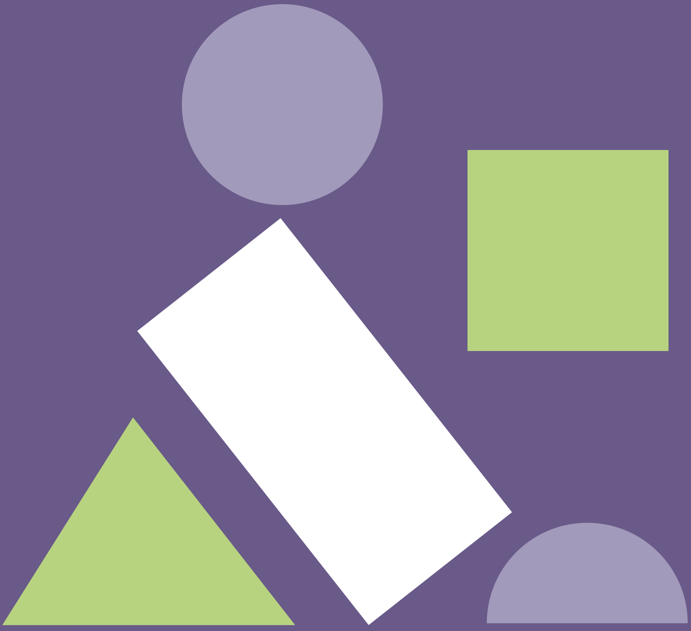
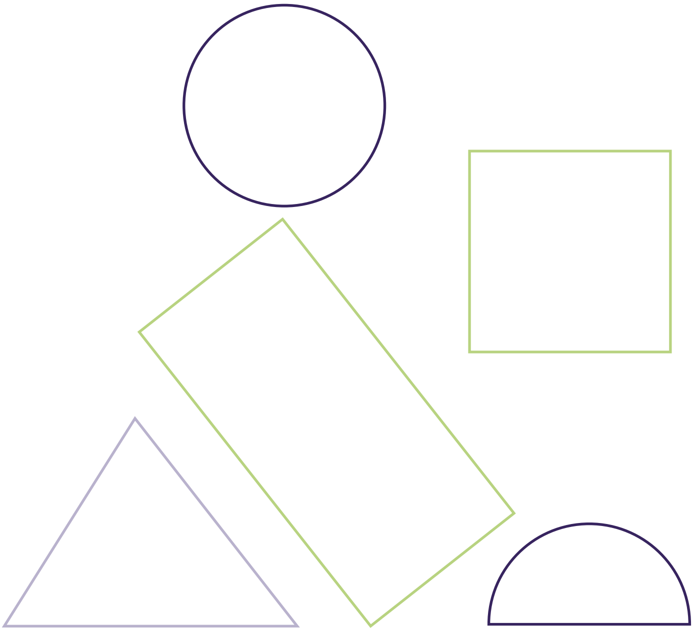
AUTISM *spectrum* DISORDER

INFORMATION FOR PARENTS



AUTISM *spectrum* DISORDER

INFORMATION FOR PARENTS



acknowledgements

We would like to thank all of the staff at the Child Development Centre for their help with this package. We would also like to say a special thank you to all of the parents who read the first draft of this package. Your valuable comments have helped to shape this package.

We are always trying to improve this information. So we would very much like to hear what you have to say about it. What did you find useful about the package? What was missing? What would you like to see included in the future? You can mail, email, or fax your comments to us.

Please send your comments to us, Lee Steel or Janice Mulligan, at this address:

Child Development Centre
The Hospital for Sick Children
555 University Avenue
Toronto ON M5G 1X8

You may fax your comments to us at 416-813-7437. Or you may email them to Lee Steel at dleesteel@hotmail.com or to Janice Mulligan at janice.mulligan@sickkids.ca.

We are looking forward to hearing from you.

Lee Steel	Janice Mulligan, MSW, RSW, Res.Dip.SW
Parent Liaison	Social Worker
(416) 813-6127	(416) 813-6305

CHILD DEVELOPMENT CENTRE
THE HOSPITAL FOR SICK CHILDREN
TORONTO ONTARIO

TABLE OF CONTENTS

1. INTRODUCTION

AUTISM SPECTRUM DISORDER:
introduction

DEAR PARENT,

We created this package to give you some information about Autism Spectrum Disorder. This is a place for you to begin your search for answers. We hope that it will help you to understand a little more about what you were told when your child was being assessed.

Many parents feel overwhelmed when they find out that their child is developing in a different way than many other children do. Like other parents you may find that you do not know where to start, what to read, where to go first. We hope that this package of information will help you begin to answer these questions.

You may have mixed feelings about your child's diagnosis. You may feel that knowing your child's diagnosis will help you get the services and support you need. You may feel that it is helpful to know that many other children behave like your child. You may take comfort in knowing that your child and family are not alone.

At the same time, you may feel that the diagnosis will now define who your child is. No matter what the diagnosis, your child, like all children, is unique. All children have their own very special personalities.

Sometimes you may feel that your child is getting lost in all the tests and assessments. Sometimes you may feel that your child's strengths and abilities are being overlooked, particularly when many of the tests seem to emphasize your child's difficulties.

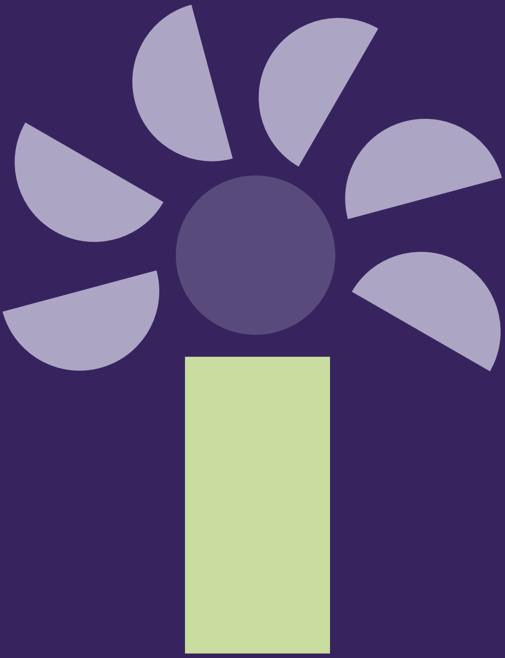
Just remember, you know your child best. You know what your child does well and what your child needs help with. Hold on to that knowledge as you do your best to help your child make the most of his or her abilities.

We hope that this package will give you information, resources, and maybe some comfort as you begin to develop the best supports for your child.

Sincerely,

Lee Steel and Janice Mulligan

AUTISM SPECTRUM DISORDER:
an overview



an overview

WHAT IS AUTISM SPECTRUM DISORDER?

Autism Spectrum Disorder, also called ASD, is the name used for a specific set of behavioural and developmental problems and the challenges that go with them. A diagnosis of ASD means that your child's communication, social, and play skills are affected in some way.

The word **SPECTRUM** in Autism Spectrum Disorder means that your child's problems may vary from mild to severe. And as your child grows and develops, these problems and challenges may change. A person with ASD will have it for the whole of his or her life.

A diagnosis of ASD is based on what the doctor observes and knows about your child's behaviour and development in the early years. The doctor will find out about your child's early years by sitting down and talking to you.

OTHER NAMES FOR ASD

Various names have been used to describe ASD. These are some of the more common names for ASD that you may hear:

- autism spectrum disorder
- pervasive developmental disorder, or PDD
- pervasive developmental disorder-not otherwise specified, or PDD-NOS
- Aspergers syndrome (or Asperger syndrome)
- high functioning autism

In this information package, we use the term **AUTISM SPECTRUM DISORDER, ASD, OR AUTISM.**

THE DIAGNOSIS OF ASD

Parents, family, teachers, and the general public are often confused by a diagnosis of autism because they think they know what autism is. Many parents say, "My child can't be autistic because he's affectionate, makes eye contact, likes to be hugged, and doesn't bang his head."

Some children with autism may not make any eye contact. Others may make eye contact sometimes. Some children with autism like to be hugged, but others do not. Your child with autism may like to be hugged and may make eye contact.

A diagnosis of ASD means that your child's development is affected in three main areas:

1 Social
2 Communication and play
3 A narrow and/or repetitive range of behaviors or interests.

Every child, with or without autism, is unique.

Like all children, children with autism have different likes and dislikes. Every child, with or without autism, is unique. Every child with autism has his or her own unique characteristics.

CHARACTERISTICS OF ASD

These are some of the characteristics of autism:

- problems with social interaction with others (for example, talking to, working, or playing with others),
- unusual interest in objects,
- need for sameness,
- great variation in abilities,
- sensory hypersensitivity (strong reactions with 1 or more of the 5 senses), and
- repeated actions or body movements

CHILDREN WITH AUTISM USUALLY HAVE DIFFICULTY WITH SOCIAL INTERACTION. That means they have problems talking to, playing with, or doing things with other people. Parents have told us that, before their child's diagnosis of autism, they thought their child was just very shy.

