone: 1-800-267-5111, or (613) 234-1188
TTY: (613) 787-3959
Areas served: Cornwall, Ottawa Carleton, Prescott & Russell, Renfrew

Hamilton-Niagara Region

Hamilton Niagara Region
119 King Street West,
Hamilton, Ontario L8P 4Y7
Phone: (905) 521-7280
TTY: 1-866-221-2229, or (905) 546-8277
Areas served: Brantford, Haldimand/Norfolk, Hamilton Wentworth, Niagara

North East Region

621 Main Street West
North Bay, Ontario P1B 2V6
Phone: 1-800-461-6977, or (705) 474-3540
TTY: (705) 474-7665
Areas served: Cochrane, Muskoka, Nipissing, Parry Sound, Timiskaming, eastern part of Kenora District along Hudson and James Bay coastline

Northern Region

199 Larch Street, 10th Floor
Suite 1002
Sudbury ON P3E 5P9
Phone: 1-800-461-1167, or (705) 564-4515
TTY: (705) 564-3233
Areas served: Algoma, Kenora, Manitoulin & Sudbury, Rainy River, Sault Ste. Marie, Sudbury, Thunder Bay

South West Region

217 York Street, Suite 203
P.O. Box 5217
London, Ontario N6A 5R1
Phone: 1-800-265-4197, or (519) 438-5111
TTY: (519) 663-5276
Areas served: Counties of Middlesex, Oxford, Elgin, Huron, Bruce, Perth, Grey, Essex, Chatham-Kent, Lambton

South East Region

11 Beechgrove Lane
Kingston, Ontario K7M 9A6
Phone: 1-800-646-3209, or (613) 545-0539
TTY: (613) 536-7304
Areas served: Hastings, Kingston, Lanark, Leeds & Grenville, Lennox & Addington, Prince Edward County

Toronto Region

477 Mount Pleasant Road, 3rd floor
Toronto, Ontario M7A 1G
Phone: (416) 325-0500
TTY: (416) 325-3600
Areas served: Toronto

LEARN MORE

USE	RESOURCE TYPE	TITLE	ORGANIZATION OR PUBLISHER	AUTHOR	LINK (IF AVAILABLE ONLINE)
School Board Contacts	Directory	Find a School board	Ministry of Education		http://www.edu.gov.on.ca/eng/sbinfo/boardList.html
Pre-School	Contact Information	Locations – Ontario Early Years Centre	Ministry of Children and Youth Services		http://www.children.gov.on.ca/htdocs/English/topics/earlychildhood/oeyc/locations/index.aspx
Reference	Resource Guide, website	Planning Entry to School: A Resource Guide	Ministry of Education		http://www.edu.gov.on.ca/eng/parents/planningentry.html
School Board Directory	Directory	Find a School Board	Ministry of Education		http://www.edu.gov.on.ca/eng/sbinfo/boardList.html
Starting Kindergarten	Website	Preparing for Kindergarten: Ideas for Families	Autism Ontario	Catherine Saul, BASc	http://autismontario.novosolutions.net/default.asp?id=78&Lang=1&SID=
Connections for Students	Website	Connections for Students: Supporting Children and Youth with Autism Spectrum Disorders (ASD)	The Council of Ontario Directors of Education (CODE)		http://www.ontariodirectors.ca/ASD/asd-english.html
Connections for Students	Policy memo	Connections for students: Supporting seamless transitions From the autism intervention program to school	Ministry of Education & Ministry of Children and Youth Services		http://cal2.edu.gov.on.ca/feb2009/AutismIntervention.pdf
Special Education Overview	Reference	An Introduction to Special Education in Ontario	Ministry of Education		http://www.edu.gov.on.ca/eng/general/elemsec/specced/ontario.html
Special Education Overview	Reference	Navigating Regular and Special Education: What you need to know	ERIN-OAKKIDS, Centre for Treatment and Development	Joe Trovato	http://www.kidsability.ca/uploads/Autism%20Forums/Trovato.pdf
Overview of IPRC roles, responsibilities, and accountabilities – including dispute resolution	Reference	Highlights of Regulation 181/98	Ministry of Education		http://www.edu.gov.on.ca/eng/general/elemsec/specced/hilites.html
ABA programming in the classroom	Reference, Policy	Policy/Program Memorandum No. 140	Ministry of Education		http://www.edu.gov.on.ca/extra/eng/ppm/140.html

USE	RESOURCE TYPE	TITLE	ORGANIZATION OR PUBLISHER	AUTHOR	LINK (IF AVAILABLE ONLINE)
Frequently asked questions surrounding children with ASD	FAQ Guide	Questions and Answers: Students with Autism Spectrum Disorders	Ministry of Education		http://www.edu.gov.on.ca/eng/general/elemsec/speced/autism.html#1
Service Directory	Directory for programs and services	Ontario Service Directory	Autism Society of Canada		http://www.autismsocietycanada.ca/index.php?option=com_sobi2&catid=1310&Itemid=139&lang=en
Individual Education Plan	Website	Individual Education Plan (IEP) Meeting	Autism Ontario		http://autismontario.novosolutions.net/default.asp?id=52&Lang=1&SID
Individual Education Plan	Tips	IEP Workshop	Autism Ontario		http://www.autismontario.com/client/aso/ao.nsf/0/55C907716A20FCF9852573650015CC0F/\$FILE/Copy%20of%20IEP%20Presentation.%20September%202007.%20Slide%20Show.ppt?openelement
Elementary Grades Transitions	Website	School Transitions in the Elementary Grades	Autism Society		http://www.autism-society.org/living-with-autism/lifespan/school-transitions-in-the-elementary-grades.pdf
Individual Education Plan	Resource Guide	The Individual Education Plan (IEP): A Resource Guide	Ministry of Education		http://www.edu.gov.on.ca/eng/general/elemsec/speced/guide/resource/iepresguid.pdf
Education Planning	Reference	Identifying Trends and supports for Students with Autism Spectrum Disorder Transitioning into Postsecondary	Higher Education Quality Council of Ontario		http://www.heqco.ca/SiteCollectionDocuments/ASD.pdf
Best Practices for Students with ASD	Resource Guide	Effective Educational Practices for Students with Autism Spectrum Disorders	Ministry of Education		http://www.edu.gov.on.ca/eng/general/elemsec/speced/asdfirst.pdf
Transition Planning	Resource Guide	Transition Planning: A Resource Guide	Ministry of Education		http://www.edu.gov.on.ca/eng/general/elemsec/speced/transition/transition.pdf
Transition Planning	Website	Supporting Youth with ASDs: Transitioning	Autism Society of Canada		http://www.autismsocietycanada.ca/index.php?option=com_content&view=article&id=45%3Asupporting-youth-with-asds&catid=58%3Ageneral&Itemid=77&lang=en
Post-Secondary Education	Information Database	Thinking of Post-Secondary Education?	Autism Ontario	Jason Manett and Kevin P. Stoddart	http://autismontario.novosolutions.net/default.asp?id=148&Lang=1&SID=

USE	RESOURCE TYPE	TITLE	ORGANIZATION OR PUBLISHER	AUTHOR	LINK (IF AVAILABLE ONLINE)
Transition Planning	Website	Involving your Child with ASD in the Post-High School Transition Process	Autism Society		http://www.autism-society.org/living-with-autism/lifespan/post-high-school-transition-process.pdf
Transition to Postsecondary Education	Guide	Supporting Students on the Autistic Spectrum	National Autistic Society		http://www.liv.ac.uk/studentsupport/disability/pdfs/NAS-Student-Mentor-Guide_LowRes.pdf
School Transitions	Tool Kit	Transition Tool Kit	Autism Speaks		http://www.autismspeaks.org/family-services/tool-kits/transition-tool-kit
Transition to Postsecondary Education	Reference	Navigating College	Autism Self Advocacy Network (ASAN)		http://www.navigatingcollege.org/
Transition to Postsecondary Education, Students with Disabilities	Website	Students with Disabilities	Ministry of Training, Colleges and Universities		http://www.tcu.gov.on.ca/eng/postsecondary/careerplanning/disabilities.html#display
Transition to Postsecondary Education	Website	Students with Disabilities	Queens University		http://queensu.ca/rarc/transitionguide/
Transitions to Adulthood	Website	Disability Services Ontario	Disability Services Ontario		http://www.dsontario.ca
Elementary/Secondary Education, Post-Secondary Education, Planning for the Future, Volunteering and Employment, and Skills Development.	Information Database		Autism Ontario – Knowledge Base		http://autismontario.novolutions.net/default.asp?id=103&Lang=1&SID=
Directory of popular blogs	Blog	Top 25 Autism Spectrum Blogs: Young People on the Spectrum	Babble.com	Various	http://www.babble.com/baby/baby-development/top-25-autism-blog-young-adult/
Directory of Popular Blogs	Blog	Blog: Autism Matters	Autism Society	Various	http://www.autism-society.org/blog/?topic=living-with-autism&audience=individuals-on-the-spectrum
Services Providers	Contact List	Autism Ontario – Local Chapters	Autism Ontario		http://www.autismontario.com/Client/ASO/ao.nsf/web/OntarioMap
Employment	Website	AI Green Resource Centre	JVS		http://www.jvstoronto.org/index.php?page=ai-green-resource-centre

USE	RESOURCE TYPE	TITLE	ORGANIZATION OR PUBLISHER	AUTHOR	LINK (IF AVAILABLE ONLINE)
Employment	Tool Kit	Employment Tool Kit	Autism Speaks		http://www.autismspeaks.org/sites/default/files/docs/employment_tool_kit.pdf
Employment	Website		Link Up Employment Services for Persons with Disabilities		www.linkup.ca
Employment	Website		Ontario Job Opportunity Information Network		http://www.joininfo.ca/
Adult Housing	Tool Kit	Housing and Residential Supports Tool Kit	Autism Speaks		http://www.autismspeaks.org/sites/default/files/housing_tool_kit_web2.pdf
Adult Housing	Contact List	Find a Community Living Near You	Community Living Ontario		http://www.communitylivingontario.ca/find
Services	Reference	Support and Services Needs of Adolescents and Adults with ASD with Psychosocial Problems	Autism Ontario		http://www.autismontario.com/client/aso/ao.nsf/object/AA8/\$file/AA8.pdf



FAMILY TRANSITIONS

Introduction

Life with children can be complicated and filled with changes. Families move, parents change jobs, household pets come and go, and siblings grow up together. You may worry about how your child with ASD will react to these changes, which can be another source of unpredictability and disruption to routines. Still, many families do successfully navigate these transitions. The tools and tips provided in this section will help to equip you for these events.

Topics Covered

This section provides information on some common transitions experienced in family life, including:

- 🏠 New house/moving
- 👪 Siblings
- 👔 Death of a family member/caregiver
- 👪 Divorce
- 🏠 Other family transitions

NEW HOUSE/MOVING

Help your child understand the move

The common experience of moving homes can cause stress and anxiety in children. This is especially true for children with ASD, for whom routines and consistency are so important.

When explaining the move, use terms that your child will understand and relate to. Try to think of examples that will make the move meaningful to your child, especially positive changes such as: getting a bigger backyard for their trampoline or garden; being closer to mom or dad's work so that they spend less time driving and more time with the family; or getting away from loud noises that bother them.

How to prepare for the move

You can support your child by helping them understand what will change and what will remain the same after the move. Try writing down the most significant things that will change and the things that will stay the same (e.g., if their school will remain the same, whether their activities will still take place on the same night). Keep in mind that while some changes that need to be discussed will be obvious, certain less obvious changes may also affect individuals with ASD. Small differences such as changes in flooring, the position of light switches and new noises may be important to your child. Making note of these differences in your new home can help you prepare your child in advance.

Try to break the move down into small steps, and involve your child by explaining the process to them. Once you have confirmed dates, you can create a calendar and visual aids to help your child understand what will happen and when. Storybooks on moving homes can also help ease the transition to the new home. You can create your own story about your new house by including:⁸⁷



Photos of the new house, their room, kitchen and neighbourhood, along with photos illustrating the moving process including boxes, moving trucks, and movers;



A map of your new neighbourhood noting locations your child may already know or that may be of interest to them;



A floor plan or rough drawing of the house to accompany the photographs.

You might also be able to arrange to visit the new home before the move to take pictures and give your child a first look at the new house.

On the day of the move, some children may benefit by participating and helping. For others, it may be best not to involve them directly. Either way, children should understand that at the end of that day,

they will be going to the new home. If possible, unpack their room first and try to set it up similarly to their old room. As your family settles into the new home, it is a good idea to keep as many other routines the same as possible, including evening activities, school routines and caregivers/babysitters.

SIBLINGS

Common parent concerns

Parents of children with ASD sometimes say they have to put parts of their life “on hold.” They may sacrifice personal interests, career ambitions, and even some aspects of their relationship with their partner. But few parents want to extend this sacrifice to relationships with their other children. And, of course, the needs of siblings should not be neglected. Trying to balance the needs of your child with ASD with those of your other children can lead to difficult choices, conflicts, tensions, and feelings of guilt. Taking some time to consider and learn about your other children's unique situation and how to address their needs can make this parental balancing act a little easier to manage.

Sources of stress for siblings

Having a sibling with ASD can cause a great deal of stress for children and adolescents. Understanding specific sources of stress is an important starting point for parents wanting to help improve the relationship between siblings. Siblings may experience:⁸⁸

- 🏠 Embarrassment in front of their friends or jealousy at the amount of time parents spend with their sibling
- 👪 Frustration over not being able to speak or play with their sibling
- 👪 Being on the receiving end of aggressive actions or tantrums
- 👪 Worry about the ability of parents to cope with difficult family situations
- 👪 Uncertainty over what role they will play with their sibling as they transition to adulthood

How to speak to your other children about autism

The Autism Society of Canada has published tools and tips to help parents support their neurotypical children. Some examples:⁸⁹

- ✔ Explain autism to children early and often, focusing on information that is suitable for the sibling's age group and relevant to their own experience (e.g., why their brother won't play).
- ✔ Help your children form a relationship with their sibling with ASD by teaching them skills that will help them engage their brother or sister, such as finding activities they can enjoy together, keeping communication simple, and praising good play.
- ✔ Set aside special one-on-one time with your children who do not have ASD. Regularly scheduled separate time, such as one evening a week, a weekend morning, or extra time before bed can help the child feel loved and important within your family.
- ✔ As you support your other children's transition to adulthood take time to discuss feelings of responsibility they may have and the role they may play in their sibling's care and guardianship.

More on sibling support

For more information, the Autism Society of Canada has developed pamphlets to help explain ASD to children and teenagers. The National Autistic Society (UK) has also addressed some of the more common questions that parents have when trying to support older

and younger brothers and sisters of children with ASD. Links to these references have been provided in [“Learn More.”](#)

Sibling support groups can be helpful for many brothers and sisters of children with ASD. Talking with children and the professionals who lead these groups can help children develop a greater sense of understanding, a fresh perspective, or simply talk freely about their own situation. Your local Autism Ontario chapter may provide a starting point for finding a regular sibling support group in your area.

DEATH OF A FAMILY MEMBER/CAREGIVER

Death is an uncomfortable subject

Discussions about death are difficult for any parent, but children with ASD may have an especially hard time understanding death or adapting to the deceased person's absence.

When explaining the death of someone close to your child, it is best to be as clear as possible and explain what happened as best you can. If someone close has become ill, explain why they are spending time in hospital. If an illness within the family progresses, there may be disruptions in normal routines. You may be able to help your child to understand and prepare for these disruptions by using calendars to document appointments or stays in hospital. These can be placed on the calendar along with your child's regular schedule so that the situation is put in the context of their life.

How to approach the subject of death

Unfortunately, there may be a time when you need to prepare your child for the possibility that someone close to them may die. Using examples and visual aids from nature and biology, such as the life cycle of plants or insects, can be helpful to explain the concept of death. In general when explaining death to a child with ASD it is important to:⁹⁰

- ✔ Prepare your child as much as possible
- ✔ Minimize disruptions to routines
- ✔ Use clear language and avoid non-literal phrases like “passing away”
- ✔ Use visual aids such as a visual schedule or story book
- ✔ Be on the lookout for unfamiliar or delayed displays of grief, such as challenging or obsessive behaviour or an increased reliance on routines.

For more information and tips on speaking to your child about the death of a family member or caregiver, a link to an information sheet compiled by The National Autistic Society (UK) is provided in [“Learn More.”](#)

Planning for your own death

One of the biggest concerns shared by all parents of children with disabilities is: “What will happen to my child after I am gone?” While planning for your own death is not something most people want to do, having a plan that details your wishes and outlines supports established for your child can ensure that they continue to receive the care they need. In fact, creating a plan with the appropriate experts (lawyer, financial planner) can significantly reduce a source of stress in your life.

“ My son's biggest worry is that no one will be willing to care for him or guide him when he is an adult and I have passed away and that he will be living on the street. ”

-PARENT FROM WELLAND

Autism Ontario has published a brief feature on the benefits of having a thorough will and plan for your child. Some key points to consider include:⁹¹

- ✔ When composing a will, consider having it legally written and registered with a lawyer. Also consider discussing the benefits of a Henson Trust for your child to so that their inheritance does not interfere with government-issued disability pensions. An electronic booklet explaining [Henson Trusts](#) is available through the Autism Ontario website link provided in the “Learn More” Section
- ✔ When considering individuals to play a role (whether as an executor or the individual(s) who will have responsibility for your child) within your will, ensure that they fully understand their roles and responsibilities.
- ✔ Speak with a financial advisor to determine your insurance needs and how to make your child's estate a beneficiary.
- ✔ Keep all relevant information (financial, medical, contacts, etc.) well documented and in a central location.
- ✔ Review your will at least annually, ensuring that the information is current and individuals referenced in it are still able to fulfill their responsibilities.



What is a Henson Trust?

A trust is a legal arrangement where an account is set up to support one individual (the beneficiary) but is in the name of another person (the trustee) who must use the money or assets of the trust to benefit the beneficiary.

A Henson Trust gives complete control to the trustee about when to pay or not pay income and capital to the beneficiary. [http://www.autismontario.com/client/aso/ao.nsf/docs/c3397f85f925779085257855004ee352/\\$file/henson+info](http://www.autismontario.com/client/aso/ao.nsf/docs/c3397f85f925779085257855004ee352/$file/henson+info).

Autism Ontario's Knowledge Base has a comprehensive section dedicated to “Just in Case Planning.” A link to Autism Ontario's full three-part feature on making post-death provisions for your child is also provided in the [“Learn More”](#) section.

DIVORCE

As is the case in any family, parents of a child with ASD may decide to separate or divorce. Divorce between parents can be difficult for any child. For children with ASD there are the added concerns associated with their possible aversions to change, difficulties communicating their feelings, and/or special care needs.

You may want to help your child through a divorce by helping them understand the divorce. This may involve pictures, stories, or any other method(s) that are best suited to helping your child understand. Using a calendar to outline how days will be spent can also be useful. This could involve a countdown to when one parent will move out or identifying the days that will be spent with each parent.

For parents who have decided to separate it can be beneficial to search recent online blogs to read the stories of other parents and/or join a local parent group for single parents. These groups can help you talk with other parents who have separated and offer support during a difficult time.

Finally, there is an “urban legend” that the divorce rate among parents of children with ASD is very high or even 80%. Fortunately, there is no evidence to support this. In fact, a recent study found that children with ASD were just as likely to live with two parents as neurotypical children.⁹²

OTHER FAMILY TRANSITIONS

Many major and minor family events—from divorce to the death of a pet—can be difficult for children with ASD and the family. There are few specific resources for these situations, and those that do exist may not fit your unique circumstances or the needs of your child. For issues like these, you are likely best off speaking with other parents of children with ASD, friends and family or searching the Internet for resources and online support groups where you may be able to connect with other parents who have had these experiences. There are many important issues for which toolkits do not exist, and like other parents, you will just need to make it up as you go along.

TOOLS

Siblings may become frustrated when playing with their brother or sister who has ASD. Part of this frustration may have to do with their sibling's underdeveloped turn-taking skills. Parents and siblings can use these tips to help promote turn taking.

Turn Taking

Turn taking is an important skill for children to learn. It is the beginning of social interaction between the child and another person. Children learn about taking turns in play. Later, children understand taking turns when they speak with others.

Choose games in which the child has to wait for a turn before taking one. You can start by having a really fast turn and then letting him have his turn for longer. Be sure to label with gestures and pointing to let him know whose turn it is, for example, "Your turn" (point to him) and "My turn" (point to yourself). These activities can be tried at home and at school. Remember, having only one item necessitates sharing and taking turns!

Activity	Making It Interactive	Use Words to Label
Ball	Play catch, roll/bounce back and forth, throw ball into a box or pail	ball, throw, bounce, catch
Music (use one drumstick, musical toy)	Take turns hitting the drum, shaking the bell, pushing buttons to activate music	bang, music, drum
Stacking rings	Take turns stacking and removing rings	ring, on, off
Blocks	Build one tower together; take blocks off one at a time	on, block, off, down
Shape sorter	Take turns putting one shape in/taking one shape out	in, out, shape
Craft activities	Use one crayon, one paintbrush, one marker Take turns colouring, painting, etc.	on, colour, paint
Doll and accessories	Take turns with one doll, one brush, one spoon, one bottle, etc.	brush, eat, hug, dolly, eat, drink, bottle, milk
Cars/trucks	Take turns driving one car down a ramp, along a road	car, drive, on, down
Sand play	Take turns using toys in the sand: one shovel, one strainer, one pail, one scoop	in, sand, shovel, pail, pour

Halton Catholic District School Board

LEARN MORE

USE	RESOURCE TYPE	TITLE	ORGANIZATION OR PUBLISHER	AUTHOR	LINK (IF AVAILABLE ONLINE)
Moving Homes	Tips	Moving House	The National Autistic Society		http://www.autism.org.uk/living-with-autism/at-home/moving-house.aspx
Moving Homes	Tips	Helping Your Autistic Child Cope with a Move	Disney Family		http://family.go.com/parenting/pkg-preschool/article-800442-helping-your-autistic-child-cope-with-a-move-t/
Siblings	Tips	Siblings	Autism Society		http://www.autism-society.org/living-with-autism/family-issues/siblings.html
Siblings	Article	Real Life Stories from Siblings	National Autistic Society		http://www.autism.org.uk/Living-with-autism/Real-life-stories/Real-life-stories-from-siblings.aspx
Important points to remember when considering the needs of siblings	Tips	Sibling Perspectives: Guidelines for Parents	Autism Society		http://www.autism-society.org/living-with-autism/family-issues/sibling-perspectives.pdf
Guide for explaining Autism to small children	Tips	Growing Up Together	Autism Society		http://www.autism-society.org/living-with-autism/family-issues/growing-up-together.pdf
Guide for explaining Autism to teenagers	Tips	Growing Up Together: Teens with Autism	Autism Society		http://support.autism-society.org/site/DocServer/NEWasa-growing-up-teen-final-rev.pdf?docID=11041
Death	Reference	Death, Bereavement and Autism Spectrum Disorders	National Autistic Society		http://www.autism.org.uk/living-with-autism/at-home/death-bereavement-and-autism-spectrum-disorders.aspx
Death	Article	A Cautionary Tale: If I Got Hit By a Bus Tomorrow... (Autism Matters Magazine)	Autism Ontario		http://www.autismontario.com/client/aso/ao.nsf/docs/32f8e617a5e6898525786b007266cc/\$file/a+cautionary+tale+part+1.pdf and http://www.autismontario.com/client/aso/ao.nsf/docs/4e1236ff4fd2aa408525786b0072778c/\$file/a+cautionary+tale+part+2.pdf and http://www.autismontario.com/Client/ASO/AO.nsf/object/ACautionaryTale3/\$file/A+Cautionary+Tale+-+Part+3.pdf
Death	Tips	Planning for the Future	Autism Ontario		http://autismontario.novosolutions.net/default.asp?id=122&Lang=1&SID=
Henson Trusts	Reference	Consider A Henson Trust	Autism Ontario		http://www.autismontario.com/client/aso/ao.nsf/docs/c3397f85f925779085257855004ee352/\$file/henson+info.pdf



SENSORY DEVELOPMENT

Introduction

Individuals on the autism spectrum can have difficulties with sensory processing. This means that they have trouble making sense of information from their five senses: sight, sound, touch, scent, and taste. One of the reasons individuals with ASD have difficulty understanding the world around them is that their brains have trouble processing sensory information. This can cause discomfort, distress, and confusion for children with ASD.

ADULTS ON THE AUTISM SPECTRUM SOMETIMES IDENTIFY SENSORY issues as being one of the most frustrating parts of their childhoods. Oversensitivity to touch is one example; children with ASD may also experience sensory overload in crowded and noisy places or when meeting a new person with an unfamiliar appearance, smell, and voice. Understanding what types of sensations are most likely to cause your child discomfort can help you avoid or manage the situations that stress your child. The topics presented in this section are intended to help you discover and better understand your child's specific sensory triggers.

“It's taken a number of years for us to completely take in the range of sensory issues our son has. We pay far more attention to it now, and by modifying his surroundings both at school and at home we are able to reduce his meltdowns and improve his ability to manage a situation.”

- PARENT OF A 9-YEAR-OLD WITH ASD

Topics Covered

Sensory triggers are as diverse and wide-ranging as children with ASD. So there is no standard list of triggers for children with ASD. When considering potential sensory stressors in your child's day-to-day environment, start with the broad categories that your child's five senses encounter every day. In this section, we discuss:

- Food
- Touch, textures, and clothing
- Sound
- Light

FOOD

Many children have “fussy eating” habits. In most children more “normal” eating habits develop as the child matures. In contrast, children with ASD often continue to display difficult behaviour around mealtime such as:^{93 94}

- ✓ Not wanting to sit for meals
- ✓ Taking food from others' plates
- ✓ Selective eating by food type such as only eating foods with certain textures, colours, smells, or within certain food groups
- ✓ Gagging on food or vomiting food they don't like
- ✓ Refusing to use cutlery or obsessively placing cutlery and food

Many families of children with ASD experience these sorts of behaviours and children with ASD often do not grow out of them the way neurotypical children do. Encountering these behaviours three times a day or more can be stressful and parents may also worry about their impacts on their child's growth and health.

Working to overcome eating problems

Developing a strategy to overcome eating issues often starts with determining what is causing the problem. Depending on the cause of your child's eating problem, a number of different approaches may help to improve challenging eating habits or behaviours. Some of these include:⁹⁵



Offering appropriate serving sizes (not overcrowding a plate) and making food attractive (e.g., using cookie cutters to make food different shapes, considering the colour of food)



Involving your child in food preparation if possible



“Hiding” nutritional elements in food your child will eat (blending vegetables into sauces your child eats, etc.)



Having a preferred toy on the table so your child plays with it instead of the food

There is no quick fix for the eating problems of children with ASD. You will need to be patient but persistent in shaping your child's behaviour. Having a routine—consistent mealtimes, for example—and sticking to it is important. If you begin to suspect that your child's eating problems are due to a physical problem such as a difficulty swallowing, diarrhea or vomiting, or a sudden loss of appetite, schedule an appointment with your child's doctor as soon as possible.

More information on understanding eating problems

If you want to learn more about eating problems and how to address them, the resources provided in the “Learn More” section include information on factors that may contribute to eating problems, such as developmental level, ritualistic behaviours and impaired skills in the areas of social interaction, play and imagination. Also included are references that suggest questions to consider prior to talking to your child's doctor about eating.

TOUCH, TEXTURE AND CLOTHING

A common and frustrating sensitivity

Textures are a common source of sensitivity for children and adults with ASD.⁹⁶ Outbursts and tantrums caused by reactions to certain textures and touch sensations are also common. Since many parents have had to manage this issue with their children, there are many tips and suggestions for overcoming or working around texture sensitivities.

Sensitivity to touch comes in many forms. Some of the more common ones include:⁹⁷



UNEXPECTED TOUCHES

(e.g., sudden hugs from Grandma or a pat on the back)



THE TEXTURE OF CERTAIN OBJECTS

(e.g., sand, playdough, glue, slimy objects)



OVERLY SENSITIVE BODY PARTS

(e.g., complaints of pain during nail clippings or haircuts)

For many parents, the most difficult sensitivities to manage are related to clothing. Some children will insist on wearing only a limited number of outfits because of the way they feel. Others will feel the need to strip down in public to get out of “stiff” or “scratchy” outfits.

How to help or cope with sensitivities to touch

Sensory Integration Therapy, a form of occupational therapy that helps people regulate their responses to sensory stimulation,⁹⁸ is one

technique that may be helpful for some children and could be worth discussing with your physician or occupational therapist.

Cutting the tags off clothing is helpful for some children while sticking to a certain brand or style of clothing may help others. Most parents feel that having their child keep their clothes on is worth the trade-off of limited wardrobe choices associated with a single brand or style!

You may also find that family, friends, and teachers need to be aware of your child's aversions to certain touches and textures.⁹⁹ Many educational and social activities can be adapted to reduce or avoid touch and texture sensitivities. Family members also need to be aware of how their hugs or kisses could be upsetting. In some cases, giving your child a warning that allows them to prepare for a hug can help.

There are also certain touch and texture experiences that many children with ASD find enjoyable. For example, Temple Grandin, a university professor and author with autism, enjoyed feelings of deep-pressure and squeezing.¹⁰⁰ A quick Internet search can help you find many products that provide similar sensations to children. Swimming is another activity that many people with ASD find calming. Some Autism Ontario chapters offer swim events in co-operation with municipalities and public pools.

SOUND

Some individuals with ASD will have a sensitivity to various sounds. In many cases these specific sounds will be ones that most neurotypical individuals do not find bothersome. This can make it challenging for parents to identify what sounds are bothering their son or daughter.

According to some research, there are three broad types of sound that individuals with ASD can find upsetting.¹⁰¹

- ❖ Sudden, unexpected noises such as car horns, alarm bells, people yelling, or balloons bursting
- ❖ Continuous high-pitched sounds including vacuum cleaners, kitchen appliances and other household items
- ❖ Complex or confusing sounds, which are created by multiple sources, as in a crowded market or store

Identifying the sound that may be causing your child distress is the first step in helping them. Children with ASD often indicate their sensitivity to sounds by covering their ears, flinching, or describing how certain sounds hurt.¹⁰²

How you can help

Some solutions to sound sensitivity can be as straightforward as removing the source of the sound from the child's environment. Others may involve a more collaborative effort, such as working with your child's teacher to make adjustments to their classroom to remove certain sounds.

“ At school, send a fidget toy or box for your child to play with. Send noise dampening headphones, a weighted blanket, toy or vest if sensory issues are a concern. Make arrangements for your child to chew gum—it can calm them down and help them make friends. ”

-PARENT FROM KINGSTON

There are various therapies that have been used to treat sound sensitivities. Two therapies that you may come across are Sensory Integration Therapy (mentioned previously) and Auditory Integration Therapy.¹⁰³ Service providers offering these therapies can be found on Autism Ontario's [SPIRALE](#) website. Discuss these options with your physician to make sure they are appropriate for your child.

LIGHT

Many individuals with ASD have sensitivities to light or other visual stimulation.¹⁰⁴ If you notice that your child has aversions to items of a particular colour, becomes agitated on sunny days or upset in buildings brightly lit by fluorescent lights, it is possible they have a sensitivity to certain types of light.

Here are a few simple strategies many parents use to help their child cope with visual sensitivities.¹⁰⁵

- ❖ Using sunglasses or hats outdoors and indoors to dim bright lights and reduce glare
- ❖ At school, having the child seated away from the window
- ❖ Providing an area where they can calm down if need be with a pleasant lighting level

Some of these strategies will require working with your child's teacher and other caregivers, but they can be effective at reducing the visual overload some children experience.

SENSORY ISSUES

Gags at common household smells



May have difficulty tolerating music



Spinning objects close to face



May appear deaf, not startle at loud noises but at other times hearing seems normal



LEARN MORE

USE	RESOURCE TYPE	TITLE	ORGANIZATION OR PUBLISHER	AUTHOR	LINK (IF AVAILABLE ONLINE)
Reference	Book	The Complete Guide to Asperger's Syndrome	Jessica Kingsley Publishers	Tony Attwood	
Meals and Food	Factsheet	Food	Monash University		http://www.med.monash.edu.au/spppm/research/devpsych/actnow/download/factsheet17.pdf
Meals and Food	Reference	Mealtime and Children on the Autism Spectrum: Beyond Picky, Fussy and Fads	Indiana Resource Centre for Autism		http://www.iidc.indiana.edu/?pageId=476
Meals and Food	References	What Is Sensory Processing Disorder and How Is It Related to Autism?	Psychology Today		http://www.psychologytoday.com/blog/the-autism-advocate/201003/what-is-sensory-processing-disorder-and-how-is-it-related-autism
Sensory Issues	Reference	Autism Physician Handbook	Autism Canada		http://www.autismcanada.org/pdfs/PhysicianHandbook.pdf
Sensory Tools and Products		Sensory Tools and Products	Autism Speaks		http://www.autismspeaks.org/family-services/resource-library/sensory-tools-products
Specific books and references	Reference Guide	Library Sensory Resources	Autism Ontario		http://www.autismontario.com/client/aso/ao.nsf/Kingston/Library+Sensory?OpenDocument&PFV
Sensory Issues		Autism Life Skills: From Communication and Safety to Self-Esteem and More	Perigee Trade	Chantal Sicile-Kira	



PHYSIOLOGICAL DEVELOPMENT

Introduction

As children mature physically they need to master new self-care tasks, develop new skills, and understand new social situations. Parents of children with ASD may find it hard to ask for help with issues related to physical development, as many of these concerns are awkward or difficult to understand for people unfamiliar with ASD. Yet the questions you have and areas you need help with are shared by many other parents in your situation.