CHILDREN WITH AUTISM MAY HAVE AN UNUSUAL INTEREST IN OBJECTS. They may play with toys in different or unusual ways. For example, one boy that we met could tell us everything we needed to know about car engines. Another young girl who came to our centre could sit for hours spinning the wheels on her toy car.

CHILDREN WITH AUTISM OFTEN HAVE A NEED FOR SAMENESS. They may have difficulty with changes in routines.

CHILDREN WITH ASD MAY HAVE GREAT ABILITY IN ONE AREA AND GREAT DIFFICULTY IN ANOTHER. But not all children with autism have the same abilities. For example,

- a child with autism may have difficulty holding a pencil, but have a strong memory for the words of songs or movies.
- a child may have difficulty knowing how to play a game with a friend, but may have a very good understanding of how computers work,
- a child who does not speak may be able to build complex structures out of Lego.

CHILDREN WITH ASD MAY ALSO HAVE UNUSUALLY STRONG REACTIONS WITH 1 OR MORE OF THEIR 5 SENSES (SIGHT, HEARING, SMELL, TOUCH, AND TASTE). For example, some children with autism react to bright sunlight. Others are bothered by tags on their clothing or by loud noises. Many children may be bothered by these things, but children with autism often have an extreme reaction to them.

Children with autism often have difficulty with the colour, smell, or feel of certain foods. This may limit what they will eat to a few foods.

CHILDREN WITH ASD MAY ALSO DO THE SAME THING REPEATEDLY. For example, they may repeatedly flap a hand, jump, or walk on tiptoes. This is common. It is something that many parents talk about when they describe their children.

Social deficits describe problems living, playing, and working with others.

Other children with ASD may talk constantly about specific things that interest them. These interests may seem to take up most of the child's time.

One adult with autism was fascinated with how washing machines work. As an adult looking back on his childhood, he realized that his neighbours did not find washing machines as fascinating as he did. He understood that he needed help choosing when, where, and whom to talk to about washing machines. That way he would not have to stop talking about them altogether. He thought it would have helped if someone could have taught him this skill.

CHARACTERISTICS OF ASPERGERS SYNDROME

Aspergers syndrome is part of the Autism Spectrum Disorder. Children with Aspergers syndrome have average intelligence, almost regular language development, but they have social and communication problems, and limited interests.

Sometimes you will hear the words **SOCIAL DEFICITS** and **PERSEVERATION** used to describe the main characteristics of Aspergers syndrome.

Social deficits

Social deficits describe problems living, playing, and working with others. Although children with Aspergers syndrome may be very intelligent, they often have problems interacting with others. This can cause them problems making friends.

Children with Aspergers syndrome may have trouble understanding other people's viewpoints and emotions, especially those of people they do not know well. This can be particularly difficult for school-aged children who are meeting new children in the classroom and schoolyard every day.

Perseveration

Perseveration describes repeated behaviours in either words or actions. Many children with Aspergers syndrome become experts on limited topics (for example, washing machines, 50s rock and roll music). They may gather detailed information about a certain topic and repeat that information over and over again.

They may have problems with the idea of taking turns. And when they are talking to others, they may not realize that other people also need to be able to talk about their interests.

Perseveration describes repeated behaviours in either words or actions.

ASD is one of the most common developmental conditions.

The term **STICKY** is sometimes used for this type of behaviour, for example, "Betty gets stuck on talking about her fascination with bugs."

HOW COMMON IS ASD?

ASD is one of the most common developmental conditions. Studies done in 1998 found that about 5 of every 1000 people have ASD. And 4 out of 5 people with autism are male. It affects people from all parts of the world. It affects people of every social class and race.

WHAT CAUSES ASD?

There are many studies looking at the causes of ASD. Although no one specific cause is known, current studies suggest that ASD may be caused by differences in the brain.

In some families there appears to be a pattern of autism or related differences which suggests there is a genetic basis to the disorder. At this time, no single gene has been directly linked to autism. In fact, autism is most likely the result of a complex interaction of several genes. Research in this area is ongoing.

Several older ideas about the cause of ASD have now been proven wrong. At one time, parents were blamed for their child's difficulties. For example,

- children with autism were believed to have a difficult time forming relationships with others because their parents were not loving enough
- mothers were particularly thought to be at fault. They were called refrigerator mothers.

For many years, such ideas stopped us from understanding autism.

We now know that the brain of a child with autism develops differently from conception. We now know that

- autism is not a mental illness,
- children with autism are not unruly kids who choose to misbehave, and
- bad parenting does not cause autism.

> We now know that the brain of a child with autism develops differently from conception.

HOW IS ASD DIAGNOSED?

Diagnosing a child with autism is challenging. One of the problems is that we cannot tell, just by looking, if your child has autism. The characteristics of autism can change over time.

The characteristics of autism in children are clearest in their communication and social behaviour.

The characteristics of autism in children are clearest in their communication and social behaviour. Other characteristics, such as limited interests, ways of playing, and repetitive behaviours, may appear over time.

These are some of the other characteristics of autism your child may have:

- shows little response when you call his name,
- may not respond when other people try to talk or play with him,
- shows little interest in getting attention from others,
- not using his finger to point at things,
- shows a lack of interest in toys or plays with toys in an unusual manner,
- may be grumpy or irritable,
- may have difficulty making eye contact.

Remember, your child may have some or many of these characteristics. Children with ASD vary greatly in the number and severity of the characteristics of autism they may have.

There are no laboratory tests for diagnosing ASD. Since the characteristics of ASD can be so varied, making a diagnosis may be difficult for a doctor who does not have experience working with children with autism. At first, your child with ASD may seem to have a developmental delay, a learning disability, or problems hearing. The doctor needs to be able to tell the difference between ASD and other conditions. So it is best if the doctor, along with a team of specially trained health care workers diagnosis your child.

This team may be made up of these health care workers:

- a developmental paediatrician,
- a psychologist,
- a speech-language pathologist,
- a neurologist,
- a social worker,
- a special education teacher,
- an occupational therapist, and
- others who know about ASD.

You can help the team members with the diagnosis by providing them with a detailed history of your child's development.

Many of the behaviours of children with autism are similar to behaviours of children with other conditions. Therefore, other medical tests may be done to make sure that there are no other reasons for your child's difficulties.

Children with ASD vary greatly in the number and severity of the characteristics of autism they may have.

Remember, as parents, you have the right to choose whom you tell your child's diagnosis to.

THE POSITIVE AND NEGATIVE EFFECTS OF LABELLING YOUR CHILD WITH ASD

Parents often worry about telling people about their child's diagnosis. Telling people that your child has autism may have positive and negative effects. Remember, as parents, you have the right to choose whom you tell your child's diagnosis to.

Some of the negative effects may be
- people may judge your child and wrongly think they know what autism is,
- people may blame all of your child's actions on the autism,
- your child may be left out of activities because others think he or she is not able to join in the activities, and
- you may fear that the label of autism will follow your child forever.

Some of the positive effects may be
- others' understanding and acceptance of some of your child's behaviour may increase,
- you may have a clearer sense of the skills your child needs to learn to progress, and
- you will have a chance to use services and resources that you might not be able to get otherwise.

Many teens and adults with autism have said how relieved they are to know that there is a name that describes the way they have felt over the years. When they get their diagnosis, many adults have said that they no longer feel so alone or different. The diagnosis of ASD helped them to realize that there were others who had similar difficulties and shared common strengths.

In the end, you need to decide what to do based on your family's needs and wishes. Talk about your concerns with health care workers or other parents of children with autism.

IS THERE A CURE FOR ASD?

There is no medical cure for the differences in the brain that cause ASD. But because we understand the brain and ASD so much better now, we may be able to influence how the brain develops and works.

Slowly we are finding ways to help people deal with different characteristics of autism. With the right treatment, some behaviours can be changed. But most children and adults with ASD will always have some characteristics of autism for the rest of their lives.

Most children and adults with ASD will always have some characteristics of autism for the rest of their lives.

The stories of adults with autism offer hope that many people with autism can have full and satisfying lives.

WHAT DOES THE FUTURE HOLD FOR YOUR CHILD?

Parents of children with autism often ask about their child's future. They wonder if their child will date or marry, have a job, or live on their own, independently.

We cannot predict the future for any child. But the stories of adults with autism offer hope that many people with autism can have full and satisfying lives.

NOW I KNOW WHAT ASD IS BUT *what do I do?*

what do I do?

WHAT DO YOU DO NOW? WHERE DO YOU GO FROM HERE?

These are 5 things you can do to get started helping your child:

- Learn about ASD.
- Find the support that you need.
- Focus on your child’s capabilities too.
- Try to set aside some time to spend with the other children in your family.
- Look after yourself.

1. LEARN ABOUT ASD.

One of the most important things you can do is to learn about ASD. Nobody knows your child the way you do. Through the years you will need to speak up for the needs of your child. The more you understand about autism, the more you will know about the best way to help your child.