Topics Covered

This section covers some of the more common concerns parents have about the physical development of children with ASD. In addition, the “Learn More” section contains links and references for a wide range of information, tools, and guides associated with other areas of physical development from childhood through adolescence. Topics covered include:

- ▶ Toilet training/bed wetting
- ▶ Self-care
- ▶ Sleeping
- ▶ Motor skills
- ▶ Puberty
- ▶ Recreational Activities

TOILET TRAINING/BED WETTING

What's causing the problem?

Toilet training can be difficult for many children. There may be additional challenges for a child with ASD. They often learn this skill later in life than other children, and sometimes require over two years of training to achieve bowel and bladder control. Understanding what your child is having difficulty with can help you develop an effective toilet training plan. Some common problems include:¹⁰⁶

- ✔ Physical or medical reasons, such as constipation or impaired neurological bladder and bowel control, that may be discussed with your child's paediatrician or physician;
- ✔ Trouble understanding and using language to ask to use the toilet;
- ✔ Difficulty removing their pants and putting them back on;
- ✔ Fears of sitting on a toilet and hearing it flush or of using different/new toilets;
- ✔ Lack of awareness of body cues indicating they need to go or that their clothes are wet.

When and how should I begin?

The first sign that your child might be ready to start toilet training is when they begin to become aware of their urination or bowel movements. Behaviours such as fidgeting before a bowel movement, appearing uncomfortable when they are wet, or the ability to stay dry for a couple of hours at a time might indicate that it is a good time to start toilet training.

Autism Speaks has a comprehensive toolkit for toilet training that includes how to develop a plan, quick points to practice, and tips to increase toilet training success.

SELF-CARE

For some children with ASD, skills that require more than one or two steps to complete can be challenging. This includes self-care skills such as brushing teeth and washing hands. Depending on your child's abilities, the thought of teaching them self-care skills may feel overwhelming. However, by using a plan and clearly breaking down self-care tasks into step-by-step activities, many parents have successfully improved their child's independence.

Break the task down

The first step to teaching a skill to your child is to break a complex task down into smaller step-by-step actions, and develop a visual schedule illustrating each step. Handwashing is a good skill to start with. Once you have a list of the actions involved in the task you can begin to teach steps to your child one at a time, reinforcing them once the step is completed. Some parents will find it more effective to have their child master the skills involved in the first action (and coaching their child through the rest of the actions) before trying to master the second action. Others may find it more effective to have their child master the last action of the task first, which involves coaching them through the steps leading up to the last action and then having the child complete the finishing action independently. Once this is successfully accomplished you can teach your child to master the second-to-last step and so on. By gradually repeating this process, they may be able to complete more and more of the task until they are completing the task independently.^{107 108}

EXAMPLE OF HANDWASHING STEPS



WALK TO THE SINK



TURN ON THE WATER



SQUIRT SOAP IN HAND



RUB HANDS TOGETHER



RINSE SOAP OFF HANDS



TURN OFF THE WATER



GET A TOWEL



RUB HANDS ON TOWEL UNTIL DRY



REPLACE THE TOWEL

Tips for reinforcing individual steps

Tips for reinforcing individual steps include:

- ✔ Creating a visual task schedule (in a style similar to a newspaper comic strip) with words and pictures representing the task (turning water on, putting hands in water, getting soap, rubbing hands, etc.) and posting the schedule in the room where the task is to be completed.
- ✔ Reminding your child of the visual task schedule and drawing their attention to it through a gentle tap on the shoulder.
- ✔ Using a playful and friendly tone to remind them of the first step.

Each time your child repeats a step in a task, try waiting a little longer before reminding your child to complete the next step. Once the last step is mastered, be sure to praise them as reinforcement.

SLEEPING

Sleeping problems are common among children with ASD

Children with ASD may have more trouble sleeping than other children.¹⁰⁹ Sleep problems can be a major source of stress for parents, especially if their nights are often disrupted. While parents of neurotypical children may have trouble understanding sleep problems in later childhood, most ASD families can relate!

Some of the more common sleeping problems that children with ASD experience include:¹¹⁰

- ▶ Difficulty falling asleep or staying asleep
- ▶ Early morning waking
- ▶ Trouble falling asleep alone (the need to sleep with a parent)

Other problems such as snoring, gasping for air while sleeping, and/or bedwetting may require evaluation from your physician or a sleep specialist.

Suggestions for helping you and your child get a better night's sleep

Approaches identified by sleep experts and other parents to help children with ASD get a better night's sleep often include:¹¹¹



PROVIDING A COMFORTABLE SLEEP SETTING

The bedroom should be quiet, dark, and the right temperature. Try leaving a dim nightlight on if it is too dark or adding heavier curtains to the windows if streetlights or sunlight shine into the room. Limit household noises (e.g., running water, washing machines) and consider your child's sensitivity to the texture or weight of their blankets and pyjamas.



ESTABLISH REGULAR BEDTIME ROUTINES

Set a short (20–30 minute) bedtime routine that includes relaxing activities to calm your child. Avoid television, computers, loud music, bright lights, and physical activity. Try creating a visual schedule or “to-do” list to remind your child of the steps.



TEACH YOUR CHILD TO FALL ASLEEP ALONE

If your child needs you close by to fall asleep, a slow and gradual change is the best approach to teaching them to fall asleep alone. You might start by sitting on the edge of the bed, then gradually move down to the foot, then to a chair beside the bed, and so on.



PROMOTE DAYTIME BEHAVIOURS TO ENCOURAGE SLEEP

Children who exercise daily and avoid caffeinated drinks and foods tend to sleep better. Caffeine can stay in your child's body for up to 12 hours and tiring activities should end 2–3 hours before bedtime.

What if these tips don't improve my child's sleeping?

A more comprehensive overview of the tips and suggestions outlined above are provided in the resources in the [“Learn More”](#) Section.

If you are stressed by ongoing sleep issues, try consulting with other parents of children with ASD in your support network and speaking to your physician. Fellow parents have likely experienced similar situations and can provide ideas on how they may have modified their child's sleep habits, while your physician can explore possible medical reasons behind your child's sleeping problems. Autism Speaks and the National Autistic Society (UK) have developed helpful sleep aid toolkits. They are available online through the links provided in the [“Learn More”](#) Section.



Our son is 9 and he sleeps in our bed. Having tried everything, we are just living with this at present, looking forward to the day something comes along to help us get him into his own room. But until that happens we can only go and stay places and with relatives that are okay with this (and don't offer unwanted advice).



– PARENT FROM PETERBOROUGH

MOTOR SKILLS

What are gross motor skills?

Gross motor skills are skills that require the coordination of large muscle groups. They include skills such as running, jumping, climbing, catching, and throwing. In some cases children with ASD may have poorly developed gross motor skills leading to uncoordinated or clumsy movements.

Difficulty mastering gross motor skills may be a result of factors such as:¹¹²

- ✔ Limited awareness of where their body is in relation to the space the child is in
- ✔ Lack of motivation or interest to participate in activities that encourage the use of these skills (or avoidance because of the social nature of many of these activities, including sports)
- ✔ Limited strength or muscle endurance
- ✔ Lack of confidence or a fear of moving equipment (such as balls, Frisbees, etc.)
- ✔ Difficulty problem solving in order to develop skills

How can gross motor skills be developed?

A tip sheet listed in the [“Learn More”](#) section details 13 activities you can do with your child to encourage gross motor skill development. These activities are designed to be short, fun, and simple while also building your child's skills and confidence. They range from beanbag throwing to “Simon Says” and balance activities. Many of them can be completed with just you and your child, avoiding the anxiety that can come with learning a new skill in a social setting.



Autism isn't the end of the world. It is a developmental DIFFERENCE and/or DELAY. No one knows what your child can accomplish WITH appropriate supports, but they are guaranteed to live better with supports than without.



– PARENT OF TWO CHILDREN WITH ASD

Here are some important things to remember when practicing gross motor skills with your child:¹¹³

- ✔ Choose activities appropriate for their developmental level.
- ✔ Present activities in a way they will be comfortable with to minimize fear or anxiety.
- ✔ If a child is fearful of a particular skill (e.g., movement), build up to it gradually, starting with other activities that are less threatening (such as balancing activities).

Whenever possible, try to keep the activities fun! Physical games and activities can be a way for your child to enjoy time with you—and learn at the same time.

PUBERTY

Talking about puberty is difficult for every parent

Every child's transition through puberty will be unique. No two children will have the exact same experience. As a parent you will want to help your child understand the physical and emotional changes they will face.

What can your child understand and where should you start

How you explain puberty to your child will depend on their language abilities and ability to understand abstract concepts. In some cases, parents decide to focus on preparing their children for appropriate responses and behaviours around specific issues such as menstruation and masturbation (e.g., hygiene needs, privacy).

IT CAN BE HARD TO KNOW WHEN TO START PREPARING YOUR CHILD FOR PUBERTY. IN GENERAL, STARTING EARLY (AROUND AGE 10) IS A GOOD IDEA.¹¹⁴

A helpful tip is to take advantage of any awareness your child might show in how older people or individuals of the opposite sex are physically different from them. If your child notices visual male/female differences such as beards, breasts, or underarm hair, that creates the opportunity to explain that as men and women grow into adults they develop these characteristics. Showing pictures of yourself at different stages in life can help explain this concept.¹¹⁵

Explaining the changes

A visual story is a good way to explain changes in your child's body. You could call this story, "I am growing into a man/woman." Some topics to cover could include: how their body will change (growth spurts, breasts, extra hair, deeper voice) and new things they will experience (menstruation, erections).¹¹⁶

Physical growth and managing your child

As your child grows, they may become bigger and stronger than you, and you may be less able to manage them physically when their behaviour is out of control. You may become concerned for their safety, your safety, or both.

If you are concerned, you should discuss your concerns with your service provider or other appropriate professionals who are providing services and supports to your child. In addition, if you are not sure about the supports that are available, you may contact the regional

Ministry of Children and Youth Services' offices or social service agencies in your area. They may be able to assist you in either crisis planning or an early transition to another setting.

More topics to consider regarding puberty

Behavioural and emotional changes will accompany the physical changes associated with puberty. Problems sometimes arise when adolescents with ASD do not understand social expectations surrounding public and private acts or social interactions with their peers.

You will find there are a number of helpful tips for explaining the differences between private and public behaviours, how to pick up on romantic social cues, sexual education, dating, and self-care/personal hygiene needs in the "[Learn More](#)" section.

RECREATIONAL AND PHYSICAL ACTIVITIES

The importance of physical activity

Physical activity is important for all children. Unfortunately, children with autism tend to have an increased risk of being overweight.¹¹⁷ This can lead to health concerns such as diabetes, heart disease, bone and joint problems, and depression.^{118 119 120} A number of factors can contribute to physical inactivity in children with ASD, including sensory overload, weak motor skills, poor physical coordination, side effects of prescription drugs and dietary issues.¹²¹ Parents may be concerned about their child's physical health but still find it difficult to engage their child in physical activities.

What options are available?

Participating in sports or other recreational activities can be a fantastic opportunity for children with ASD. Sports and recreational activities can provide your child with an opportunity to become more physically active and may provide some therapeutic benefit. As you know your child best, you can decide whether a team sport, individual sport or other recreational activity is best. A team sport could help develop social relationships and promote learning how to recognize social cues and non-verbal communication. Alternatively, individual sports can provide physical benefits with less anxiety and stress. In some areas, sports are organized both traditionally and in forms adapted to meet the specific needs of children with disabilities.

Some recreational activities such as swimming, horseback riding, dance and creative arts, and wilderness/outdoors clubs can involve some level of physical activity while also providing an opportunity to participate in social groups.¹²² In some cases these activities may also have a therapeutic benefit for individuals with ASD (therapeutic horseback riding and swimming are often said to have a positive impact for some individuals with ASD).^{123 124}

I think my child could benefit. What do I do next?

Your local Autism Ontario chapter may have a directory of sports and recreational activities recommended for children with ASD and related organizations. If you register your child in a fitness or sports program, remember to keep the receipts. Children 16 and under are eligible for a \$500 Fitness Tax Credit for qualifying recreation programs, and those 18 and under who receive the Disability Tax Credit are eligible for an additional \$500 credit.¹²⁵

TOOLS

Activities to encourage the development of gross motor skills

- Scooter board fun 1:
Ask the child to lie, sit or kneel (more difficult), on a skateboard and encourage him to propel himself around the floor using his hands.
- Scooter board fun 2:
Alternatively, ask the child to sit/kneel/lie on the scooter board/skateboard and pull on a suspended rope (or you can hold it) to move around the room
- Walking/Marching:
Raise knees as high as possible with each step – a nice activity when done to marching band music
- Obstacle courses:
Make your own. Climb through, under, over objects, walk on lines, footprints, planks, rough ground, etc.
- Simon Says:
Simon says be as small/tall as you can, stretch out, be stiff/floppy, be happy/sad, be still/wiggly, roll up/stretch out
- Throwing beanbags in sequence:
Throw beanbags into 3 containers 1,2,3, and then 1,2,3 again. Repeat and do it as fast as possible.
- Balls up Jumper:
Place ping pong balls up his jumper and see if he can get them out without looking.
- Balance activities:
Walk on a line, a beam, backwards on a beam, stand still with eyes shut, on all fours and take same leg and arm off ground, stand on one leg and then with eyes shut.
- See-saw:
Carry things (blocks, puzzle pieces, etc.) from one side of the see-saw to the other, trying to keep your balance as you complete your task. You may like to sing “Jack and Jill”, as the child carries a bucket of water, trying not to spill it as he walks.
- Washing laundry:
Tell the child you are going to pretend that he is dirty washing, and that you’re going to put him in your pretend washing machine. Roll him up in a blanket, and then add some balls or beanbags as the detergent. Swing the blanket from side to side and wiggle it around as you “wash” him (for as long as he’s enjoying it). Tell the child it’s time to rinse off. This is when you spin him, by moving the blanket around in a circular motion (rather than side-to-side). Now he can get out of the machine, but you roll him up in a different blanket nice and tight to dry him off. If you have monkey bars, or something he can hang from easily enough, you might like to get him to hang from the “washing line” for as long as he can.
- Swing and Kick:
Set up some empty bottles like skittles in front of a swing. Ask the child to try to swing over to the bottles and kick as many of them over as possible. Alternatively, he can lay on his tummy on the swing, and try to knock the bottles over with his hands as he swings.
- Shop ‘til you drop:
Give the child a “shopping list” of different pictures they are to find hidden around the room. Use a laundry basket for the trolley, that he is required to push around the room as he goes. Make the items that you hide different weights, so the basket gets heavier as he goes along (rice bags, pumpkins, laundry powder, juice containers are all good heavy items). You may like to give him some clues to work on prepositions (under, behind, in, on, etc.), or just leave him to his own devices.
- Shoe box path:
Keep boxes of different sizes. Ask the child to line them up or make a road with them. Tell him that they are stepping stones in the “water”, and to see if he can make it from one side of the room to the other only using the boxes, or “stepping stones” to stand in.

LEARN MORE

USE	RESOURCE TYPE	TITLE	ORGANIZATION OR PUBLISHER	AUTHOR	LINK (IF AVAILABLE ONLINE)
Toilet Training	<i>Guide</i>	Toilet Training – A Parent’s Guide	Autism Speaks		http://www.autismspeaks.org/docs/sciencedocs/atn/atn_air_p_toilet_training.pdf
Toilet Training	<i>Article</i>	Toilet Training	The National Autistic Society (UK)		http://www.autism.org.uk/living-with-autism/understanding-behaviour/toilet-training.aspx
Toilet Training	<i>Tip Sheet</i>	Toilet Training	Monash University		http://www.med.monash.edu.au/sppppm/research/devpsych/actnow/download/factsheet40.pdf
Self-Care	<i>Tip Sheet</i>	Teaching Children with Autism Daily Living Skills	Trumpet Behavioural Health		http://www.tbh.com/autism-parenting/teaching-children-with-autism-daily-living-skills-hand-washing/
Self-Care	<i>Guide</i>	Dental Guide	Autism Speaks		http://www.autismspeaks.org/family-services/tools-kits/dental-tool-kit
Self-Care	<i>Guide</i>	Haircutting Training Guide	Autism Speaks		http://www.autismspeaks.org/family-services/tools-kits/tips-successful-haircuts
Sleeping	<i>Reference</i>	Strategies to Improve Sleep in Children with Autism Spectrum Disorders	Autism Speaks Autism Intervention Research Network on Physical Health		tp://kc.vanderbilt.edu/kennedy_files/SleepBooklet02.10.12.pdf
Sleeping	<i>Reference</i>	Promoting Sleep in Children with Autism Spectrum Disorders	Beth Malow, Vanderbilt Sleep Disorders Centre		http://card-usf.fmhi.usf.edu/conf_files_07/Sun_BO3_Track4-Promoting_Sleep_(Malow).pdf
Sleeping	Reference	Sleep and autism: helping your child	National Autistic Society (UK)		http://www.autism.org.uk/living-with-autism/understanding-behaviour/sleep-and-autism-helping-your-child.aspx
Sleeping	<i>Guide/story</i>	Encouraging Good Sleep Habits Children with Learning Disabilities	National Autistic Society (UK)	Dr. Paul Montgomery, Dr. Luci Wiggs and Duncan Kay	http://www.autism.org.uk/~media/NAS/Documents/Living-with-autism/Encouraging%20good%20sleep%20habits.aspx
Gross Motor Skills	<i>Tip Sheet</i>	Developing Gross Motor Skills	Monash University		http://www.med.monash.edu.au/sppppm/research/devpsych/actnow/download/factsheet35.pdf
Puberty	<i>Reference</i>	Development, Growth and Sexuality	Autism Ontario		http://www.autismontario.com/client/aso/ao.nsf/docs/d7bdf6c761b160c585257abb006ef6c7/\$file/growth+sexuality.pdf

USE	RESOURCE TYPE	TITLE	ORGANIZATION OR PUBLISHER	AUTHOR	LINK (IF AVAILABLE ONLINE)
Puberty	<i>Article</i>	Autistic Teens and Adults need plain talk on sex	Toronto Star		http://www.thestar.com/news/world/autismproject/article/1276850--autistic-teens-and-adults-need-plain-talk-on-sex
Puberty	<i>Fact Sheet</i>	Puberty and Autism Spectrum Disorders	Autism Victoria		http://www.amaze.org.au/uploads/2011/08/Fact-Sheet-Puberty-and-Autism-Spectrum-Disorders-Aug-2011.pdf
Puberty	<i>Reference</i>	Health	Autism Speaks		http://www.autismspeaks.org/sites/default/files/documents/transition/health.pdf
Sports	<i>Reference</i>	Sports, Exercise, and the Benefits of Physical Activity for Individuals with Autism	Autism Speaks		http://www.autismspeaks.org/science/science-news/sports-exercise-and-benefits-physical-activity-individuals-autism
Sports	<i>Directory</i>	Services – Sports	Autism Ontario		http://www.autismontario.com/client/aso/ao.nsf/Toronto/Services+-+Sports



SOCIAL DEVELOPMENT

Introduction

Communication and social situations present daily challenges for people with ASD. While children with ASD can often understand the words people use (e.g., food, the weather), they tend to miss social cues and non-verbal aspects of a conversation—things like facial expressions, voice tones, speed of speech, and gestures that communicate emotion and meaning. While some children with ASD may have trouble imagining another person's point of view, which makes it hard for them to develop empathy,¹²⁶ they have a wide range of feelings and emotions.

ALL OF THESE FACTORS MEAN CHILDREN WITH ASD MAY HAVE difficulty making and keeping friendships. As a parent you may worry about your child's social life outside your home.

Topics Covered

Depending on the severity of your child's ASD, there may be intervention techniques or tips you can practice to encourage the development of some of these skills. This chapter provides information on how to work with your child, their teacher, and health care professionals to address:

- Communication skills
- Speech and Language skills
- Friendship and other relationships
- Play Skills
- Bullying

COMMUNICATION SKILLS

The importance of non-verbal communication

Communicating involves many skills that go beyond spoken language, including non-verbal skills such as reading facial expressions, tone of voice, and gestures. Neurotypical children begin to develop these skills in interactions with adults before they can even talk.¹²⁷ For children with ASD, these non-verbal communication skills do not develop as easily. As a result they tend to miss non-verbal cues that would help them interact with others,¹²⁸ making it difficult to read and comprehend social situations.¹²⁹ The degree to which children with ASD have difficulty interpreting social cues varies from child to child. It is usually necessary to teach them certain non-verbal communication skills.

Teaching children something that is normally not taught

Because of their different ways of experiencing the world, individuals with ASD often must be taught to read the social cues that neurotypical individuals use on a daily basis to navigate the social world safely and comfortably. Because most of us use these skills without even thinking about it, it can be difficult to “deconstruct” them and figure out how to teach them. Autism Ontario's nonverbal skill factsheet (listed in “[Learn More](#)”) provides an overview of one technique for developing an understanding of facial expressions, body language, and tone of voice. This can be used at home to help build communication and social understanding.

There are various techniques used to help individuals with ASD to develop social skills include:¹³⁰



Video Modeling

Involves the child watching videotaped demonstrations of skills and then imitating the behaviours shown.



Social Stories

Use short graphic stories that describe a social situation that has been challenging for the individual and then outline the appropriate response expected for that social situation.



Social Skills Training Group

Instruction to a small group of individuals using ABA principles to break down complex social behaviours and skills into components, and teach them in a step-by-step manner.



Cognitive Behavioural Training

An approach that teaches social skills to individuals with ASD by linking knowledge of the social world to underlying thoughts and challenging behaviours.



Self-Management Training

An approach where the individual learns to monitor and reinforce their own behaviour.



Activity-Based Intervention

Builds appropriate social and play skills by capitalizing on special skills or interests of the child.



Peer-Mediated Intervention

Typically involves classmates providing social training instructions.

Searching the website of your local Autism Ontario chapter is a good starting point for finding these services. Service providers for Communication and Social Skills are also listed on Autism Ontario's [SPIRALE](#) website.

SPEECH AND LANGUAGE SKILLS

Language and verbal communication are often core challenges for some individuals with ASD. For others, typically those with Asperger's Syndrome, speech skills are not significantly delayed¹³¹ and individuals are often very well spoken. For individuals on the more severe end of the autism spectrum symptoms can range from limited or no development of speech to abnormalities in speech (such as pitch, stress, rate, rhythm, etc.). It is important to note that the development, or lack, of speech does not necessarily impact other abilities or intelligence. Often, language difficulties are caused by a separate condition that prevents speech.^{132 133}

A number of strategies and tools can help children acquire spoken communication skills. However, whether or not your child is verbal, what's most important is that your child has a way to communicate with others. Without a way to communicate, they can't ask for things, tell you what they need, or participate in the world around them.

EXAMPLES OF NON-VERBAL LANGUAGE TOOLS:



PICTURE EXCHANGE COMMUNICATION SYSTEM



SIGN LANGUAGE



WRITTEN LANGUAGE



VOICE OUTPUT DEVICES



TABLET COMPUTERS



APPS

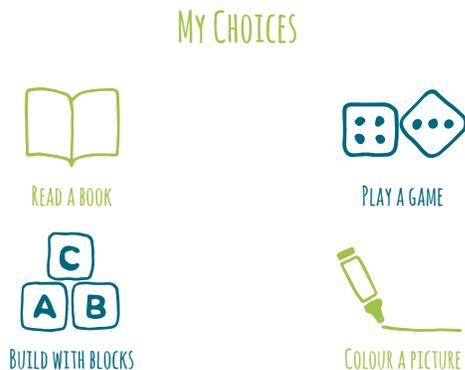


Picture Exchange Communication System

The Picture Exchange Communication System (PECS) is an alternative communication tool that uses pictures/symbols of objects, activities, and items to assist communication. References to PECS have been included in the “[Learn More](#)” section.¹³⁴

Using visual aids

Visual aids are an effective way to both communicate with your child and improve their auditory-verbal skills. A common aid for communication is a visual choice board. Visual choice boards have pictures and labels of locations, foods, toys, activities, or other items that your child can point to when making a selection. You can build on language skills by repeating the word associated with the image or asking your child to say it out loud, depending on their abilities.



Ontario's Preschool Speech and Language Program

A child's first years of life are very important for their learning of speech and language. The "[Learn More](#)" section has a list of speech and language development milestones. If you are concerned that your child has not reached the milestones for their age it is important to seek professional help as soon as possible.

WHAT DOES IT DO?

- Helps your child begin or continue to develop their language skills.
- Helps to identify, assess, and treat language disorders and to support language development.

IS THERE A COST?

- There is no cost.

DO I NEED A DOCTOR'S REFERRAL?

- You **do not** need to get a referral from your doctor to discuss your child's needs with professionals from this program.

WHERE DO I START?

- Your Regional Ministry of Children and Youth Services office can help you contact a local Preschool Speech and Language Program.

The role of speech-language pathologists

Speech-language pathologists (SLP) are specialists who diagnose and treat communication disorders. Some children with ASD may require the assistance of SLPs. Common signs that your child may benefit from the assistance of an SLP include:¹³⁵

- No use of spoken words or not using words in a meaningful way
- Unfamiliar people (neighbours, teachers, etc.) cannot understand them
- Language is not being used for communication purposes, such as making requests or answering yes/no and other simple questions

Speak to your health care professional for additional information and/or to help you locate speech-language pathologists in your area.

FRIENDSHIP AND OTHER RELATIONSHIPS

The challenge of friendship

Making friends can be difficult for children with ASD. It is often said that people with ASD prefer to be alone. While this may often be true in some cases, children and teens may find themselves alone more than they would like. They may desire friendship and inclusion but find it difficult to make and keep friends. The resulting sense of isolation can contribute to feelings of depression.¹³⁶

It's very troubling for parents when they know their child would like to have friends but is socially isolated. Worse, parents may feel powerless to help since they are outside of the school environment and it is, in any case, difficult for adults to intervene effectively in school-aged children's friendships.

Work with your child's teacher to build friends

Your child's teacher is in a better position to encourage friendships between your child and their classmates. With your help, your child's teacher can:¹³⁷

- ✓ Provide information about ASD to the class and how it impacts your child;
- ✓ Use a buddy system at school and pair your child with a confident classmate who can help promote social behaviour (this can also help reduce the risk of bullying);
- ✓ Use visual schedules to explain the day's events to your child and prevent challenging behaviour, which could be off-putting to other children;
- ✓ Find opportunities for your child to demonstrate their skills and abilities in the class (such as in math or computers) or join a school club and show that they likely have many of the same interests as other children.

Making friends may not be easy for your child.¹³⁸ But with encouragement, the building of social skills and a supportive environment at school it is possible to improve the odds of long-lasting friendships developing.

Think about why you want your child to attend social events

Children are often invited to birthday parties and other social events that can be either enjoyable or challenging, depending on the situation and the child's sensitivities. These events can contribute to achieving important social goals for your child or give them an opportunity to improve their language and social skills. They can also be difficult or even overwhelming for your child. So, attending social events should not be treated as an end in itself. It's important to think carefully about the potential costs and benefits of each event.

PLAY SKILLS

Why are play skills important?



PLAY PROMOTES SKILLS ASSOCIATED WITH SOCIAL CONTACT, CREATIVITY AND IMAGINATION.



SOCIAL PLAY IS A WAY TO CONNECT WITH OTHER PEOPLE.



PLAY HELPS CHILDREN LEARN TO TAKE TURNS, SHARE, CO-OPERATE, COMMUNICATE.



SOLITARY PLAY CAN BE RELAXING AND CALMING.

A lack of make-believe play is a diagnostic feature of many children with ASD.^{139 140}

Teaching children with ASD to play is important but difficult. Developing play skills can help children with ASD improve their social and communication skills and decrease rituals and repetitive routines.¹⁴¹ As your child develops better play skills, it will become easier for them to interact and form bonds with classmates and siblings who may otherwise isolate or become frustrated with them.

How to teach play skills

Many Autism Ontario chapters offer play skills groups that provide an opportunity for children and their families to connect socially and practice play skills. [Kerry's Place](#) and the [Geneva Centre for Autism](#) also provide programs to promote social and play skills. You can search for programs offered by these organizations through their online program directories.

When at home, there are a few things you can do to help your child develop play skills.¹⁴²

- If your child is isolated, try to find pleasant ways to intrude on their isolation. You do not want them to isolate themselves further, so try to make it an enjoyable experience for them by offering them a toy to play with and teaching them how to play with it. This will demonstrate the possibilities for future play together.
- Teach eye contact to promote connection between you and your child. Teaching eye contact also helps promote attention, which is important for group play that often involves instructions from peers.
- Help them learn to stay on task by practicing with activities that have a defined ending (e.g., puzzles) and providing a reward at the end of the task.

Specific examples of how to promote these play skills are provided in the “Pre-schoolers with Autism: Work and Play” tip sheet referenced in [“Learn More.”](#)

BULLYING

Bullying in Ontario schools is considered to be a serious issue. Staff who work with children must respond to incidents of behaviour that have a negative impact on the school.

CHILDREN WITH DISABILITIES ARE MORE LIKELY TO BE BULLIED

WHAT?

Bullying can happen to any child, and it is very common for parents to worry about how their child interacts with children at school and out of the home. Unfortunately, children with ASD may be more vulnerable to bullying as they reach middle school.¹⁴³

WHY?

Because children with ASD can stand out in their social interactions they may be seen as “easy targets.” And because they don’t easily understand social nuance, children with ASD can find it hard to tell whether actions or comments are part of friendly banter or malicious.¹⁴⁴

WHAT CAN I DO?

Dealing with bullying is difficult for parents as it usually occurs at school and away from the home. Autism Speaks has partnered with a number of organizations to publish a tool kit to help parents identify and address concerns about bullying. Three key points from this document are:

- speak to your child about bullying
- inform the school of any bullying immediately
- work with your child’s school to educate their classmates

CHILDREN WITH DISABILITIES CAN ALSO BULLY OTHERS

WHAT?

Children with disabilities can also bully other children. Some signs that your child may be bullying others include:

- bruises, scrapes, and torn clothing
- new possessions such as toys, clothing, or anything else that could have been taken from a classmate
- bullying behaviour at home between siblings

WHY?

Bullying behaviour can develop over time as children grow and are exposed to changes and new situations.

WHAT CAN I DO?

It is important that you speak with your child to make sure that they understand:

- what bullying is
- how it affects others
- the impact that poor behaviour can have on them (limited friendships, suspension, expulsion)

Speak to your child about bullying

Children with ASD don't always know that they are being bullied. The first thing you may want to do is describe the differences between friendly behaviour and bullying behaviour. Often children think of bullying as being physically hurt. You may want to consider explaining that bullying includes any behaviour that hurts them or makes them feel upset physically or emotionally.

THERE ARE MANY TYPES OF BULLYING, INCLUDING:



PHYSICAL

Hitting, shoving, stealing, or damaging property



VERBAL

Name calling, mocking, or making sexist, racist, or homophobic comments



SOCIAL

Excluding others from a group or spreading gossip or rumours about them



ELECTRONIC (CYBERBULLYING)

Spreading rumours and hurtful comments through the use of e-mail, cellphones, social media websites, and text messaging



Questions you can ask your child to help understand their situation:

- Who did you sit with for lunch? Did you talk to them about anything?
- Has anyone said anything to you to make you feel bad or angry?
- Has anyone ever touched you in a way that did not feel right?

MORE ON CYBERBULLYING

WHAT IS IT?

Cyberbullying is a relatively new form of bullying with which some parents may not be familiar. It has emerged with the increasing popularity of mobile technology and social networking. As some children with ASD will spend a significant amount of time on computers, cyberbullying is a real concern.

TIPS

Some tips you may want to discuss with your child as they begin to use computers independently include:

- The importance of keeping passwords private and changing them regularly
- Exploring options to block, delete, or report individuals on social networking sites
- Making sure they understand the privacy options available on different websites

OTHER RESOURCES

The Ministry of Education has published some background information on cyberbullying, as well as identified other organizations that may help you to understand cyberbullying and what you can do to help your child. A link to this has been provided in the "Learn More" Section. The "Learn More" Section also contains a link to a summary of the *Accepting Schools Act* (Bill 13), which is designed to help schools and school boards prevent bullying and inappropriate behaviour.

Work with the school to find a solution

If you suspect that your child has been bullied, it is important to work with the school to find a solution:

- Speak with your child's teacher or principal to discuss why you believe your child is being bullied.
- Ask them to monitor the situation and keep an eye out for bullying behaviour.
- It is also worthwhile to follow up with a letter to the school to document the nature of any bullying.
- Ask for a formal response detailing what is being done to prevent the bullying from occurring again.

Informing your child's classmates about ASD can help to prevent bullying and encourage friendship. This typically needs to be done in partnership with your child's teacher. Your child's teacher should have access to resources to help explain ASD to the class.

TWO OTHER HELPFUL RESOURCES, ALSO LISTED IN THE "LEARN MORE" SECTION:

CREATED BY:

Autism Ontario

CALLED:

Bullying & Proactive Inclusion of Youth with Autism Spectrum Disorder

DESCRIPTION:

A pamphlet that is available to teachers. You may want to suggest that your child's teacher request a copy of this for the school.

Tony Attwood

The Complete Guide to Asperger's Syndrome

Contains a section on teasing and bullying. It offers insights into the causes of bullying as well as some tips and suggestions geared towards the parents of children with ASD.

TOOLS

Developmental milestones

These developmental milestones show some of the skills that mark the progress of young children as they learn to communicate. There are also some tips on how you can help your child develop speech and language skills. If your child is not meeting one or more of these milestones, please contact your local Preschool Speech and Language Program.