2. FIND THE SUPPORT THAT YOU NEED.

Many parents find it helpful to get support to help them find the services they need. Some parents have one person that they can talk to and solve problems with. Other parents join a support group and meet with a number of parents to talk about their situation. Choose whatever feels right for you.

Other parents of children with autism can help you to understand how the school system works and how other services work in your community.

Remember, you are not alone.

3. FOCUS ON YOUR CHILD'S CAPABILITIES TOO.

It is easy to think only about your child's difficulties. Focus on your child's capabilities too.

Look at the skills your child may need help with. But do not forget to look at the things he or she does well. Build on those skills.

Celebrate your child. Your acceptance and encouragement are essential to your child's feelings of worth.

Your acceptance and encouragement are essential to your child's feelings of worth.

4. TRY TO SET ASIDE SOME TIME TO SPEND WITH THE OTHER CHILDREN IN YOUR FAMILY.

Many parents have difficulty balancing the needs of their child with autism with the needs of their other children. These siblings, the brothers and sisters of the child with autism, have a lot of feelings about having a brother or sister with autism. They may feel frustrated, confused, embarrassed, guilty and jealous. They may also feel proud, compassionate and loving toward their brother or sister.

Many parents find that setting aside a special time for their other children is very important. It can help these siblings feel included when they may feel left out. It can also give them a chance to talk about their feelings. Or they can simply enjoy spending time on their own with their parents. (See the section called Resources for more information about support for siblings of children with ASD.)

5. LOOK AFTER YOURSELF.

It is easy to focus all your attention on the needs of your child and your family. Do not forget your own needs in the process. And do not feel guilty when you do take time for yourself.

Take time to care for yourself. Draw on the supports that you may already have. Work on finding others if you need them. Looking after yourself is an overlooked, but very important part of caring for your child.

WHAT DO YOU NEED TO KEEP IN MIND WHEN WORKING WITH YOUR CHILD?

Information about ASD is growing fast. You may find it difficult to know which programs and services are the best for your child.

No single treatment offers the solution. But studies show that children with ASD respond well to highly structured, specialized education programs that meet the specific needs of the child.

A good program may have these characteristics

- communication therapy,
- training in social skills development,
- sensory motor therapy, and
- behavioural teaching.

We have found that a structured, intensive educational and behavioural program is best for treating the more severe challenges of some children with autism. In this type of program the child usually works one on one with a teacher or in a small group.

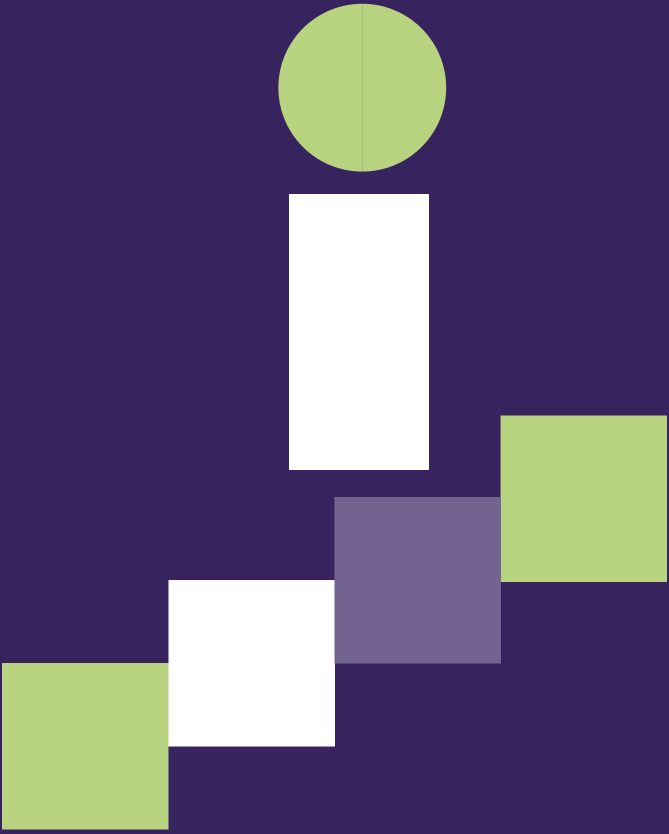
An effective program should be flexible and reward the child for things done well. The effectiveness of the program should be checked regularly.

> No single treatment offers the solution.

A good program also offers training and support for parents, other caregivers, and teachers. Often it can be difficult for the family, classroom teacher, or other caregivers to help a child with autism effectively without some training. They also need to be able to talk to a person who specializes in ASD and its treatment.

Remember, no one knows your child better than you do. Your opinions about and understanding of your child are important to the development of an effective program that will meet your child's needs.

AUTISM SPECTRUM DISORDER:
personal accounts



personal accounts

LIVING WITH AUTISM

In this section, 3 people living with autism tell their stories in their own words. Their stories are just a few of the many different voices of the autism community.

One mother's viewpoint

I clearly remember the day we received the diagnosis of autism spectrum disorder for our son, Eric. I didn't know anything about autism and I didn't know where to start. Unfortunately, I started with an outdated book that described a dismal present and a frightening future.

I remember the enormous pressure I felt to learn about autism and to put intervention into place. It felt as if my son's entire future was in my hands and I needed to make informed choices as quickly as possible. It was as if grains of sand were running through an hourglass.

If I didn't make the right decision as soon as possible, I was wasting precious time that could not be recovered.

This was a tremendous pressure placed upon us as parents. There was little time to deal with the feelings, the grief, the loss of dreams. The tests and language used to describe our son dealt entirely with his deficits. I was so caught up with what he couldn't do, I forgot all the things Eric was very capable of doing; his amazing memory, his humour, and his joy in being a little boy who was loved very much. During that time, Eric went from the child I celebrated to the child I was fearful for, the child I felt compelled to change, the child I felt I needed to fix.

This is one of the greatest regrets I have and one of the most important things I would like to share with parents who have just received a diagnosis of autism for their child. Even though autism represents challenges of many kinds for your child and for your family, there are things to be celebrated as well. Every child, regardless of their difficulties, has strengths and gifts. Who in life would succeed if we focused solely upon their deficits? I needed to remember that Eric was beautiful and wonderful just the way he was, and he wasn't "damaged goods" that needed fixing.

I didn't know anything about autism and I didn't know where to start.

I needed to understand that Eric had many things to teach me as well.

I needed to understand that autism wasn't a part of Eric I could cure, but it was the lens through which he saw the world. To quote Jim Sinclair, an adult with autism:

> Autism isn't something a person has, or a "shell" that a person is trapped inside. There's no normal child hidden behind the autism. Autism is a way of being. It is pervasive: it colours every aspect of existence. It is not possible to separate the autism from the person-and if it were possible, the person you'd have left would not be the same person you started with.

I needed to understand that Eric had many things to teach me as well. As I help him develop some of the skills necessary to navigate our world, I learn to stay open to what he has to teach me about the autistic world. And this journey is ongoing. Yes, we live in a world that is not all that accepting of differences. And for that reason our children will struggle, and we who love them will struggle along beside them. It was important for me to learn not to dwell only upon the struggles, but to have fun, to play, and to celebrate my child.

I'm not going to say that the path isn't lonely or frustrating. It is at times. You will draw upon wells of strength in yourself that you never knew existed. You may have to deal with the misunderstandings and judgments of people who see our children looking so typical, yet talking and behaving in a not so typical way.

When you are ready, try to get in touch with other parents of children with autism. They will help you learn that your child's frustrating or difficult behaviour is his or her best attempt to communicate. You as a parent understand better than anyone what your child needs and wants. I think a child's attempts to communicate in their own unique ways needs to be honoured.

A group of adults with autism was recently asked what would have been the most beneficial thing their parents could have given them. Overwhelmingly, their response was "acceptance." This doesn't mean that we don't try to help our children in every way possible, but I needed to learn to trust myself and my child in this process.

Autism spectrum disorder reveals itself in a very wide range of ways. Each child has a unique place in that range. There is no single universal treatment that suits every child, just as every child you meet within the range is unique. As you learn more about various treatment options, you will come to know what will work for your child. Listen and learn, but have faith in your wisdom, for you truly are your child's best advocate.

Listen and learn but have faith in your wisdom, for you truly are your child's best advocate.

Please know that you are not alone. Many of us who have gone before you can offer our own experience that may help you along. Most of the health care professionals really do care. Adults with autism can shed unique light on this alternative way of viewing the world. Try to look after yourself. And remember, labels aside, before you is your wonderful child who will blossom with your acceptance, encouragement, and support.

Lee Steel
Eric's mom

One father's viewpoint

I am the father of an autistic child.

I've known this, I think, since he was born, but it took a long time to accept it, to move past the label and get on with being his father the way he needs it.

It took a long time to accept it, to move past the label and get on with being his father the way he needs it.

My son is now 3. He was diagnosed with autism when he was just 22 months old, 3 months after his sister was born. He has an older brother, now 5, who, like most boys his age, has tons of friends, is obsessed with dinosaurs and generally keeps his parents hopping.

With 3 small children, we're certainly very busy, and having to learn about and deal with autism adds a great deal. We're learning far more about parenting than I think we ever thought possible, almost all of it applicable to all 3 children.