BY 6 MONTHS

- turns to source of sounds
- Startles in response to sudden, loud noises
- Makes different cries for different needs – i'm hungry, i'm tired
- Watches your face as you talk
- Smiles and laughs in response to your smiles and laughs
- Imitates coughs or other sounds – ah, eh, buh

BY 9 MONTHS

- Responds to his/her name
- Responds to the telephone ringing or a knock at the door
- Understands being told “no”
- Gets what he/she wants through sounds and gestures e.g., reaching to be picked up
- Plays social games with you e.g., peek-a-boo
- Enjoys being around people
- Babbles and repeats sounds – babababa, duhduhduh

BY 12 MONTHS

- Follows simple one-step directions – “sit down”
- Looks across the room to something you point to
- Uses three or more words
- Uses gestures to communicate – waves “bye bye”, shakes head “no”
- Gets your attention using sounds, gestures and pointing while looking at your eyes
- Brings you toys to show you
- “Performs” for attention and praise
- Combines lots of sounds as though talking – abada baduh abee
- Shows interest in simple picture books

BY 18 MONTHS

- Understands the concepts of “in and out”, “off and on”
- Points to several body parts when asked uses at least 20 words
- Responds with words or gestures to simple questions – “Where’s teddy?”, “What’s that?”
- Demonstrates some pretend play with toys – gives teddy a drink
- Makes at least four different consonant sounds – b, n, d, g, w, h
- Enjoys being read to and looking at simple books with you
- Points to pictures using one finger

BY 24 MONTHS

- Follows two-step directions – “Go find your teddy bear and show it to Grandma”
- Uses 100 or more words
- Uses at least two pronouns – “you”, “me”, “mine”
- Consistently combines two or more words in short phrases – “daddy hat”, “truck go down”
- Enjoys being with other children
- Begins to offer toys to peers and imitates other children’s actions and words
- People can understand his/her words 50 to 60 per cent of the time

- Forms words and sounds easily and effortlessly
- Holds books the right way up and turns pages
- “Reads” to stuffed animals or toys
- Scribbles with crayons

BY 30 MONTHS

- Understands the concepts of size (big/little) and quantity (a little, a lot, more)
- Uses some adult grammar – “two cookies”, “bird flying”, “I jumped”
- Uses more than 350 words
- Uses action words—run, spill, fall
- Begins taking short turns with other children, using both toys and words
- Shows concern when another child is hurt or sad
- Combines several actions in play – feeds doll then puts her to sleep; puts blocks in train then drives train and drops blocks off
- Puts sounds at the start of most words
- Produces words with two or more syllables or beats – “ba-na-na”, “com-pu-ter”, “a-pple”
- Recognizes familiar logos and signs – McDonalds golden arches, stop sign
- Remembers and understands familiar stories

BABIES LIKE IT WHEN YOU

- Get down to their level so they can see your face. This tells them that you’re interested in what they’re doing and saying. It makes it easier to interact with you.
- Repeat the sounds they make. Babies enjoy making noises, and like it when you imitate them over and over.
- Sing and laugh, especially when you are feeding, bathing, and changing them. Remember to talk to your baby throughout the day about things you do and see – “Mommy’s putting on her coat”, “That’s a big truck.”
- Tell them the names of the objects they are looking at and playing with. Babies are interested in exploring and learning about new things, and like to hear what things are called.

TODDLERS LIKE IT WHEN YOU

- Let them touch and hold books while you point to and name the pictures.
- Use real words instead of baby talk – “give me” instead of ta ta or “bottle” instead of baba.
- Take the time to listen to them – they want you to hear all of their new sounds, words and ideas.
- Give them simple directions to follow – “Go find your red boots”.
- Use lots of different words when you talk to them – opposite words like up/down, in/out; action words like “running”, “splashing”, and descriptive words like “happy”, “big”, “little”, “clean”, “dirty”.
- Encourage them to play with other children – at the library, play groups, park.

Source: Ministry of Children and Youth Services. ‘Your baby’s speech and language skills from birth to 30 months’ http://www.children.gov.on.ca/htdocs/English/topics/earlychildhood/speechlanguage/brochure_speech.aspx

LEARN MORE

USE	RESOURCE TYPE	TITLE	ORGANIZATION OR PUBLISHER	AUTHOR	LINK (IF AVAILABLE ONLINE)
Summary of intervention techniques for communication and social skills	Article	Social Matters: Improving social skills interventions for Ontarians with Autism Spectrum Disorder	Autism Ontario		http://www.autismontario.com/Client/ASO/AO.nsf/object/SocialMatters/\$file/Social+Matters.pdf
Teaching Tip	Factsheet	Direct Teaching of Non-Verbal Social Communication Skills	Autism Ontario		http://www.autismontario.com/Client/ASO/AO.nsf/object/ASDNonverbalSkills/\$file/ASDNonverbalSkills.pdf
Social skills programs	Recommendations	What to Look for When Choosing Social Skills Programs for People with ASD	Autism Ontario		http://autismontario.novosolutions.net/default.asp?id=107&Lang=1&SID=
Ontario's Preschool Speech and Language Program	Program Overview	Preschool Speech and Language	Ministry of Children and Youth Services		http://www.children.gov.on.ca/htdocs/English/topics/earlychildhood/speechlanguage/index.aspx
Summary of how Speech and Language Pathologists can assist your child	Article	Speech and Language Pathologists	Autism Ontario – SPIRALE		http://www.autismontario.com/client/aso/spirale.nsf/object/qa/\$file/qa+slp+en.pdf
Visual Aids	Article	Use of Visual Aids to Improve Communication Skills	Autism Ontario		http://www.autismontario.com/Client/ASO/AO.nsf/object/ASDVisualSupports/\$file/ASDVisualSupports.pdf
Communication Aids	Article	The Picture Exchange Communication System	Autism Society	Anne Overcash, Catherine Horton and Andy Bondy	http://www.autism-society.org/living-with-autism/treatment-options/pecs.pdf
Service provider database	Database	Provider Listings	Autism Ontario: SPIRALE		http://www.autismontario.com/client/aso/spirale.nsf/ProvSearch?OpenForm
Chapter dedicated to Teasing and Bullying	Book	The Complete Guide to Asperger's Syndrome	Jessica Kingsley Publishers	Tony Attwood	
Ordering details for Autism Ontario – Bullying & Proactive Inclusion of Youth with Autism Spectrum Disorders	Resource Guide	Registry of Resources for Safe and Inclusive Schools	Ministry of Education		http://www.edu.gov.on.ca/eng/safeschools/bullyprevention.html

USE	RESOURCE TYPE	TITLE	ORGANIZATION OR PUBLISHER	AUTHOR	LINK (IF AVAILABLE ONLINE)
Anti-bully tip sheet	Tip sheet	Help Your Child Recognize the Signs of Bullying	PACER Centre		http://www.pacer.org/publications/bullypdf/BP-2.pdf
Bullying	Reference, Tool Kit		Autism Speaks, The Bully Project, and others		http://specialneeds.thebullyproject.com/
Bullying	Reference	Combating Bullying	Autism Speaks		http://www.autismspeaks.org/family-services/bullying
Bullying	Reference	Creating Safe and Affecting Schools: Information for Parents about the Accepting Schools Act (Bill 13)	Government of Ontario		http://www.edu.gov.on.ca/eng/safeschools/SafeAcceptSchools.pdf
Cyberbullying	Reference	Safe Schools: Cyberbullying	Ministry of Education		http://www.edu.gov.on.ca/eng/safeschools/respect.html
Emotional Intelligence, Empathy	Website homepage		Roots of Empathy		www.rootsofempathy.org
General	Database of articles by topic		Autism Ontario Knowledge Base		http://autismontario.novosolutions.net/default.asp?id=103&Lang=1&SID=
General Social Skills	Book	Social Skills Training for Children and Adolescents with Asperger Syndrome and Social-Communication Problems	Autism Asperger Publishing Co.	Jed Baker	
Friendship	Article	Social/ Relationships	Autism Society (US)		http://www.autism-society.org/living-with-autism/lifespan/adulthood/social-relationships.html
Friendship	Book	Children's Friendship Training	Routledge	Fred D. Frankel and Robert Myatt	
Play Skills	Factsheet	Using a Play Ideas Mat	Monash University		http://www.med.monash.edu.au/spppm/research/devpsych/actnow/download/factsheet30.pdf
Play Skills	Factsheet	Core Features of Autism: Play and Behaviour	Monash University		http://www.med.monash.edu.au/spppm/research/devpsych/actnow/download/factsheet06.pdf

USE	RESOURCE TYPE	TITLE	ORGANIZATION OR PUBLISHER	AUTHOR	LINK (IF AVAILABLE ONLINE)
Play Skills	Factsheet	Pre-schoolers with autism: Work and Play	Monash University	Dr. Avril Brereton	http://www.med.monash.edu.au/spppm/research/devpsych/actnow/download/factsheet20.pdf
General Social Skills	Book	Social Skills for Teenagers with Developmental and Autism Spectrum Disorders – The PEERS Treatment Manual	Routledge	Elizabeth A. Laugeson and Fred D. Frankel	
General Social Skills	Book	The Hidden Curriculum: Practical Rules for Understanding Unstated Rules in Social Situations	Autism Asperger Publishing Co.	Brenda Smith Myles, Melissa Trautman and Ronda L. Schelvan	
Communication for Non-verbal Children	Book	Carly's Voice: Breaking Through Autism	Touchstone	Arthur Fleischmann and Carly Fleischmann	
Emotional Intelligence, Empathy	Article	Heartstart: Teaching Emotional Literacy	Vanier Institute		http://www.vanierinstitute.ca/include/get.php?nodeid=748



EMOTIONAL AND MENTAL HEALTH

Introduction

Mental or emotional health problems can affect any child of any age. Children with ASD can be more vulnerable to mental health problems such as low self-esteem, anxiety and depression,¹⁴⁵ and it can be even more difficult to identify and address these concerns, especially if the child has challenges communicating. Because of this, some parents may worry that their child is suffering in silence. The tips and recommendations provided in this section focus on helping you identify signs that your child may be experiencing an emotional or mental health issue.

Topics Covered

Understanding the signs associated with different states of emotional health can help you recognize your child's emotions. In this section you will see useful information on how to identify symptoms of anxiety and depression and learn where you can turn to for help if you think something is not right. Topics covered include:

- Understanding your child's feelings
- Repetitive or obsessive behaviour and interests
- Anxiety and depression

UNDERSTANDING YOUR CHILD'S FEELINGS

If you are a parent of a child with ASD it will not take long to recognize that your child's feelings with respect to others can be just as complex as your own.

However, those feelings can be hard to understand or interpret when children have difficulty expressing their emotional needs or wants. This makes it difficult for parents to communicate with their child about those feelings.¹⁴⁶ You may often wonder how your child is doing emotionally.

“ Understand what may not be anything significant to you may be of monumental importance to your child. Try not to take their emotional outbursts personally. They still love you and you love them. ”

-PARENT FROM WHITBY

Parents and professionals have found some ways to gain a better understanding of the feelings of children with ASD. Some of these are:¹⁴⁷

- ✓ Using alternative ways to help children express feelings, such as pointing to pictures of happy or sad faces, writing in a journal, or pointing to degrees of a specific feeling on a “feeling thermometer” a template for a feeling thermometer has been provided in the “[Learn More](#)” Section;
- ✓ Paying attention to changes in behaviour that indicate how your child is feeling—for example, are they sleeping more or isolating themselves in their room more than usual?
- ✓ Watching for signs of a possible emotional problem: loss of interest in normal activities, changes in routine behaviours, increased tiredness, anxiety or emotional outbursts, weight changes or other physical symptoms.

Learning how to understand the emotions your child is dealing with can be a relief for parents. But it can also lead to the next question: visualize “What can I do to help and support them?” Many Autism Ontario chapters run autism and mental health workshops for parents and professionals to learn more about the links between ASD and mental health and the supports available in the community to help. Checking with your local Autism Ontario chapter for these workshops is a good way to learn more about how to spot and deal with your child's emotions. [Autism Ontario's online Knowledge Base](#) and the National Autistic Society (UK) also have a considerable amount of material discussing mental health in children and adolescents with ASD.

REPETITIVE OR OBSSESSIVE BEHAVIOUR AND INTERESTS

Assessing the impact of behaviours

Children with ASD can often develop rigid routines or obsessive interests. These are sources of enjoyment and security for them and help them cope with the world. Obsessions can centre around many different objects or events—toy cars or animals, certain TV programs or fictional characters, licence plates or digital clocks. In young children, routines sometimes include stacking or lining up items such as toys or cutlery. Repetitive mannerisms, repeating verbal questions, or compulsive behaviours are often seen in children with ASD.¹⁴⁸

If you have noticed a repetitive behaviour or obsession in your child you may wonder what you should do about it. However, you may not need to intervene at all. Consider asking yourself the following questions:¹⁴⁹

- ? Does the behaviour put your child or others at risk of physical harm?
- ? Will your child have difficulty in social situations if the behaviour continues?
- ? Will the behaviour be unacceptable 5 years from now?
- ? Is the behaviour limiting your child's ability to fully participate in family, social or school activities?
- ? Is your child unable to stop the behaviour by themselves or unable to engage in a range of activities or play?

If the answer to any of these questions is yes, then it may be worthwhile to intervene and try to limit the behaviour.¹⁵⁰

How to intervene

If you have made the decision to try to limit a behaviour, early intervention is critical.¹⁵¹ The National Autistic Society (UK) has developed a useful guide for intervening in repetitive behaviours and obsessions, which highlights the need to reduce your child's anxiety by structuring the environment around them. Some of these recommendations include:¹⁵²

WHAT?	EXAMPLES	WHY?
 VISUAL SUPPORTS	<ul style="list-style-type: none">• Photos• Symbols,• Written lists,• Timetables	Helps make events more predictable
 SELF-REGULATION SKILLS	<ul style="list-style-type: none">• Deep breathing,• Playing with fidget toys	Helps your child manage their own behaviours and emotions
 SOCIAL SKILL TRAINING	<ul style="list-style-type: none">• How to read social cues• Speak to others	Helps your child engage without relying on obsessive interests



SET LIMITS ON WHERE BEHAVIOURS ARE ALLOWED TO OCCUR

- Home vs. the mall or school
- A timer to show minutes passing can help when setting limits for time spent with TV, video games, a favourite activity or toy

Limiting time spent on obsession



OTHER

- Introduce your child to other activities
- Leading the child from computer gaming into computer programming, from historical date tracking into a history club

Provides the same enjoyment in a different setting. Helps develop interests into more developed skills.

“ Try to use structure (e.g., charts, photos, routines) as much as possible in helping your child to “get it.” After much repetition, they WILL eventually become more independent. Staying calm is key but not always possible! ”

-PARENT FROM TORONTO

Dangerous or risky behaviour

If you believe that a repetitive behaviour can be a risk to your child, yourself, or someone else it is very important to reach out to your physician (family/primary care, specialist, and paediatrician) for help. Your physician may be able to provide additional guidance or refer you to someone with expertise in behavioural interventions.

ANXIETY AND DEPRESSION

If you are concerned about your child’s mental health it is important to speak with a psychiatrist or other mental health professional with experience in treating individuals with ASD. Two mental health conditions that individuals with ASD may be more prone to are anxiety and depression.¹⁵³

Anxiety

Anxiety may be more common among individuals with ASD than in the general public.¹⁵⁴ Anxiety may relate to ongoing stressful situations, social settings, thinking about future events¹⁵⁵ or specific issues such as fear of public places or crowds, germs, or animals.

Common indicators of anxiety in individuals with ASD include:¹⁵⁶

- ✔ Emotional outbursts
- ✔ Avoidance of situations
- ✔ Repetitive talking/questioning/movements
- ✔ Increased voice volume
- ✔ Verbal or physical aggression
- ✔ Behavioural problems/rigidity
- ✔ Inappropriate social behaviours
- ✔ Obsessive or compulsive types of behaviours

If you believe that your child may be suffering from anxiety, finding ways to give them a greater sense of control over their environment may help. Tips for reducing anxiety levels include:¹⁵⁷



Developing schedules they can follow (including a sequence of events)



Preparing them for future events (what will be expected of them, who will be there)



Gradual exposure to the situation causing the anxiety

Helping your child to relax many also assist with lowering anxiety levels. Depending on their age, this could involve making sure they have a quiet room to retreat to, watching a favourite movie or television show, or listening to calming music.¹⁵⁸ If anxiety is caused by sensory inputs (such as loud places, people brushing up against them in public, etc.), you might consult with your physician to discuss treatment options.¹⁵⁹

Depression

Unfortunately children with ASD are at increased risk for developing symptoms of depression. Children and teens with ASD have desires for friendship and inclusion, but a sense of isolation can contribute to feelings of depression.¹⁶⁰



Indicators of depression among individuals with ASD

- Feeling low in energy or sleeping problems
- Feeling blue, sad, hopeless, worthless, or lonely
- Lack of interest
- Poor appetite
- Crying

Parents may often be the first to notice these symptoms, but it can be hard to know how to help.