I am the father of an autistic child.

I probably think of that 100 times a day, 7 days a week. On initial inspection, one might think I'm obsessing over something I can't change, or that I somehow feel slighted by what I've been handed.

Nothing could be more wrong.

My son is an amazing child, and is making enormous gains as he learns about life with the help of everyone around him, including his siblings, his therapists, his peers and his parents. Of which I am one.

When I think of autism, it is almost always in the context of something I've just experienced that I need to be able to relay to him, in a way he can understand. Many of these things are years away since he's only 3. I don't have to teach him to ride the TTC, to buy clothes, or even navigate through school for some time yet. What's interesting is that these are things we have to teach all our children, that we should and probably do obsess over, autism or not. It's just that for our autistic son, we may have to teach him in a different manner than we do the others.

> My son is an amazing child, and is making enormous gains as he learns about life.

He can be spontaneous, imaginative, funny and infuriating. Just like his siblings.

It is vital to him that I understand what life has presented to him. He will rely far more on his parents to help him learn life's skills than his siblings will. They acquire social skills seemingly without trying. With our autistic son, we teach him these skills in small steps. He is quite brilliant and has so far mastered everything we've taught him. When he was diagnosed, he not only couldn't talk, he didn't see the need to. While our other children learned that most difficult of skills, we, his parents, along with his therapists, laid it out for him, and now he can talk. He can be spontaneous, imaginative, funny and infuriating. Just like his siblings.

Without our help, he'd probably be silent.
I am proud of what I am:

I am the father of an autistic child.

One autistic adult's viewpoint

I live in Oakville and am presently employed at Sheridan College, working on the telephone switchboard. I have lived a challenging life, dealing with many hardships in many different situations, being different for unknown reasons, and unable to mesh smoothly into society. Ultimately, they were all learning experiences.

Through conversing with people, I am surprised to learn that nobody seems to remember being a baby. I, however, remember my days as a baby very well. I remember sleeping in a crib, sitting in a highchair, eating from a Gerber jar, drinking from a baby bottle, and doing many other things that go along with being a baby. I was born in the late sixties, and I remember clearly what was "in" at that time. I remember seeing cars that are now known as classics and the clothes that people wore at that time. Mostly, I remember constantly hearing the music of those days. The first song that I ever recognized was "Hey Jude" by the Beatles. I was only a year old when that song was on the charts.

As a child, I did many things repeatedly. One thing I used to do was move a toy car back and forth on the table for a long period of time. I vaguely remember watching the spinning motion of its wheels. My repetitions became rituals, and they always had to be followed through; otherwise, I became very upset.

A major problem with me as a child was my temper tantrums. I easily became upset when things did not work out the way I anticipated. I was irritated by situations that included my rituals being broken, transitions between activities, being disciplined, being ridiculed and disapproved of, being left out, and having to end a pleasurable activity. Such situations caused me to resort to screaming, crying, swearing, and stomping. Sometimes I experienced undesirable consequences. Teachers sometimes reprimanded me for being noisy, and neighbors sometimes complained to my parents about my screaming out profanities. I threw those fits simply to express my feelings of displeasure, hoping that people would cooperate with me, but it never worked.

Hypersensitivity created unusual fears for me as a child.

Hypersensitivity created unusual fears for me as a child. I was often traumatized by unexpected or excessive noise. I was often afraid of audio equipment - even though I always loved music! I was frightened by static or the noise resulting from the needle not landing properly on a record. Power tools and equipment in use often terrified me. The sound of an air-raid siren, or even a train whistle, spooked me. I was even frightened of toilets! I made a point of staying away from washrooms as long as I had no need for them. In fact, I found many objects looked frightening to me, in one way or another - for practically unknown reasons! Sleeping was a problem for me throughout my childhood, since I had nightmares very often. Being spooked was one of my major stresses during my early years.

I was extremely hypersensitive to taste and extremely picky about food. There were only a few certain foods that I loved as a child. My taste buds were so sensitive that many foods tasted bad to me. If it didn't taste right, I was totally unable to ingest it. My parents were very strict about making certain that all our dinner was finished, so suppertime was often a bad time for me.

I was also hypersensitive to touch and, therefore, very sensitive to pain. When I was really little, I used to get so uncomfortable and resist whenever my mother washed my face. Going to see my family doctor was a major ordeal to my parents and me. Some of my doctor's methods of checking me were very uncomfortable. Whenever we went to see him, as soon as we got to the parking lot, I would recognize the building, and that was it. My parents had a tough time getting me out of the car, into the building, to the waiting room, and worst of all, into the examining room. I would be violently kicking and screaming all the way. It must have been an entertaining show for all the other patients to watch! In my early years, visits to the doctor were the worst times in my life.

I had some accomplishments and displayed talent as a child. In Grade 3, at the age of 8, I created a pastel mural of The Cat in the Hat, which impressed my teacher and all of my classmates. This art piece was taped on the window of our classroom door for the entire school to see. My drawing skills became the one thing that my peers complimented me about. In Grade 8, I remember my whole class having a detention. In order for all of us to be excused, one student had to memorize an entire poem. After many students failed, I made the attempt and got it correct, and the whole class was dismissed from the detention. I had numerous other achievements, such as perfect test scores and high efforts in games, that were impressive to others.

Throughout my life, but especially as a child, I have been fascinated by things that were superficial to other people. I used to be mesmerized by windshield wipers in motion, and I used to always stare at running fans. The basement of our home was my entertainment centre as a child. I would watch our sump pump whenever it was running, and I would inspect our furnace whenever it was active. I would observe and memorize the actions of our washer and dryer as they went through their cycles.

Throughout my life, but especially as a child, I have been fascinated by things that were superficial to other people.

A major hobby of mine as a child was making inspections to fulfill my interests. Whenever we visited friends, I would go through their basement looking for items of interest. I used to go around the neighbourhood inspecting chimneys, clothes dryer exhaust vents, and sewers. I used to go through all of the ditches, watching water pour out of sump pump drain pipes and flow through culverts. I often called on neighbours, asking to see their basement utilities and laundry appliances. Some people knew me well and gladly complied, while some were unpleasant, telling me to get lost and slamming their doors in my face. I must have been quite the pest.

I drove many people crazy, talking only about my interests. I often socialized with my neighbours, mostly talking and questioning them about items that included appliances and basement utilities. Other children did not want to socialize with me, since they were unimpressed about how I was turned on by these interests.

I was an extreme introvert throughout my life, especially as a child. As a toddler, I objected to excessive interaction with people outside of my family. I was extremely shy and became uncomfortable whenever people acknowledged me. Most adults have a tendency to mimic the babbles of young children. However, I used to hate it when people mimicked me. I always found it annoying, and if only I knew how, I would have said, "I don't need a parrot!"

Throughout elementary school, I had no desire to socialize with other children, and I spent recess occupying myself in solitude. I had childhood friends in my neighbourhood, but I never wanted to socialize with them. Whenever people called on me, I would either turn them down or hide someplace. I was intimidated by the responsibility of entertaining other people, and I needed time and space to myself. Whenever other children became persistent about spending much time with me, I became repelled by them. In lieu of playing with other children, I preferred to watch TV or live in a make-believe world at home.

I was intimidated by the responsibility of entertaining other people, and I needed time and space to myself.

I have been an avid daydreamer ever since I was a child. I used to design, for myself, a highly complex fantasy world. I pretended that my house was an individual town, and I populated this town with make-believe people and characters from TV sitcoms and cartoons. These people were my real friends, as opposed to people from the real world. I liked them because they were exactly what I wanted them to be. I pretended that I was an adult, married with children, and that my actual bedroom was my own house. My fantasy world was a perfect world. Everything was the way I wanted it to be, providing me an escape from the hardships of reality.

My fantasies continued and evolved as I became a teenager, but their purpose remained the same. I lived the customized life that I wanted to live, escaping from the real world. I fantasized about the things that I always wanted, which included being popular, owning a car, and having a girlfriend. I always fantasized about the future, optimistically hoping my life would change for the better. I fantasized about moving to a new town and starting a new life. I fantasized about being highly successful and making an immense amount of money. I dreamed of owning a beautiful home and raising a perfect family. Fantasizing was like an addictive drug; it was a wonderful high and it allowed me to forget about the stressful times.

I fantasized about the things that I always wanted, which included being popular, owning a car, and having a girlfriend.

Since I've entered adulthood, I have outgrown my fantasy world. With my increasingly busy and active lifestyle, I don't have much time to fantasize. However, during idle times I tend to drift off into thought, something that happens to everybody. I sometimes enjoy reminiscing about the good times in my past. I often think about the things that I hope to acquire in the near and distant future. I think about landing a successful career that I would enjoy. I think about where I would like to live and how my life would evolve. It's the optimistic thoughts that keep me going.