While clinical depression requires treatment from a professional, you can support your child’s mental health by encouraging some of the following:^{161 162}



Participating in a support group or drop-in centre to develop new friendships and enjoy social activities



Self-management strategies (e.g., deep breathing)



Physical activities (walks, swimming, sports)



Ongoing counselling



Calming, relaxing, and enjoyable activities (music, massages, hobbies)



Keeping a schedule and maintaining healthy sleeping and eating routines

Autism Ontario has published a summary of Tony Attwood’s “[Emotional Toolbox](#)” on its Knowledge Base website (listed in the “[Learn More](#)” Section). The Emotional Toolbox provides some strategies designed to help individuals with ASD prevent and manage negative emotions.

Being alone

It is often said that people with ASD prefer to be alone. While this is may be true, some may find themselves alone often because they are still developing social skills. Indeed, they might want more friends but find them difficult to keep. When thinking about your child, consider all the possibilities.

Getting additional help

The sooner a mental health problem is diagnosed, the sooner your child can get help, so talk to your physician or psychiatrist/counsellor about any concerns you may have. Providing your child with the skills and support they need can help their long-term ability to manage their emotions.¹⁶³

Physicians may suggest using medication to treat mood disorders such as depression. In this case it is important to carefully consider all of the factors involved in medication (the "[ASD Diagnosis and Treatment](#)" section contains some helpful resources for making medication related decisions). Remember that even with medication, your child may need additional supports (such as counselling with a mental health professional) to manage mental health concerns.

TOOLS

Example of a Stress Thermometer that children can use to indicate their feelings by pointing.

Stress Thermometer

Stress Signals		Relaxation Techniques
_____	6	_____
_____	5	_____
_____	4	_____
_____	3	_____
_____	2	_____
_____	1	_____

Feeling Good

McMaster Children's Hospital, Hamilton/Niagara Region

LEARN MORE

USE	RESOURCE TYPE	TITLE	ORGANIZATION OR PUBLISHER	AUTHOR	LINK (IF AVAILABLE ONLINE)
Reference	Book	The Complete Guide to Asperger's Syndrome	Jessica Kingsley Publishers	Tony Attwood	
Routines	Website	Obsessions, repetitive behaviour and routines	National Autistic Society (UK)		http://www.autism.org.uk/living-with-autism/understanding-behaviour/obsessions-repetitive-behaviours-and-routines.aspx
Special Interests	Fact Sheet	Managing special interests in young children with autism	Monash University	Dr. Avril Brereton	http://www.med.monash.edu.au/spppm/research/devpsych/actnow/download/factsheet47.pdf
Routines	Fact Sheet	Restricted, repetitive and stereotyped patterns of behaviour, interest and activities	Monash University	Dr. Avril Brereton	http://www.med.monash.edu.au/spppm/research/devpsych/actnow/download/factsheet48.pdf
Summary of Tony Attwood's 'Emotional Toolbox'	Tool Kit	The Emotional Toolbox	Autism Ontario		http://autismontario.novosolutions.net/default.asp?id=34&SID=&Lang=1
Overview of emotional and mental health concerns	Informational Article	Psychosocial Issues in "More Able" Adolescents and Adults with ASD	Autism Ontario		http://www.autismontario.com/client/aso/ao.nsf/object/AA2/\$file/AA2.pdf
Information on the signs, symptoms, and treatment recommendations	Website Homepage		Centre for Addiction and Mental Health (CAMH)		http://www.camh.ca/en/hospital/Pages/home.aspx
Background information	Website	Mental health and Asperger syndrome	National Autistic Society (UK)		http://www.autism.org.uk/working-with/health/mental-health-and-asperger-syndrome.aspx
Background information	Factsheet	Do young children with autism get anxious?	Monash University		http://www.med.monash.edu.au/spppm/research/devpsych/actnow/download/factsheet45.pdf
Television and Autism	Factsheet	Television and Autism: To Watch or Not to Watch? (ACT-Now Fact Sheet 44)	Monash University		http://www.med.monash.edu.au/spppm/research/devpsych/actnow/download/factsheet44.pdf



ENCOURAGING YOUR CHILD

Introduction

Some of the most frequently asked questions about ASD have to do with special abilities. Although many people associate ASD with special abilities, sorting myths from reality tends to be difficult, partly because the intellectual abilities of children with ASD are so diverse. The best approach for parents is to be open-minded but realistic about their child's abilities.

THE MAJORITY OF CHILDREN WITH ASD WILL NOT DEVELOP

extraordinary skills. Nonetheless, as a parent you will want to learn what your child is capable of and support the growth of their abilities.

Topics

In exploring special skills and talents, a good starting point is to understand some of the more common abilities of people with ASD. Having an idea of what to look for can help parents identify skills or talents that could be explored further and possibly fostered. Parents often start with interests their children have and work to turn these into a relaxing hobby and potentially a life skill, which could help the child gain independence. In this section we explore:

- Identifying a child's unique aptitudes
- Helping children with ASD build on their strengths

“ Remember your child has many GOOD characteristics as well! Try and see all the things that your child CAN do and is GOOD at.

- PARENT OF 7-YEAR-OLD WITH ASD

IDENTIFYING UNIQUE APTITUDES

A small proportion of people with ASD develop talents in a specific area. For example, a fair number of children with ASD exhibit high levels of skill in areas related to visual-spatial abilities such as:^{164 165 166}

- ✔ Artistic abilities
- ✔ Musical abilities
- ✔ Mathematics
- ✔ Reading fluency at a young age
- ✔ Understanding of mechanics and machines (dismantling and reassembling household items)
- ✔ Computers
- ✔ Memorizing facts on specific subjects
- ✔ Calendar calculations
- ✔ The ability to intensely focus on an interest

It is important to remember is that only a minority of children with ASD will exhibit “savant” abilities.¹⁶⁷ However, people with ASD do commonly show behaviours, interests, and activities that are restricted and repetitive, or sometimes abnormally intense or focused. Children with ASD may stick to inflexible routines, move in stereotyped and repetitive ways, or preoccupy themselves with parts of objects. These sorts of specific and narrow areas of interest are actually one of the most common traits of children with Asperger's Syndrome.¹⁶⁸

“ My son's special interests are the key to his behaviour, learning capabilities, and ability to cope. He uses his special interests as a way to control the world, to keep the chaos of everyday social interactions at arm's length. He has taught us through trial and error (many trials, many errors) to manage his behaviour and anxiety through the prism of his interests. They are an essential tool for us now.

- PARENT OF 9-YEAR-OLD WITH ASD

HELPING CHILDREN WITH ASD BUILD ON THEIR STRENGTHS

While not every child with ASD will develop exceptional talents, many do have particular abilities that can be encouraged.¹⁶⁸ Often these abilities will be related to a child's special interests. These interests may seem odd to other people, but in some cases they turn out to be gateways to a successful career.¹⁶⁹

Take the example of a child who has the unexpected ability to dismantle and reassemble electronic devices from around the home. While this is frustrating for parents and potentially dangerous for the child, it can also be an opportunity for later in life. Therapies and interventions can help children build the social and emotional skills needed to apply a particular ability, or above-average intellect, to a productive activity or career.¹⁷⁰

One caution: you may want to guard against “overprogramming” activities for your children with ASD just as you would with your neurotypical children. Children tend to learn new skills best when they are well rested and able to concentrate. If they are already attending therapy and/or other activities, they may not always be ready for new activities.

“ There is so much that is wonderful, or unexpected, so simply absurd. Living with my son is close to unbearable some days. But, I imagine, for example, if it weren't for my insistent son with ASD I never would have read the entire Iliad aloud (two months, every night). I wouldn't know reams of factoids on Big Foot or tornadoes. I have passively learned more about insects than I would have thought possible.

- PARENT OF 9-YEAR-OLD WITH ASD

LEARN MORE

USE	RESOURCE TYPE	TITLE	ORGANIZATION OR PUBLISHER	AUTHOR	LINK (IF AVAILABLE ONLINE)
Building on strengths	Web-based Video	Temple Grandin: The World Needs All Kinds of Minds	TED	Temple Grandin	http://www.ted.com/talks/temple_grandin_the_world_needs_all_kinds_of_minds.html
Building on strengths	Book	Developing Talents: Careers for People with Asperger's Syndrome and High-Functioning Autism	Autism Asperger Publishing Company	Temple Grandin and Kate Duffy	
Academic studies	Book	Autism and Talent	Oxford University Press	Francesca Happé and Uta Frith	
Reference	Book	The Complete Guide to Asperger's Syndrome	Jessica Kingsley Publishers	Tony Attwood	
Reference	Book	Autism: A Very Short Introduction	Oxford University Press	Uta Frith	
Reference	Guide	"Diagnostic criteria for 299.80 Asperger's Disorder (AD)": Diagnostic and Statistical Manual of Mental Disorders	American Psychiatric Association		



HEALTH CARE

Introduction

As the parent of a child with ASD, your interactions with the health care system will be important for two reasons. First, your child's physician and other health care practitioners will be important parts of your overall support network. Second, your child's primary health care provider will be critical to your ability to access many of the support services your child may require. You will need to find a physician and/or paediatrician you are comfortable with, as they will be a source of knowledge and referrals to other specialists and services. This section provides some tips on your relationship with your child's doctor and preparing for visits with health care practitioners.

Topics Covered

- + Your primary care physician
- + Other health or medical concerns
- + Hospital visits
- + Other health care practitioners

“ 1) Document and/or keep a journal of your concerns and the concerns of people interacting with your child; 2) Track and log specific “events” and or “behaviours” that are concerning; 3) Gather all medical and milestone records concerning your child’s development; 4) Arrange for a diagnosis. The sooner you know what you are dealing with the sooner you can put a plan in place to ensure that your child has access to all the resources available. ”

-PARENT FROM TORONTO

YOUR PRIMARY CARE PHYSICIAN

Developing a good relationship with your child’s family physician, paediatrician or primary care physician—and, equally importantly, their administrative assistant or receptionist—is important. You may want to turn to these professionals frequently for support of all kinds as your child grows.

Some physicians will have more training and/or expertise with ASD than others. If you do not feel comfortable with your child’s physician, find another if you can. The Ministry of Health and Long-Term Care’s Health Care Connect program can provide information on how to change and/or locate a new health care provider. The College of Physicians and Surgeons of Ontario also has a searchable database of active physicians and contains information on qualifications.

After your child has been diagnosed it may be necessary to make relatively frequent visits to doctors or specialists. As a result, you may want to: have easy access to assessments, medical records, referrals and other documents.

Developing ways to make trips to the doctor as easy as possible for you and your child is a goal of many parents. Some suggestions include:¹⁷¹



Using visual aids to describe the process of going to the doctor’s office (reception area, waiting room, procedures, etc.)



Calling ahead of time and asking what tests or procedures will be conducted and what instruments will be used can give you an opportunity to describe these to your child and help them prepare



Asking if there is a quiet area for you to wait in

OTHER HEALTH OR MEDICAL CONCERNS

Individuals with ASD can have health problems just like anyone else. However, some research has indicated that some health problems tend to occur more frequently among individuals with ASD. The presence of an additional health problem (what health care professionals call a “comorbidity”) can result in more frequent trips to health care professionals. Some health problems that may be more common in individuals with ASD include:¹⁷²

- + Gastrointestinal (GI) Problems
- + Fragile X Syndrome
- + Tuberous Sclerosis
- + Neurofibromatosis
- + Epilepsy
- + Vision Problems
- + Hearing Problems
- + Neurological Problems

These are conditions that you may want to discuss with your health care provider and may result in more frequent trips to the doctor’s office.

HOSPITAL VISITS

Hospital visits can be difficult for children with ASD. The sights, sounds, and smells of a hospital can contribute to sensory overloads. Also, unlike visits to the doctor, it is more likely that you will need to visit a hospital without time to prepare for the trip (often during an emergency). In these circumstances, your [Emergency Information Sheet](#) will help ensure that everyone working with your child can be made aware of their needs as quickly as possible (even if the situation is not strictly an emergency). Hospital waits can be long. It may be helpful to take along some snacks, books and perhaps a favourite small toy to help your child feel more comfortable in the unfamiliar setting.

OTHER HEALTH CARE PRACTITIONERS

Finding health care practitioners

Your physician and/or paediatrician will likely be the starting point for your professional health support network and team. However, depending on your child’s specific needs, your child’s physician may be supplemented by additional specialists (for example, dietitian, occupational therapist or developmental psychologist—these professions are defined in the [Glossary Section](#)). While in many cases your physician will refer you to a specific specialist, in some cases you may want to research potential providers yourself.

Keep in mind that in some areas there are differences in how primary health care is provided. For example, in some areas there are Family Health Teams and Community Health Centres who may use inter-professional teams that can help you and your child. This team-based approach to health care can help access the range of care that may be available to you and your child. For instance, team based approaches allow medical professionals to access social workers and/or mental health workers who may have more knowledge and expertise in working with children with ASD. You may want to speak to your health care practitioner about these team-based approaches.

Other professionals

Autism Ontario has created a website called [SPIRALE](#) that aims to provide parents, caregivers, and the general community the information they need to locate service providers in Ontario. The [SPIRALE](#) website allows parents to search for both regulated professionals and experienced autism workers. Regulated professionals and experienced autism workers are terms you are likely to hear when looking for services.^{iv}

REGULATED PROFESSIONALS

are members of professions that are regulated (with specified qualifications, licenses, etc.) to protect public health and safety. Examples include social workers, dietitians, occupational therapists, and psychologists.¹⁷³

EXPERIENCED AUTISM WORKERS

are professionals who are trained to work with and support people with ASD, but not overseen by a regulatory body. Their roles can include respite worker, social skills coach, behaviour therapist, life coach, psychotherapist, support worker, job coach, and many more. They may be working independently, within a business group and with or without supervision or support from other colleagues or other experienced autism workers.¹⁷⁴

[SPIRALE](#) allows parents or caregivers to search for providers by specific services or regions. Examples of services you can find on this site include:

- + Audiologist
- + Dentist and dental hygienist
- + Dietitian
- + Early childhood educator
- + Massage therapist
- + Occupational therapist
- + Optometrist
- + Psychologist
- + Social worker
- + Speech language pathologist
- + Academic tutoring
- + Adaptive sports and recreation
- + Adaptive technology
- + Adaptive (life) skills
- + Adult services
- + Arts-based programming
- + Behaviour and communication
- + Community integration
- + Social skills
- + Teacher

^{iv} The camps/individuals listed on CALYPSO are self-described. Neither Autism Ontario nor the Ministry of Children and Youth Services endorses or checks the credentials of these individuals.

LEARN MORE

USE	RESOURCE TYPE	TITLE	ORGANIZATION OR PUBLISHER	AUTHOR	LINK (IF AVAILABLE ONLINE)
Finding Physicians	Database	Public Register – All Doctors Search	The College of Physicians and Surgeons of Ontario		http://www.cpso.on.ca/docsearch/
Finding Physicians	Website	Health Care Connect	The Ministry of Health and Long-Term Care		http://www.health.gov.on.ca/en/ms/healthcareconnect/public/
Types of service providers	Database		Spiral – Autism Ontario		http://www.autismontario.com/client/aso/spirale.nsf/web/provider+types?OpenDocument
General information about children's health	Website	Autism Spectrum Disorder Resource Centre	The Hospital for Sick Children		http://www.aboutkidshealth.ca/En/ResourceCentres/AutismSpectrumDisorder/Pages/default.aspx
Doctor visits	Article	Doctor: preparing for a visit	The National Autistic Society (UK)		http://www.autism.org.uk/living-with-autism/out-and-about/doctor-preparing-to-visit.aspx
Doctor visits	Tool kit	Blood Draw Toolkit	Autism Speaks		
Information guide on medicines	Tool kit	Medication Decision Aid	Autism Speaks		
Advocacy channel		Ontario Ombudsman	Government of Ontario		www.ombudsman.on.ca
Dentist visits (Dental professional focused)	Tool kit	Dental Professionals' Tool Kit	Autism Speaks		http://www.autismspeaks.org/science/resources-programs/autism-treatment-network/tools-you-can-use/dental



FAMILY SUPPORT

Introduction

In addition to the challenges already discussed, parents of children with ASD must navigate other aspects of family life—such as caring for their other children, managing finances, building a career, and maintaining healthy relationships with their partners. It’s important to find ways to look after your own needs as well as the needs of your children.

THIS SECTION CONTAINS A RANGE OF TIPS AND RESOURCES FOR day-to-day family and personal life for parents of children with ASD. As mentioned elsewhere in this Parent Resource Kit, a consistent suggestion of parents of children with ASD is to join a support group. These groups can be enormously helpful to parents, offering guidance and support on nearly every topic in this kit. And, in fact, topics covered in this section are particularly good ones to discuss in support groups. Your local Autism Ontario chapter is a good starting point for finding a parent support group or workshop. Your Autism Ontario chapter can also explain how you and your child could benefit from the Autism Ontario Potential Programme. The Potential Programme is designed to support families of children with ASD and is further described in [“ASD Diagnosis and Treatment”](#) of this kit.