I was misunderstood as a child. I was thought to be a lazy child since I was unable to understand, exercise motivation, and have a sense of responsibility. Nearly all of my time was spent fantasizing and watching TV, and everything else had little priority for me. I failed to remember about hygiene, and my parents often had to get after me to keep myself groomed. My parents also had a rough time getting me to cooperate with domestic chores. Whenever they asked me to do anything, I would complain and argue, often causing a confrontation. That's an example of unwanted transitions; I had a hard time accepting being interrupted in order to participate in a task. I could not handle studying for school due to confusion and my intermittent attention span, and that had a negative impact on my grades.

> I could not handle studying for school due to confusion and my intermittent attention span, and that had a negative impact on my grades.

School was a major problem for me during my growing years. I faced severe difficulties with my studies and ultimately had an extreme dislike of school. I was intimidated by the workloads, the peer pressure, and the treatment from the teachers. I felt that I was imprisoned, and preferred to be at home fantasizing and watching TV. I was unable to pay attention in class, and often couldn't bring myself to do my homework. The teachers added to the problem, chastising me on a regular basis. They would yell at me, strike me, and deliberately humiliate me before my peers. I certainly hope that our school system has evolved since those medieval times. As a result of my challenges, my grades suffered. I failed Grade 4 and several high school courses, and usually averaged slightly above passing. Report card day was seldom a good one for me.

One of my biggest problems in school was peer pressure. Children can be the cruellest people in the world. They can find everything different about someone and capitalize on it. I was a prime target for many reasons. Since I was unable to gain social skills, my peers noticed that I was behind. Since my mannerisms were quirky, my peers always mimicked me. Since I struggled in school, my peers considered me to be stupid. Since I had eccentric interests, my peers considered me to be weird. And since my sense of personal hygiene was inconsistent, my peers considered me a slob.

My reputation in school made me totally unattractive to girls. No girl would ever consider dating me; in addition, many girls ridiculed me. I have been attracted to many different girls, but I only ended up heartbroken. In my early adult years, I developed the courage to ask out girls, but I was always unsuccessful in landing a date. I tried joining extracurricular activities in the hope of meeting girls, but there were never any in my age group. It took me until mid-adulthood to finally find a significant other.

I have received counselling many different times throughout my life. When I was 6, my parents sent me to see a child psychiatrist. The spectrum of autism was not well known in the seventies, and this doctor came to the conclusion that I was highly intelligent, but lacking in motivation. I was diagnosed as sanguine. He recommended introduction to responsibilities (tidying my bedroom, setting and clearing the dinner table, etc.) and strict discipline. He designed a demerit-oriented system to motivate me to keep on top of my responsibilities and maintain good behaviour. I would acquire demerit points for misbehaving and neglecting responsibilities. If I exceeded a couple demerits in a week, I would be penalized by forfeiting certain privileges. However, there was a reward for good behaviour - I would not be punished. I saw this doctor for many years, and as time went on, he became impatient with me. I was not progressing to maturity; I was still living in a fantasy world and struggling with my studies. If things did not improve immediately, he advised my parents to send me to military school. As a result, I lived my childhood in fear and intimidation.

When I was a teenager, I was severely stressed over my problems at home and in school. My family doctor sent me to see a guidance counsellor. It did not have a major effect on my life, but he was a person for me to talk to. He tried to boost my self-esteem, and gave me advice on social skills and ways to minimize stress.

Occasionally throughout my life, I entered periods of severe depression for no apparent reason. In the early nineties, I began experiencing extreme cases of depression and was unable to pinpoint the source. This continued to occur regularly for over 2 years. The worst thing about depression I found was the mystery of it - not being able to understand why it was happening. During that period of time, I regularly saw a psychiatrist, who prescribed antidepressants for me. Once I was diagnosed with autism spectrum disorder, it was agreed that my depression may possibly be related to it. The mystery was now gone and I began to see things in better perspective. And after a few years, I no longer needed psychiatric care.

Employment was a complicated issue for me as a teenager. I landed my first job, in a distribution warehouse, one summer when I was 17. It was a difficult situation for me to adjust to since I had never worked before. I was used to having my summer holidays throughout my life and was looking forward to the freedom again this year. Suddenly, I was having to wake up early and report to this place everyday throughout the whole summer. This was something that I did not like. It was like going to school throughout the summer, only worse! In addition, I was having a lot of difficulties with this job. I first thought it was like high school, but then I quickly realized it was much tougher. I often came in late, like I did in school, but got severely reprimanded for it. I also was unable to comprehend instructions, and they often became very impatient with me. I was constantly pressured to keep up the pace, which often fluctuated. It was a very rough way for me to be introduced to the work force.

After I graduated from high school, my parents had a difficult time getting and keeping me employed. I was extremely reluctant to have a job, since it was far beyond my state of comfort. I did not want to go to a strange place everyday to take on undesired tasks. As well, being a sensitive person, I was always terrified of supervisors. I preferred to be at home where I was comfortable. I never understood the importance of money until I began supporting myself. Since I was being supported by my parents, I did not care whether I had any money at all. It was always so hard for me to make the transition from a free lifestyle to a regimented schedule. The only job I really wanted, and could handle at that time, was one that wasn't too demanding. When my parents made me go out to look for work, I would bike around town stopping at very few places and partially filling out applications. They also looked through the papers, finding employers for me to contact, which I did against my will. All that I wanted throughout my growing years was total freedom and minimal stress. During that time, I have been through temporary successes and failures in employment.

I maintained a casual winter job at the CN Rail for 3 years. My duties entailed removing snow and de-icing chains on the flat cars that the Ford Plant used for shipping their newly made vehicles. I did not mind that job, since the workload was not too demanding and the pay was high.

I began my employment at Sheridan College when I was 19. I was a casual summer employee, setting up offices and repairing furniture over the summer break. I worked at that job for two summers. I quickly became accustomed to it and began to enjoy working there. Nobody was overly demanding of me, and the duties were all straightforward. This became a very familiar place for me, and I got to know and like many of the people there.

After I worked there for 2 summers, an opening for a permanent position in the Shipping & Receiving Department was posted, and I immediately bid on it and was hired. I was extremely happy since I was now permanently employed in familiar surroundings and there was no longer an uncertain future for me. I worked there for 6 years and it became a routine lifestyle for me.

> I was extremely reluctant to have a job, since it was far beyond my state of comfort. I did not want to go to a strange place everyday to take on undesired tasks.

I attended college for the first time in the late eighties, at Sheridan College. I studied major appliance servicing. I chose that program because of my interest in laundry appliances. The curriculum was not too complex and I did not experience many difficulties in the program. I successfully completed the program; however, I did not embark on any career relating to my studies. I decided that it was not my preference.

I bought my first car when I was 20. It was a 1978 Plymouth Volare 2-door with a slant 6 engine. I found it to be an amazing experience to finally own my own set of wheels. For the first while I became "car happy," driving this car all of the time - even when I had no place to go! I was so proud of my car. Sadly, it lost its life in an accident 2 years later.

In the early nineties, my parents retired and moved to Dunnville, a small town in the Niagara area. They made their home in an upstairs apartment of a building that they owned in town. As opposed to selling the house in Oakville, they allowed my brothers and me to rent it. Even though I was living in the house that my parents owned, the one that I was raised in, I was officially living on my own. I had no problem adjusting to it, and I handled all of the responsibilities with minimal difficulties. This became proof that I could look after myself with no special guidance or supervision. This was the time that I became an adult.

I continued to experience some difficulties during my adulthood. One problem that persisted was my inability to deal with people assertively. I often accepted wrongful treatment from other people, as opposed to standing up for myself. Being a sensitive person, I always wanted to avoid a confrontation and remain on good terms with everybody. Unfortunately, many people noticed that in me and took advantage of it, pushing me as far as they could get away with. It is sad how some people in this world operate, and personally, it angers me.

A major problem that I had to deal with as I was maturing was my lack of self-esteem. In dealing with most young adults my age at the time, it appeared to me that I was far behind in knowledge and life experience. In the years before my diagnosis, I could not figure out what was wrong with me, and I blamed myself. I struggled to catch up, but I did not know how. It was that, along with the negativity that I have received throughout my life, that has made me down on myself. There were times when I felt so low that I became physically sick.

> In the years before my diagnosis, I could not figure out what was wrong with me and I blamed myself.

My temper has continued to be a problem for me, often going off over trivial issues. Whenever I was inconvenienced in any way, I would either yell out profanities, or hit something, or both. I also had a tendency to go on a vicious tirade whenever a family member approached me in a manner that I did not like. I often ended up feeling embarrassed about my fits.

My condition was finally discovered when I was in my twenties. One day, when my brother was watching Shirley, a TV talk show, With this knowledge, a heavy weight was lifted from my shoulders. It was great to actually know and understand what had been going on with me. I no longer blamed myself for my challenges. This was the turning point in my life.

the subject was autism. He noticed that many of the characteristics described matched my own, so he sent for a transcript and obtained a phone number for one of the doctors on the show. My mother contacted the doctor, who referred me to a psychiatrist in Hamilton. When I met with this doctor, he confirmed that my characteristics matched those of Aspergers syndrome. With this knowledge, a heavy weight was lifted from my shoulders. It was great to actually know and understand what had been going on with me. I no longer blamed myself for my challenges. This was the turning point in my life.

In the mid-nineties, I once again attended Sheridan College to study executive office administration. This course has had a major and positive impact on my life. In this program I learned about computers and software. That's when I bought my first computer. This program has also taught me skills in business communications, letter formatting, and public speaking - all of which come in handy for my current projects.

My motivation and confidence greatly increased because of this program, and I was constantly studying whenever I was home. My interest in these studies was so high that I actually enjoyed putting all of this time into it. It is ironic that after years of my family chasing me to study, they were now trying to make me slow down!

The course has also improved my social experience. I was very popular with all of my classmates. None of them seemed to notice anything odd about me whatsoever. Most of my classmates were girls, so I learned a lot about interacting with people of the opposite sex, which was helpful for me in dating. It was a major boost to my self-esteem to be liked by many girls and also to be able to handle a university-level program. I look at those days as my second chance to enjoy the happy school days that I never had the first time around. I graduated from this program in good standing.

After school, I resumed employment at the college, working part time in Distribution Services. I worked in that department until the spring, when I accepted my present job at the switchboard. The work is straightforward, and it took me almost no time to get it down pat. In the beginning, I found dealing with irate callers to be an intimidating experience. And as well, for the first while, my intermittent attention span complicated things a bit. I often missed important information and, therefore, frequently made mistakes. As a result, others became impatient with me at times. Over the

> I look at those days as my second chance to enjoy the happy school days that I never had the first time around.

> In many ways, I am just like anybody else, and my challenges have little effect on that.

years, I feel I have improved in these areas, and have developed the confidence to be tactful and make demanding callers realize that I am the one in control. I've now been at this job for several years.

Today, I feel that, in many respects, I have come a long way. I am living independently and working at a full-time job. I can handle all of my responsibilities, including shopping, projects, and financial issues, with minimal help. I can do anything that any neurotypical adult can do, such as support myself, maintain a job, and drive a car. I am well educated - I have 2 college diplomas. In many ways, I am just like anybody else, and my challenges have little effect on that.

I lead an active social life. I have a large circle of friends. Some of my oldest friends are people that I have known from high school. Many of my friends are long-time friends of my brothers - and my brothers have many friends. When I was a child, there was a large age gap between them and me, but since I have grown up, the gap has closed and I am now in the circle. Recently, I have also made many friends from college. I also have some friends who are deaf, and I am presently practising sign language. My signing skills are somewhat slow, but I can basically communicate. Through my recent involvements, I have met a number of friends who are also on the autism spectrum. And, I can happily say, I now have a girlfriend.

I still experience some difficulties due to my challenges. I am an exceptionally sensitive person. I become easily hurt when involved in a personal confrontation. I also tend to become paranoid and think the worst if times seem a bit challenging. My temper is a major problem for me. I still lose it easily whenever I am inconvenienced in any way. My self-esteem also hits its lows at times.

It becomes very difficult for me whenever something suddenly comes up, and I find it hard to readjust.

I am very hypersensitive to sound. I am often startled and annoyed by sudden or loud noise. Unfortunately, I cannot escape it, but I do take steps to lessen certain noisy situations for me. For example, whenever I shut my car off, I always make a point of turning off the radio so that it does not blast me when I start my car again. We have a chiming clock, which at countless times, I have thrown corks at. I can turn the chimes off, but then, I may as well turn off the fridge, the furnace, the dishwasher, my family members' voices, and everything else in the house that makes any noise. It would be an awkward, unusual course of action to take, but at least the place would be nice and quiet.

I have difficulty accepting transitions. When my mind is set on something, I prefer that

I still prefer my solitude much of the time.

things turn out exactly as I anticipate. I have an electronic planner which I live off, and I schedule my life around it. I plan my days far in advance, so if anybody needs me, they have to make an appointment. It becomes very difficult for me whenever something suddenly comes up, and I find it hard to readjust. I prefer to be notified in advance about any change of plans whenever possible.

I still prefer my solitude much of the time. I am sometimes very territorial about my space and tend to become annoyed whenever it is invaded. When I first get up in the mornings, it takes me a little time before I am comfortable interacting with anybody. I also have my own little TV room, where I can spend time alone. I spend most of my evenings there, as well as other times when I need my space, which is often. That little room is my sanctuary, which is a necessary part of my life.

My mannerisms can use some fine tuning. When speaking, I tend to use over-exaggerated gestures to accompany my speech. I also have a tendency to drift off, especially in a large crowd in public. People sometimes have to wave a hand in front of my face to get my attention. I have even been cut off from being served alcohol because I was mistaken for being intoxicated. However, I have no problem when conversing one on one with an individual. Perhaps it is the obligation to respond that motivates me to stay in tune.

My attention span is inconsistent. Sometimes I can only focus on something for a limited time, then my mind wanders. At other times, I tend to be mesmerized by something simple and not fascinating to others. I can focus on only one thing at a time and have difficulties paying attention to or performing multiple things. This causes difficulties for me when keeping track of important things, such as my finances. If my finances were the only thing I had to keep track of, then I would have no troubles with them. Unfortunately life doesn't work that way; I have many things I have to keep track of. After getting caught up with my finances, I'll forget all about them and lose track once again. One of my big weaknesses is keeping track of my money, which is scary. I just need to find a way to balance my attention equally.

I do not mean to instill any pessimism in anyone; I am simply sharing all of my experiences with you - negative and positive.

In recent years, I have developed a great interest in having a career helping people on the autism spectrum. I feel that, being on the spectrum myself and having progressed as much as I have, I would be a great asset to people on the spectrum, guiding them in a promising direction. I would like to give children on the spectrum the opportunity to get proper help at a younger age. Because I am on the spectrum myself, I am able to understand and relate to them. As well, I see myself as living proof of success. If I can be successful, there is a positive future for anybody on the spectrum.

I am a member of Autism Society Ontario (ASO). I have taken on the role of chair of the newsletter committee. I also participate in

I see myself as living proof of success. If I can be successful, there is a positive future for anybody on the spectrum.

various other functions of ASO. To name a few, I participate in such functions as garage sales and bike-a-thons, and volunteer as one of the baseball coaches for autistic children. In addition, I have given many presentations for different organizations, including the Geneva Centre. My involvements have given me much experience and a very rewarding feeling.

Fortunately, autism spectrum disorder is becoming recognized and understood, so today's children on the spectrum have the major advantage of being properly treated and guided. My dream is to assist in giving these children the happy and fulfilling maturing years that I never had. I did not let my challenge defeat me, and I am determined not to let it defeat others!

In my opinion, autism does not seem to be a complex situation. I believe that it is not much more than just a maze that must be simplified, and I believe that it can be done through skillful counselling. In all neurotypical people, the human brain has an amazingly high capacity for intelligence, and it is extremely thirsty for knowledge. It rapidly absorbs and processes any information fed into it. A neurotypical child grows up constantly absorbing all of the information that he or she is exposed to, steadily gaining experience and wisdom. In people who are developmentally challenged, the brain has a limited capacity for intelligence and processes information at a slower rate. People on the autism spectrum, however, have the same brain as neurotypical people, but their autism forms a maze-like pattern of communication between the brain and the senses, causing the brain to absorb only selected pieces of information. With the limited information that it does gather, this powerful brain can process and clarify it in amazingly precise detail. This may explain why people with autism have an incredible memory for certain subjects.

Their autism forms a maze-like pattern of communication between the brain and the senses, causing the brain to absorb only selected pieces of information

The emotions of a person on the spectrum seem to be magnified, compared with those of a neurotypical person. Strong emotions, such as anger and fear, may be rather traumatic for the individual. As well, the individual tends to mentally withdraw to escape reality. This usually starts at a young age, and the emotional hardships of life bring this on. I believe, however, that this situation can be reduced with treatment, especially at a young age.

I honestly do not know what it is like to be like the majority of the human population who are neurotypical. In turn, neurotypical

> I do not look at autism as a disability but simply as a way of being.

people truthfully do not know what it is like to be on the spectrum. The feeling may be quite similar, yet it may be altogether different. I do not look at autism as a disability, but simply as a way of being. I also believe that people on the spectrum can be assisted to function more easily in this norm-oriented society. They may have to think and practise differently, but I do not think it is impossible to bridge the gap. The techniques may not be totally figured out yet, but if we have come this far, imagine what we will be able to achieve down the road! The future looks hopeful, and I honestly believe that there is a light at the end of the tunnel.

Gary Waleski

HOW CAN A COUNSELLOR HELP YOU?

One Social Worker's Viewpoint

A counsellor such as a social worker, psychiatrist, or psychologist, can help you understand and make sense of your feelings after getting your child's diagnosis of autism.

Many parents have told me that receiving a diagnosis of autism for their child was one of the most overwhelming experiences of their lives. The word autism can be very powerful, mysterious and sometimes scary.

Many parents described feelings of fear of the unknown, uncertainty about the future, and a general sense of emotional overload. Autism can seem to be an all-consuming experience.