Topics Covered

The topics covered in this section relate to everyday family life concerns most commonly voiced by parents of children with ASD. These include:

- ♥ Dealing with the diagnosis
- ♥ Employment issues
- ♥ Engaging with your community
- ♥ Family finances
- ♥ Your relationship as a couple
- ♥ Single parents
- ♥ Support groups/therapists
- ♥ Respite care
- ♥ Friends and extended family
- ♥ Supporting siblings

DEALING WITH THE DIAGNOSIS

Each parent handles this in their own way

After the diagnosis, many parents experience a period of grieving for the relationship and experiences that they thought they were going to have with their child. Most parents wonder if birthday parties, graduations, or participation in sports and lessons will be different from what they had imagined. It is important that you understand this is normal, and that each parent needs to handle this in their own way.

“ Autism Ontario, contact them, their staff are GREAT! ”
- PARENT OF 3-YEAR-OLD WITH ASD

Explaining the diagnosis to your child

The decision of when and how to tell their child that they have ASD is commonly identified by parents as one of the most difficult decisions and conversations they must have. It is also a very personal decision. How you approach this topic will likely depend on your personal values and family situation. In many cases the child's age is a key factor in determining how and when to explain their ASD to them. Children in preschool will not be able to understand while an individual with a diagnosis at the age of 12 may be able to understand its implications. Also, older children undergoing diagnostic evaluation will typically know, or ask why, they are visiting a doctor or psychiatrist.

While every child is different, some things you may want to consider are:¹⁷⁵

- ✔ Thinking about what your child understands and is ready to know. The terms and level of detail used to explain ASD would be different for a teenager compared to an elementary school child.
- ✔ Explaining ASD in relationship to your child's situation (how it impacts their sensory issues, social intelligence, behaviour).
- ✔ Letting your child know that ASD is a common condition, that they are not alone, and that there are many individuals who have benefited from therapies and interventions to overcome challenges.

The [“Learn More”](#) section contains links to websites that can provide you with additional information and help guide you through this conversation.

EMPLOYMENT ISSUES

Finding work and staying employed when you have caregiving duties can be difficult. In some cases parents of children with ASD will change either their careers or their expectations for their careers, depending on the situation. Often, one spouse may not work or work only part-time to ensure they are available to address any issues that might arise with their child.

“ Another tip is to be open about your situation with your employer. There will be times when you will miss work, arrive late or need to leave early. The more information you share the better they are prepared and able to make accommodations for you. ”
- PARENT OF 7-YEAR-OLD WITH ASD

Consider your options carefully and, as with so many issues discussed in this Parent Resource Kit, do what is right for you.

ENGAGING WITH YOUR COMMUNITY

One strategy some parents find helpful in navigating their autism journey is to engage with their community about ASD. This helps them connect with people with similar experiences or interests and do their part to make their community a better place for all people with ASD. Some of the ways parents do this include: joining their local Autism Ontario chapter, participating in online discussion groups, speaking to community groups about their experiences, and working with local community organizations to ensure that the needs of people ASD are met.

FAMILY FINANCES

“ Most important that parents must save enough \$\$\$ to support their adult child through his/her lifetime! ”
- PARENT FROM WINDSOR

Concerns over financial pressures are very real for many families in general. However, having a child with ASD can cause additional strain on family finances because of expenses related to therapies and treatments, education, dietary needs, caregiver costs, and home safety modifications.

Applying for financial support

Parents of children with ASD may qualify for financial support from a number of sources to help pay for a variety of different services. The exact level of financial support will depend on your child's specific needs and your family's financial situation. Here are some tips for completing applications for funding support:

- ✔ Always keep an original copy of any application you send by mail.
- ✔ Keep a calendar that marks renewal dates for funding programs that must be renewed.
- ✔ If you have any questions about a specific financial program, call the agency responsible directly.
- ✔ Try to develop relationships with staff from each agency so that you have someone to turn to with your questions.

Sources of financial support

The following is a list of financial support programs/benefits that you may apply to as a parent of a child with ASD. Each program will have different requirements, eligibility, and application processes.

“ Learn about the Registered Disability Savings Plan (RDSP). With many children getting their diagnosis at a young age, the earlier the parent can start this fund, the better. ”

- PARENT OF TWO CHILDREN WITH ASD

Provincial Government programs

SPECIAL SERVICES AT HOME PROGRAM (SSAH)

Funded by the Ministry of Community and Social Services (MCSS), this program provides financial assistance to families of children with a physical and/or developmental disability. If approved, the funds are given directly to your family to hire a support worker to help your child learn new skills and abilities. These funds can also be used to help pay for respite services.¹⁷⁶

ASSISTANCE FOR CHILDREN WITH SEVERE DISABILITIES (ACSD)

This program, offered by the Ministry of Community and Social Services (MCSS), provides financial assistance to parents of children with a disability on a monthly basis. Eligibility depends on your family income and your child's level of need. There is a detailed application to complete and a worker will visit your home to talk to you about your situation in greater detail.^{177 178}

INCONTINENCE SUPPLIES GRANT PROGRAM

Administered by Easter Seals Ontario and fully funded through the Ministry of Health and Long Term Care (MOHLTC), this program provides funding to help with the cost of diapers and other similar supplies for children three to 18 years old. In order to qualify children must have a condition that causes a lack of control over the bladder for six months or longer. A doctor or nurse practitioner must complete the medical section of the application.^{179 180}

ONTARIO DISABILITY SUPPORT PROGRAM

Delivered through MCSS, this program helps support people over 18 with disabilities through Income Support and/or Employment Support. As your child approaches 18 you may want to contact your regional MCSS office to discuss how the program can benefit your child and their eligibility.

THE TRILLIUM DRUG PROGRAM

Offered by the MOHLTC, The Trillium Drug Program provides medication coverage for Ontario residents who have a valid Ontario health card. If you or your family spend a large part of your earnings on medication, the Trillium Drug Program may be able to help with the costs. Applications are available online or at local drug stores.¹⁸¹

Federal Government programs and tax credits

DISABILITY TAX CREDIT

This tax credit lowers the amount of tax you may owe if your child has severe, long-lasting mental or physical disabilities. A qualified physician must complete the medical section of the application.^{182 183}

CHILD DISABILITY BENEFIT

This benefit is offered to families with low to modest income and a child with a severe and prolonged disability. To apply for this program, you must have a signed Disability Tax Credit Certificate as well as a completed Canada Child Tax Benefit application form (RC66).

Your local Autism Ontario chapter and/or social worker can help you access these funding sources and provide information on other sources of financial assistance. Kerry's Place Autism Services and The Hospital for Sick Children have both prepared summaries of financial assistance available for families. Links to these summaries are provided in "[Learn More](#)."

Programs and contact information

PROGRAM	SOURCE	CONTACT INFORMATION
Special Services at Home Program (SSAH)	Ministry of Community and Social Services	www.mcsc.gov.on.ca. To locate your nearest office, check the directory located in the " Learn More " Section.
Assistance for Children with Severe Disabilities	Ministry of Community and Social Services	1-877-832-2818 Ext. 341 www.cdrcp.com/cip_snf_acsd.html
Incontinence Supplies Grant Program	Ministry of Health and Long-Term Care	1-800-668-6252
Ontario Disability Support Program	Ministry of Community and Social Services	www.mcsc.gov.on.ca/en/mcsc/programs/social/odsp/ 1-800-875-6213
The Trillium Drug Program	Ministry of Health and Long-Term Care	www.gov.on.ca/health 1-800-575-5386

Disability Tax Credit (DTC)	Canada Revenue Agency	www.ccr-a-adrc.gc.ca/E/pub/tg/rc4064 1-800-959-2221 Request a copy of Guide RC4064
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Child Disability Benefit	Canada Revenue Agency	www.ccr-a.gc.ca/benefits 1-800-387-1193
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YOUR RELATIONSHIP AS A COUPLE

Having a child diagnosed with ASD can strain any marriage or relationship. Parents often have different reactions to a child's diagnosis. These differing, and common, initial reactions can be one of the first sources of strain in a relationship because the one parent, who is trying to learn all about their child's condition and supports available, cannot easily turn to their partner who doesn't accept the diagnosis. Other relationship stressors for parents of children with ASD can include:¹⁸⁴

- ♥ The stress and confusion of understanding and working with agencies, funding sources, and constant applications and paperwork;
- ♥ Loss of income as one parent withdraws from the workforce to provide care, combined with additional costs associated with caregivers and specialized care;
- ♥ Disagreements over the best course of treatment and interventions for your child;
- ♥ Concerns over friends and family distancing themselves;
- ♥ Long-term uncertainty related to retirement, vacations or other plans you had for the future.

How to maintain a relationship with your spouse

It is important to find time for one another and to talk about both the immediate future and long-term plans. While it may not be easy with the hectic schedule of appointments that can follow a diagnosis, try to find time (perhaps after your children are in bed) to share what is on your mind with your partner. Some of the more common recommendations about maintaining partner relationships include:¹⁸⁵

- ✔ Keep communicating with each other, especially if there are disagreements over how you react to diagnosis and other news or treatment options.
- ✔ Develop an approach to working together and learn all you can about ASD.
- ✔ Ask how you can make your partner's day better today and share daily responsibilities and chores.
- ✔ Find time to spend together alone, no matter how brief, to have fun and relax in ways you did before your child was diagnosed with ASD.

Some of resources listed at the end of this section provide advice on maintaining a healthy relationship while parenting a child with a disability. For couples who need additional help, a marriage and family therapist or professional counsellor can be an invaluable resource. They can help you sort out difficulties and help you re-establish a healthy relationship.

SINGLE PARENTS

While married and common-law couples continue to make up the majority of families in Canada, single parent families have become

more common over the last 50 years.¹⁸⁶ Raising a child as a single parent can be difficult. In many cases single parents are not able to step out of the workforce to care for their child full-time at home. Single parents often need to be both the primary caregiver and primary wage earner in the family.

In addition to working, activities such as dating, going to school, or regular household tasks can be difficult. As a single parent, there are some things you may consider to help with you in raising your child:

- ✔ Search for blogs or personal stories online that tell the story of other single parents
- ✔ Join a local parent group, ideally one for single parents and discuss the child care needs you have to attend meetings with other parents
- ✔ Take advantage of respite care to recharge or complete important tasks
- ✔ Try to develop both male and female role models in your child's life

SUPPORT GROUPS/THERAPISTS

Many parents are ambivalent about joining a support group. They may feel uncomfortable sharing their experiences or find it difficult to set aside time to attend a group.

However, many parents find that support groups are worth the time and effort. One of the most important benefits is that you can learn from other parents about resources, programs, and supports available in your local community. Some kinds of information, tips and resources are more easily obtained from other parents than by searching in books or on the Internet.

Here are some of the other benefits of support groups reported by parents:

EMOTIONAL SUPPORT

While people have different levels of comfort about sharing in groups, many parents of children with ASD find that telling their stories and hearing other parents' experience is an important source of emotional support that lightens their load just a little bit.

LEARNING NEW SKILLS

Some support groups hold educational sessions on skills that will be helpful to parents.

MAKING FRIENDS

Some parents develop important friendships through their participation in support groups.

RESPITE CARE

“ Accept the help of others, even if it is to babysit, help with research, or cut your grass. ”

- PARENT OF 17-YEAR-OLD WITH ASD

Parenting a child with ASD can be a full-time job; it can be overwhelming and tiring and comes with few opportunities take a break and relax. Caregiver burnout is a real concern. Although you

will naturally want to focus on your child's health and well-being, it is important to remember that as a parent you need to consider your own physical and mental health so that you can care for your child over the long term.

Respite services are an important resource for parents who need a break from the ongoing effort and stress of caring for a child with ASD. "Respite services provide temporary relief to families of children and youth with special needs. While parents get a well-deserved break, their children have the opportunity to engage with peers and adults outside of their family in meaningful activities."¹⁸⁷ However, some parents are reluctant to use respite care out of feelings of guilt or abandonment. When considering respite services, remember that no one is physically or emotionally able or prepared to provide care 24 hours a day, 7 days a week, 365 days a year. To help parents take advantage of respite services, MCYS funds a number of ASD-specific initiatives including:¹⁸⁸

THE AUTISM SPECTRUM DISORDERS RESPITE SERVICES INITIATIVE

Provides a range of specialized respite services to families caring for children and youth with autism. Families get relief while their children engage in meaningful activities that help develop new skills and relationships. One component of this program is the opportunity for children and youth with ASD to attend seasonal camps.

SUMMER CAMP FOR CHILDREN AND YOUTH AND WITH ASD

Families are reimbursed for hiring one-to-one support workers and the ministry funds 54 day and overnight camps that offer swimming, cooking, crafts and weekly community outings. Information can be found on Autism Ontario's website or through MCYS regional offices.

MARCH BREAK CAMPS FOR CHILDREN AND YOUTH WITH ASD

Like summer camps, families are reimbursed for the costs of hiring a one-to-one support worker or for a camp space to their children can participate in March break camps. Information can be found on Autism Ontario's website.

WWW.RESPITESERVICES.COM

A website operated by the Geneva Centre for Autism that provides information about agencies and organizations that offer respite services in Ontario. Supported by the Ontario Government, the website helps families access respite services wherever they live.

Additional respite services may be applicable to your family. These include:

- ♥ The Out-of-Home Respite program for families of children with multiple special needs
- ♥ The Enhanced Respite Program for families caring for medically fragile and/or technologically dependent children living at home

The Ministry of Community and Social Services also funds two programs—the Special Services at Home Program and the Assistance for Children with Severe Disabilities Program—which provide families with funds to purchase various services, including respite care.¹⁸⁹ These programs are described in more detail in the [funding section](#) of this Parent Resource Kit.

“ Things do get better...though some days you may want to pull your hair out, throw a glass, scream, or walk out the door! It's all part of the process...remember to rely on others, ask for help, access all the resources you can, and lastly, make time for yourself, your partner and your other children. Take a break regularly for the benefit of your family. ”

PARENT FROM CENTRAL-EAST ONTARIO

FRIENDS AND EXTENDED FAMILY

Telling others can be hard

It is not easy to tell your friends, extended family, and coworkers that your child has ASD. Parents may find it hard to discuss their child's diagnosis, perhaps because they do not feel ready to talk about it or are unsure about how others may react. Telling others about your child's diagnosis is a very personal decision, and also dependent on the age of your child in many cases. For individuals diagnosed as adolescents you may want to discuss with them the topic of telling others about their ASD. Some parents also tell only a select group of individuals. These are typically people who interact frequently with their family or child—for example, they may tell the parents of their child's friend (to help encourage social interactions), but not every tenant in their apartment building.

There is a natural fear that those close to you may withdraw when they themselves are unsure of how to act or what to do after hearing your child has ASD. However, many parents report most friends and family do not withdraw after hearing that about a child's diagnosis. Instead, many respond by offering their support and help.

How to explain the diagnosis

When first telling someone about your child's ASD, keep in mind that they may not know very much about ASD or how to respond at first. One way to help is to give them some information about your child and their needs that they can take home and read over. This will help them develop a better sense of your child's condition and how they can support your family.

What you can provide to your friends and family

“ The library is a wonderful resource for various topics...simple books to help children/siblings understand ASD and books for grandparents. The library was the greatest resource. We have over 100 titles on ASD in the Stratford library alone. ”

PARENT FROM LONDON

There are a number of existing toolkits and resources that are very helpful for sharing information with others about ASD. Most local libraries have books and resources on ASD, including many of the books referenced in this kit. Checking a book out of your library and lending it to a friend or family member who doesn't use the Internet is one way you can provide them with the information they need to become familiar with ASD.

Autism Speaks has Family Support Tool Kits that can help friends and family understand ASD. When speaking to someone close to you about your child's ASD, consider printing a copy of these tool kit(s) for them or emailing them a copy. Those you may find useful include:

- ♥ A Grandparent's Guide to Autism
- ♥ A Friend's Guide to Autism
- ♥ 100 Day Kit

One concern of many parents is that they will not be able to maintain their friendships because of the seemingly full-time care requirements and other demands of having a child with ASD. Explaining your child's condition to your friends can result in a better understanding of why your child acts out in certain circumstances and why you do not spend the same amount of time with your friends as you did in the past. Taking advantage of respite services (discussed in the previous section) is one way to not only recharge your batteries but also spend time with friends and family.

SUPPORTING SIBLINGS

If you have one or more neurotypical children in addition to your child with ASD you may find yourself trying to enforce “two sets of rules” at home—one set for your child with ASD, and one for their sibling or siblings. The focus and attention you need to provide to your child with ASD may also leave you drained and with less time and to devote to your other children. This naturally leads to feelings of guilt or worry that you are not close enough to them. This will most likely be an ongoing challenge. One way to support your other children is by helping them learn about ASD so they can understand their brother or sister's experience and the challenges your family is managing.