You may find yourself feeling the same way as other parents. One thing that seems common for all families is that time is needed to fully grasp what the diagnosis of autism means for your child and your family.

The word autism can be very powerful, mysterious and sometimes scary.

HOW DO YOU KNOW IF YOU NEED TO TALK TO SOMEONE?

Many parents I have talked with tell me that during most other times in their life, when they have been faced with difficult feelings, they have been able to sort through them on their own. They are usually able to solve most of life's problems by talking with a friend, family member or even co-worker.

But getting a diagnosis of autism was different. The diagnosis caused a problem for themselves, their relationship, or their family situation, that felt too difficult to solve alone. This is when they looked for support from a counsellor.

Having a child with autism often means that every hour is filled with something to be done, people to talk to, and services to put into place.

HOW WILL TALKING TO SOMEONE HELP?

- Taking the time to talk to a counsellor can give you the chance to talk about what autism means in your life. Going through a difficult time can affect your ability to remain strong, solve problems or sometimes just keep going. Supportive counselling can help make life more manageable and the view of the future more hopeful.
- Having a child with autism often means that every hour is filled with something to be done, people to talk to, and services to put into place. Sometimes it can feel as though you are on automatic pilot moving through your day. Taking the time to talk to someone can give you the break you need to collect your thoughts. You will have time to sit back and think, talk, or actively solve a specific problem.

- Talking to a counsellor gives you a safe place to talk about feelings that may be too difficult to share with family or friends.
- As a couple, talking to a counsellor can give you and your partner a chance to solve problems in your relationship and learn how to support each other better.
- As a single parent, talking to a counsellor may help you to sort out the many responsibilities that you have to balance when you have a child with autism.

HOW CAN YOU FIND A COUNSELLOR?

Finding a counsellor is like buying a pair of shoes. You must find the right fit. This usually means shopping around.

You may find counselling services
- at no charge, for example, from a psychiatrist, some hospital clinics or mental health agencies or
- at a small charge, depending on your income, such as from the The Family Service Association.

Your insurance company may pay a certain amount of money toward private counselling from psychologists or social workers.

Some employers offer a limited number of counselling sessions through their employee assistance program, also called EAP.

No matter where you find the support make sure that it is right for you. Ask yourself these questions:
- Do I feel comfortable talking with this person?
- Does this person listen and seem to understand what I say?
- If counselling is not meeting my needs can I talk to this person about making changes so I feel better supported?

Overall, remember to trust your instincts. Your instincts will tell you if the counsellor is the right person for you.

If you have any questions about this information or would like to book an appointment with a social worker, please contact me at (416) 813-6305.

Janice Mulligan
Social Worker

AUTISM SPECTRUM DISORDER: resources

resources

This section lists some resources you may find useful. It is not complete, but lists some of the resources that we thought would be most helpful. Over time, you will create your own list based on your child's specific needs and the area where you live.

As you may notice, many of these resources are in Toronto. If you live outside Toronto and do not know where to find similar resources, we suggest you call the agencies listed here. Ask them where you can find similar services in your area.

We have tried to group these resources as much as we can, but some of them have similar services. For example, an agency that has parent support groups may also offer behavioural support. When you call an agency, make sure that you find out about all their services.

Many of these agencies have long waiting lists for service. Do not be discouraged. Put your name on all the lists you can. Call the agencies regularly to find out where you are on their waiting list.

Write down all your calls in case you need this information later. We have provided a form in the section called Appendices that you can photocopy and use to keep notes about all the agencies you call.

Remember, while you are waiting for services, you can start working with your child on your own. To begin working with your child on your own,

- read about autism,
- talk to other parents, and
- try some of the suggestions that you read about.

When you understand a little more and trust yourself, you will find that there is a lot that you can do.

BENEFITS

Financial benefits, money the government or other groups offer to help pay for your child's care, can vary. The amount of money will depend on your child's needs and your family's financial situation.

The government does not offer respite services or staff. Respite services provide temporary help with care inside or outside the home. But they do offer money to cover some of these expenses.

Please note, The Hospital for Sick Children's website has a section called **RESOURCES FOR FAMILIES.** This section gives more information about financial benefits. You can find this information at www.sickkids.ca/resources. Click on **HELP WITH EXPENSES.**

The list that follows describes some of the financial benefits you may be able to get from the government or other groups.

Special Services at Home Program

The Ministry of Community and Social Services manages the money for the Special Services at Home Program, or SSAH. Getting this money depends on your child's needs. The amount of money you earn **DOES NOT AFFECT** whether you get this money.

You can use the money to pay for
- respite service, but not for babysitting,
- some of the cost of programs such as special summer programs, or
- someone to work with your child to develop his or her skills.

The money is given for only 1 year at a time. That means you must apply for the money every year.

Assistance for Children with Severe Disabilities

(Previously called Handicapped Children's Benefits)

The Ministry of Community and Social Services manages the money for Assistance for Children with Severe Disabilities, or ACSD. The amount of money you earn **DOES** affect whether you get this money.

To apply for ACSD, you must give the Ministry a list of all the extra expenses you have to pay for because your child has autism. Examples of these expenses could be extra laundry expenses and expenses for travelling to appointments. A worker will visit your home to talk to you about your situation in greater detail.

Applying for SSAH or ACSD

If you live in the Toronto area, call 416-325-0623 to get copies of the applications for SSAH or ACSD. If you live outside the Toronto area, call 416-325-0623 and ask for the office closest to you.

When you complete your application, always keep a copy for yourself. Mail the original application to the office of the agency that will review it. After they review it, the agency will send you a letter about the amount of money you will get.

If you have any questions, please call the office and your worker when you are applying for these funds. You will find that having a good relationship with your worker can be helpful as they can offer information about other resources.

Incontinence Supplies Grant Program, Easter Seal Society

The Incontinence Supplies Grant Program can help with the cost of diapers and other similar supplies for children 3 to 18 years old. Your child must have a condition that causes a lack of control over the bladder permanently or for longer than 6 months. For example, every year, you may get $400 for diapers for a child 3 to 5 years old or $900 for diapers for a child 6 to 18 years old.

For more information, call the program at 416-421-8778, extension 314, or 1-888-377-5437 (a free call).

Disability Tax Credit

The disability tax credit lowers the amount of tax you may owe if your child has severe, long-lasting mental or physical disabilities.

Call 1-800-959-2221 and ask for a copy of Form T2201. For more complete information, ask for the guide called Guide RC4064.

Canada Child Tax Benefit

The Canada Child Tax Benefit is money you can get every month without having to pay tax on it. This money helps families with the cost of raising children under 18 years of age.

For more information, call 1-800-387-1193.

The Trillium Drug Program, Ministry of Health & Long-Term Care

The Trillium Drug Program helps people who have high drug costs. The amount of help depends on the amount of money you earn. If you or your family spend a large part of your earnings on drugs, the Trillium Drug Program may be able to help with the costs.

THE TRILLIUM DRUG PROGRAM
5700 Yonge Street, 15th Floor
North York ON M2M 4K5
Telephone: 1-800-575-5386
Website: www.gov.on.ca/health
(In the Quicksearch box, type "Trillium Drug Program".)

The Jennifer Ashleigh Foundation

The goal of the Jennifer Ashleigh Foundation is to improve the quality of life for children with a long-lasting or serious illness and their families. The Foundation pays for the costs of a child's illness for people who live in Ontario.

The Foundation may pay for
- emergency financial relief,
- care giving,
- education,
- computers,
- medical treatment that is not covered by government health plans or insurance, and
- recreational programs.

For an application,
- call Karin Dobson at 905-852-1799, extension 23, or
- fax your application to her at 905-852-0124.

A Child's Voice Foundation

A Child's Voice Foundation tries to improve the lives of children and their communities. They accept many different kinds of requests for help.

For more information, call Roslyn Yearwood at 905-275-3434 or 1-888-837-3354 (a free call).

SERVICES

Many of the services you may need may be listed in the Directory of Community Services Blue Book. This important book gives information about many services and resources in the city (for example, childcare services, counselling services, health services, legal services).

You can call the Community Helpline at 416-397-4636 anytime, 24 hours a day, 7 days a week. Within Toronto you can simply dial 211. Ask about any services you are trying to find. You can also visit their web site at www.211toronto.ca

RESPITE SERVICES

RESPITESERVICES.COM

Respiteservices.com provides respite care for families. Respite care is a support service for families. It offers temporary relief from the physical and emotional demands of caring for your child with autism.

There are two types of respite care, one in your home and the other outside your home.

1. For respite care in your home, a caregiver comes into your home to care for your child and gives you time to do other things.
2. Respite care outside your home provides care for your child in programs offered in other homes, residences, or camps.

Respite Services offers two programs to families with a child with autism.

1. The respite program helps to find respite care for your child.
2. The Community Helpers for Active Participation, or CHAP, program helps you to find a worker who is interested in supporting your child with autism. Special Services at Home funding can be used to pay for a CHAP worker.