Common concerns of siblings

The siblings of children with ASD have their own adjustment and challenges. Understanding how your neurotypical children are feeling is the first step to finding ways to help them.¹⁹⁰

- ✔ Younger children often struggle to understand the diagnosis or why their brother or sister acts the way they do.
- ✔ Jealousy and resentment sometimes occurs when parents spend a disproportionate amount of time with one child.
- ✔ Children may feel embarrassed when their sibling acts out with unusual behaviour around their friends or in public settings.
- ✔ They may be frustrated or confused about their relationship with their sibling, which may be quite different from the relationships that their friends have with their brothers and sisters.
- ✔ They may be concerned about their future role as caregivers when their parents are no longer able to care for them.

Supporting your other children

One way to support your other children is to set aside special one-on-one time with them. This often requires creative planning (completing errands with a child, having special time before bed or early in the morning), but regular schedules can help ensure that all children get individual attention from each parent. Other strategies include:¹⁹¹

- ✔ Talking to your child at an early age to explain their sibling's condition in an age-appropriate manner. Autism Speaks has a comprehensive list of resources that can help you do this;
- ✔ Teaching your child how they can form a relationship with their sibling. This includes how they can get their sibling's attention, play with them, and communicate in ways their sibling can understand;
- ✔ Enrolling them in sibling support groups where they can build friendships with others who have brothers or sisters with ASD;
- ✔ Reaching out to a professional if you feel that your child needs additional help. Asking for help is not a sign of parenting failure; knowing when to seek help is the sign of a strong parent.

The [Family Transitions](#) section of this Parent Resource Kit offers more ideas for helping the siblings of a child with ASD understand the diagnosis. The Autism Society, Autism Speaks, and the National Autistic Society (UK) have all published toolkits and/or articles targeted towards helping children understand ASD. Autism Ontario offers sibling support groups to help siblings understand that their situation is not unique, connect them to other kids who share their feelings, and help them make the best out of having a brother or sister with ASD.

LEARN MORE

USE	RESOURCE TYPE	TITLE	ORGANIZATION OR PUBLISHER	AUTHOR	LINK (IF AVAILABLE ONLINE)
Respite Services	Directory of Respite Services in Ontario	Respite Services	Ministry of Community and Social Services & Ministry of Children and Youth Services		http://www.respiteservices.com/
Respite Services	Website	Backgrounder: Respite Services for Families of Kids with Special Needs	Ministry of Children and Youth Services		http://www.children.gov.on.ca/htdocs/English/news/backgrounders/08142008.aspx
Financial Support	Website/ Resource Directory	Funding Sources	Geneva Centre for Autism		http://www.autism.net/resources/funding-resources.html
Financial Support	Website/ Resource Directory	Financial Support	The Hospital for Sick Children		http://www.aboutkidshealth.ca/En/ResourceCentres/AutismSpectrumDisorder/ResourcesforASD/Pages/FinancialSupport.aspx
Financial Support	Website	Incontinence Supplies Grant Program	Easter Seals Ontario		http://www.easterseals.org/services/incontinence-supplies-grant
Description of financial support available	Website/ Resource Directory	Financial Assistance	Kerry's Place Autism Services		http://www.kerrysplace.org/Public/Financial-Assistance
Tax Information	Website	Tax Info	Autism Ontario		http://www.autismontario.com/client/aso/ao.nsf/Durham/Tax+Info?OpenDocument
Parenting, Maintaining a healthy marriage	Book	Special Children, Challenged Parents: The Struggles and Rewards of Raising a Child with a Disability	Brookes Publishing Company	Robert A. Naseef	
Parenting, Maintaining a healthy marriage	Book	Bad Animals: A Father's Accidental Education in Autism	Arcade Publishing	Joel Yanofsky	
Parenting skills		Helping Children with Autism: Autism Treatment Strategies and Parenting Tips	Helpguide.org (UCLA Centre for Autism Research and Treatment)		http://www.helpguide.org/mental/autism_help.htm

USE	RESOURCE TYPE	TITLE	ORGANIZATION OR PUBLISHER	AUTHOR	LINK (IF AVAILABLE ONLINE)
Parenting skills		Parent Education and Skills Training: A Practical and Effective Way to Help (ACT-Now Fact Sheet 50)	Monash University (Australia)		http://www.med.monash.edu.au/spppm/research/devpsych/actnow/download/factsheet50.pdf
Siblings		Brothers & Sisters: Sibling Issues (ACT-Now Fact Sheet 14)	Monash University (Australia)		http://www.med.monash.edu.au/spppm/research/devpsych/actnow/download/factsheet14.pdf
Parenting skills		A Parent's Guide to Autism	Autism Speaks		http://www.autismspeaks.org/family-services/tool-kits/family-support-tool-kits#parents
Siblings		A Sibling's Guide to Autism	Autism Speaks		http://www.autismspeaks.org/family-services/tool-kits/family-support-tool-kits#parents
What to Tell Your Child	Reference, Tips	ASD Diagnosis: What Do We Tell the Kids?	Interactive Autism Network	Teresa Foden, Connie Anderson	http://www.iancommunity.org/cs/articles/telling_a_child_about_his_asd
What to Tell Your Child	Reference, Tip	Diagnosis: telling a child about their diagnosis	The National Autistic Society (UK)		http://www.autism.org.uk/about-autism/all-about-diagnosis/diagnosis-the-process-for-children/after-diagnosis/diagnosis-telling-a-child-about-their-diagnosis.aspx
Friends and Family		A Friend's Guide to Autism	Autism Speaks		http://www.autismspeaks.org/family-services/tool-kits/family-support-tool-kits#parents
Friends and Family		A Grandparent's Guide to Autism	Autism Speaks		http://www.autismspeaks.org/family-services/community-connections/celebrating-grandparents



ASD RESEARCH

Introduction

The field of autism research is very rich, producing new findings at a fast pace. As a parent it is natural to be interested in the latest developments and prospects for new therapies. However, keeping on top of new research and developments within the ASD community is hard enough for professionals and researchers, let alone parents!

“ Most of the information and tools we used we found on our own by reading, researching and speaking with other parents. In hindsight this seems wrong and we probably should have asked or spoke up, but you are in such an emotional haze you don't think straight. This is very sad to me even at this time as I think about it!

- PARENT OF 18-YEAR-OLD WITH ASD

It is often tempting to think that the newest claims coming out of ASD research may be the breakthrough that will make a huge difference for your child. However, it is important to avoid falling victim to poorly supported and often grand claims from unreliable sources. Below are some tips that can help you keep abreast of ASD research from credible sources.

Topics Covered

This section covers the following topics:

- Accessible and credible sources
- How to filter news for relevance and credibility
- How to determine whether new interventions are promising
- Gauging advice/services received in light of new research

ACCESSIBLE AND CREDIBLE SOURCES

“ Autism Ontario, one of the best; Kerry's Place has great workshops (various locations and times, depends on where you live, etc.).

- PARENT FROM YORK REGION

As parents you will ultimately need to decide which information sources you trust based on your child's condition, your family situation, and personal values.

One place to start is by finding out more about the following organizations, which are considered to be credible information leaders in the field of ASD.¹⁹² Some may have regular newsletters. Organizational newsletters are a good way to stay up to date on the latest developments and research in the ASD community.

- Asperger's Society of Ontario
- Autism Ontario
- Autism Society Canada
- Autism Speaks Canada
- Canadian Autism Intervention Research Network
- Interactive Autism Network
- Geneva Centre for Autism
- Province of Ontario Neurodevelopmental Disorders (POND Network)

HOW TO FILTER NEWS FOR RELEVANCE AND/OR CREDIBILITY

Stories about the latest ASD research and potential breakthroughs are commonplace in the media and on the Internet. There are countless information sources. This can sometimes make it difficult to filter the good from the bad and the credible from the unreliable.

“ READ lots of books, articles whatever you can get your hands on. DON'T believe everything you read or hear about. EVERY child with an ASD is different—so not everything will be useful or even applicable to your child. DON'T EVER give up—keep on fighting for your child and their rights as an individual/and for your family as a unit.

- PARENT FROM CORNWALL

Learning how to assess research findings and other information about ASD takes time and effort. Here are some guidelines to keep in mind as you consider the vast array of information that is available:^{193 194}

- Who is writing, publishing, or creating the new information? Do they have a reputable track record?
- Has the research been peer reviewed? Peer review is a process through which other experts or professionals have performed an impartial review of the information to validate the quality of the underlying research.
- Has the new research been replicated, that is, have other similar studies reported the same findings?
- Are the findings considered to be credible by reputable organizations or professionals within the ASD community?

HOW TO DETERMINE WHETHER NEW INTERVENTIONS ARE PROMISING

Even when new ideas, tips, therapies or interventions come from a credible source, they may not necessarily be helpful to your family. If you are exploring a new intervention or therapy, you will want to consider:¹⁹⁵

- Are there potential risks with this new therapy? How much of a financial impact would it have on your family? If the risks and costs are potentially high, it is important to have strong evidence to support any claims before you consider proceeding.
- What are the long-term results and risks of the intervention?
- Can the new intervention be integrated into your child's current therapy? What are the opinions of the current provider?

Finally, like so much in life, consider new findings with “a grain of salt” and carefully consider them before taking action. Whatever the source, it is important to keep in mind that no single new intervention is likely to solve all of the problems and challenges of ASD.

“ Make sure you find out the science behind each type of therapy you investigate. There are lots with anecdotal results and you can choose to try those but do it only if you have extra funds and do it exclusively to ensure you can measure results. Don't do a bunch of different therapies at the same time because if the child improves, you have no idea which therapy is responsible for the improvement.

- PARENT OF 7-YEAR-OLD WITH ASD

¹⁹²These organizations were identified by stakeholders that were consulted as part of this process to develop this resource kit.

GAUGING ADVICE/SERVICES RECEIVED IN LIGHT OF NEW RESEARCH

Any service provider should be willing to consider research from credible sources. Ideally, your physician, therapy provider or other support services should act as your partners to help your child. If you have reason to believe that new research is credible and that new interventions are safe, discuss these ideas and their potential benefits with your partner and health care providers.

LEARN MORE

USE	RESOURCE TYPE	TITLE	ORGANIZATION OR PUBLISHER	AUTHOR	LINK (IF AVAILABLE ONLINE)
Information about research	Summaries of current research, treatments and related evidence	Cochrane Summaries	Cochrane Summaries		http://summaries.cochrane.org/search/site/asd?rows=200
Information about research	Summaries of current research, treatments and related evidence		Canadian Autism Intervention Research Network (CAIRN)		http://www.cairn-site.com/en/index.html
Information about research	Summaries of current research, treatments and related evidence		Province of Ontario Neurodevelopmental Disorders (POND Network)		http://pond-network.ca/ and http://pond-network.ca/ndd/asd/asd-select-work/12-ndd/asd
Information about research	Linking autism community with researchers		Kennedy Krieger Institute		http://www.ianproject.org/
Information about research	Summaries of current research, treatments and related evidence		Autism Speaks		http://blog.autismspeaks.org/category/science/

GLOSSARY OF TERMS AND ORGANIZATIONS

ABACUS	Online directory of Applied Behaviour Analysis providers in Ontario to help families find and hire qualified private service providers.
Applied Behaviour Analysis (ABA)	ABA employs methods based on scientific principles of learning and behaviour to build useful behaviour repertoires and reduce problematic ones. ¹⁹⁶
Autism Intervention Program (AIP)	Program offered by the Ministry of Children and Youth Services that provides Intensive Behavioural Intervention services to children towards the severe end of the autism spectrum.
Autism Spectrum Disorder (ASD)	A term used to describe a group of developmental disorders that include: Autism, Asperger's Syndrome, Pervasive Developmental Disorders (PDD), Rett's Disorder, and Childhood Disintegrative Disorder (CDD). ¹⁹⁷
CALYPSO	Website for parents, caregivers, and the general community to locate camps and camp programs for individuals with Autism Spectrum Disorder (ASD) in Ontario.
Children and Youth	Ontarians of age 0 to 17 (up to 18 th birthday). ¹⁹⁸
Community Care Access Centre (CCAC)	There are 14 CCACs throughout Ontario, each responsible for connecting individuals within a specific region with the care they need at home and in the community. CCAC staff assess needs and determine care requirements, answer questions, and develop customized care plans. CCACs can also arrange for nurses, physiotherapists, social workers, registered dietitians, occupational therapists, speech therapist and personal support workers as necessary. ¹⁹⁹
Connections for Students	A collaborative model that supports the transition of children who are leaving IBI services provided by the Autism Intervention Program (AIP) and starting or continuing in a publicly funded school. ²⁰⁰
Developmental Paediatrician	Medical doctor with specialized training in paediatrics who has additional training and expertise in developmental paediatrics. This sub-speciality of paediatrics involves consultation regarding normal growth and development, childhood behaviour, and development the context of chronic medical illness. ²⁰¹
Dietitian	“Trained food and nutrition experts recognized in translating scientific, medical and nutrition information into practical individualized therapeutic diets and meal plans for people. Dietitians work with a variety of health professionals such as medical doctors and social workers to manage nutrition for health promotion, disease prevention, and treatment of acute and chronic diseases.” ²⁰²
Early Childhood Educator	Professionals able to assess a child's developmental needs and design a curriculum to support developmental progress and maintain a healthy emotional and social presence. ²⁰³
Emotional Intelligence	Within an individual, emotional intelligence refers to the capacity to understand and reason about emotions, to use emotions to assist with thought, and reflectively regulate emotions. ²⁰⁴
Exceptional Pupil	Students who would benefit from being placed in a special education program because of behavioural, intellectual, physical, or multiple exceptionalities. ²⁰⁵
Individual Education Plan (IEP)	Written plan describing the special education program and/or services required by a particular student based on a thorough assessment of the student's strengths and needs that affect the student's ability to learn and demonstrate learning. ²⁰⁶
Identification, Placement, and Review Committee (IPRC)	Committee formed during the process of defining a student as exceptional and deciding the student's placement within the education system. ²⁰⁷

Intensive Behavioural Intervention (IBI)	IBI is an intensive application of Applied Behaviour Analysis (ABA) designed specifically for children with autism in which children typically receive 20 to 40 hours of intervention per week, delivered by a therapist who works 1:1 with the child or in a small group. The intervention is delivered with the goal of increasing the child's developmental trajectory or rate of learning.
Motor Skills	Divided into gross motor skills and fine motor skills. Gross motor skills involve the coordination of large muscle groups to complete physical activities such as running, jumping, climbing. Fine motor skills involve the coordination of smaller muscle groups to complete tasks such as dressing, eating, and drawing.
Multi-Disciplinary Team	A team of individuals who each have skills and expertise in a different field or specialization.
Neurologist	Medical doctor with specialised training in the nervous system. Paediatric neurologists can assess children for cognitive, behavioural, and developmental problems. ²⁰⁸
Neurotypical	An individual not on the autism spectrum.
Occupational Therapist (OT)	"Health care professionals who help people learn or re-learn to manage the everyday activities that are important to them, including caring for themselves or others, caring for their home, participating in paid and unpaid work and leisure activities." ²⁰⁹
Physiotherapists (PT)	Professionals who work with individuals of all ages to assess physical function and support the development, maintenance, or rehabilitation of physical abilities. ²¹⁰
Psychologist and Psychological Associates	Professionals trained in the assessment, treatment and prevention of behavioural and mental conditions. They diagnose neuropsychological disorders and dysfunctions as well as psychotic, neurotic and personality disorders and dysfunctions. ²¹¹
Respite Care	Programs that can give families a break (or "respite") from the day-to-day care of their child with special needs. ²¹²
School Support Program (SSP)	Program that connects school boards with Autism Spectrum Disorder consultants to help school staff support the learning and social needs of students with autism. ²¹³
Self-Care	Day-to-day skills individuals complete without the assistance of professionals such as washing and hygiene, appearance, and elimination, eating, dressing.
Social Stories™	A Social Story™ is a trademarked approach to describe a situation, skill, or concept in terms of relevant social cues, perspectives, and common responses in a specifically defined style and format. ²¹⁴
Social Worker	"Social workers assist individuals, families and communities to resolve problems that affect their day-to-day lives. Social workers help identify the source of stress or difficulty, make assessments, mediate between conflicts, offer various forms of counselling and therapy, and help people to develop coping skills and find effective solutions to their problems." ²¹⁵
Special Education	Educational program that is based on the results of a continuous assessment and evaluation of the student. Includes an Individual Education Plan for the student containing specific objectives and an outline of the educational services that meets the needs of the exceptional pupil. ²¹⁶
Speech-Language Pathologists	Autonomous professionals who have expertise in typical development and disorders of communication and swallowing, as well as assessment and intervention in these areas. ²¹⁷
SPIRALE	Website for parents, caregivers and the general community to locate regulated professionals and experienced autism workers for individuals with Autism Spectrum Disorder (ASD) in Ontario.
Tactile Sensitivity	Sensitivity to different types of touch (e.g., hugs) and/or textures (e.g., specific clothing fabrics).
Transitions	All individuals experience transitions throughout a day as they change from activity to activity and from one setting to another. Examples include changing classrooms at school, traveling from school to home, and changing from TV time to dinnertime.
Visual Story/Schedule	Use of pictures and words to display actions, timelines, emotions, or other concepts.

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