RESPITESERVICES.COM
112 Merton
Toronto ON M4S 2Z8

CONTACTS

- Meagan Blunt, respite coordinator for autism
  416-322-6317, extension 8
- Tatjana Smrekar, CHAP program coordinator
  416-322-6317, extension 3
  Website www.respiteservices.com

SPEECH AND LANGUAGE SERVICES FOR PRESCHOOL CHILDREN

Toronto Preschool Speech and Language Services

The Toronto Preschool Speech and Language Services offers speech and language services to preschool children from birth until they enter senior kindergarten. The services are free.

A speech-language pathologist, a person specially trained to help people with speech and language problems, will assess your child's needs. He or she will then decide what kind of program your child needs.

TORONTO PRESCHOOL SPEECH AND LANGUAGE SERVICES CENTRAL REFERRAL AND INFORMATION LINE
Telephone 416-338-8255 (416-338-TALK)
Website www.tpsls.on.ca

Hanen Centre

The Hanen Centre offers a unique program called More Than Words. The program is for parents of children with ASD and other social communication disorders who are younger than 6 years old. It will give you practical tools to help your child communicate.

THE HANEN CENTRE
Suite 515-1075 Bay Street
Toronto ON M5S 2B1
Telephone 416-921-1073
Website www.hanen.org

SPEECH AND LANGUAGE SERVICES FOR SCHOOL-AGE CHILDREN

The school board or private speech and language services offer speech and language support for your school-aged child.

School board speech and language services

Your local school board may have a fairly long waiting list for speech and language services. And usually the help is given to your child's teacher rather than directly to your child.

The school board may have specialists called low incidence coordinators. They work with children with ASD, as well as other special needs children. Talk to your child's teacher, school principal, or school board about what these specialists do. Ask about speech and language services in general.

If you live in Toronto,
- call the Toronto District School Board at 416-397-3000, or
- the Toronto Catholic District School Board at 416-222-8282.

If you live outside Toronto, call your local school board.

Private speech and language services

When you look for a private speech and language pathologist, you should try to find someone who has experience working with children with autism. Call the Ontario Association of Speech and Language Pathologists and Audiologists for information.

- If you live in Toronto, call the Private Practice Referral Service at 416-920-0361.
- If you live outside Toronto, call 1-877-740-6009. Or visit their website at www.osla.on.ca.

BEHAVIOURAL SERVICES

Toronto Preschool Autism Service Early Intensive Intervention Program (TPAS)

The Toronto Preschool Autism Service Early Intensive Intervention Program is an intense program that treats behaviour. It is available for children 6 years old or younger who have ASD and live in Toronto.

TORONTO PRESCHOOL AUTISM SERVICE
EARLY INTENSIVE INTERVENTION PROGRAM (TPAS)
Telephone 416-925-5808
Contact Mark Macdonald, intake coordinator
Website www.surreyplace.on.ca

Geneva Centre for Autism

The Geneva Centre for Autism provides a wide range of services for children and youth 18 years old or younger who have ASD. They consult on child behaviour.

The Centre suggests methods of helping your child, such as
- educational programs,
- methods of communicating,
- ways of managing your child's behaviour, and
- ways of developing your child's social skills.

GENEVA CENTRE FOR AUTISM
112 Merton Avenue
Toronto ON M4S 2Z8
Telephone 416-322-7877
Contact Intake social worker
Website www.autism.net

CHILD CARE SERVICES

Toronto Children's Services

The City of Toronto and its partners in the community offer or manage a wide range of services for children and their families. Among these services are partly paid, or subsidized, child care and family resource centres.

If you are a parent, foster parent, or legal guardian, you may qualify for money to help pay for all or part of your child care. It will depend on your income and job. Your child must be 9 years old or younger and he or she must live with you.

The Children's Services Division places, or integrates, children with special needs in more than half of the child care centres they operate.

TORONTO CHILDREN'S SERVICES
Telephone 416-392-3479 (for children with special needs)
Contact Linda Lee
Website www.toronto.ca/children

Toronto & District Parent Cooperative Preschool Corporation

The Toronto & District Parent Cooperative Preschool Corporation consults on special needs for children in nursery programs throughout the Toronto area.

TORONTO & DISTRICT PARENT COOPERATIVE PRESCHOOL CORPORATION
Telephone 416-410-2667, extension 2
Contact Mary Stuart

CHILD AND FAMILY SUPPORT SERVICES

Ability Online

Ability Online uses a computer friendship network to help children and youth with disabilities or chronic illnesses talk to one another and to their friends, family, caregivers, and supporters.

It is free and easy to use. It gives children and youth the chance to share information, hope, and encouragement, build self-confidence, and make valued friends.

ABILITY ONLINE SUPPORT NETWORK
104-1120 Finch Avenue West
Toronto ON M3J 3H7
Telephone 416-650-6207
Website www.abilityonline.org

Volunteer Grandparents Program

The Volunteer Grandparents Program is a service linking volunteer grandparents with families.

VOLUNTEER GRANDPARENTS PROGRAM
Telephone 416-595-0307, extension 235
Contact Volunteer Coordinator

Parent Outreach Program

Parent Outreach Program, called P.O.P., is made up of parents of school-aged children who have developmental delays. These parents are trained to help other parents take an active role in helping their children gain independence, community living skills, social acceptance and to encourage experiences for the child through the use of community resources.

PARENT OUTREACH PROGRAM
835 Queen Street East
Toronto ON M4M 1H9
Telephone 416-469-5211, extension 1167
Contact Mary Anne Welsh
Website www.woodgreen.org

Parents Help Line

Parents Help Line, a telephone information service, offers online discussion and support groups for parents. The help line offers support and information about all parenting concerns, big or small.

PARENTS HELP LINE
Telephone 1-888-603-9100
Website www.parentsinfo.sympatico.ca

Extend-A-Family Toronto

Extend-A-Family Toronto finds a volunteer companion for children with special needs who are 18 years of age or younger and live in Toronto.

There are other Extend-A-Family chapters in Ontario, but each chapter offers different services. If you live outside of Toronto, call Cate Hougton from Extend-A-Family Toronto at 416-484-1317 . She will give you the telephone number for the chapter in your area.

EXTEND-A-FAMILY TORONTO
Telephone 416-484-1317 (Call Monday to Thursday from 9 in the morning to 3 in the afternoon.)
Contact Cate Houghton

Toronto Family Network

The Toronto Family Network is a group of parents and extended family who come together to promote the inclusion and well being of family members who have disabilities.

TORONTO FAMILY NETWORK
3300 Yonge Street, Suite 200
Toronto ON M4N 2L6
Telephone 416-484-1536
Website www.tfn.volnetmmp.net
Contact Janis Jaffe-White

Family Service Association of Toronto

The Family Service Association offers counselling and community development programs for all families. They also offer services specifically for persons 18 years old or younger who have developmental disabilities and for their families.

FAMILY SERVICE ASSOCIATION OF TORONTO
Ste. 498 - 700 Lawrence Avenue West
Toronto ON M6A 3B4
Telephone 416-971-6326
Website www.fsatoronto.com
Contact Developmental Disabilities Services

RECREATION SERVICES

Reach for the Rainbow

Reach for the Rainbow offers children with special needs the chance to go to camp with other children with and without disabilities. This organization also helps with providing children with other recreational activities, such as after school programs.

REACH FOR THE RAINBOW
20 Torlake Crescent
Toronto ON M8Z 1B3
Telephone 416-503-0088, extension 110
Website www.reach.on.ca

Variety Village

Variety Village Sport Training and Fitness Centre gives children of any level of ability the chance to grow and develop to their full potential through play and physical activity.

VARIETY VILLAGE
3701 Danforth Avenue
Scarborough ON M1N 2G2
Telephone 416-699-7167
Website www.varietyontario.com

Ontario Camping Association

The Ontario Camping Association, or OCA, can give you information about where your child can go to camp. The OCA lists camps for children with and without special needs.

ONTARIO CAMPING ASSOCIATION
250 Merton Street, Suite 403
Toronto ON M4S 1B1
Telephone 416-485-0425
Website www.ontcamp.on.ca

Camp Winston

Camp Winston offers a recreational summer program for campers with complex neurological disorders including autism. They also offer workshops on behaviour management and weekend retreats for parents and caregivers.

CAMP WINSTON
9005 Leslie Street, Unit 203
Richmond Hill ON L4B 1G7
Telephone 905-707-3427 (Fall and Winter)
705-689-9096 (June to August)
Website www.campwinston.com

Blooming Acres

Blooming Acres is a farm community for people with neurological disorders, including autism. Blooming Acres provides specialized one-on-one education programs. People live at the farm while they attend these programs.

They offer a summer program for teenagers and adults who have ASD and are 15 years or older. They also offer respite for children of various ages.

BLOOMING ACRES
1208 Concession 5 North
Oro Station ON L0L 2E0
Telephone 705-487-3076
Website www.bloomingacres.com

Camp Greenhouse

Camp Greenhouse offers educational treatment programs for children 3 to 12 years of age who have autism, neurodevelopmental disorders, Down syndrome, developmental delays, and learning exceptionalities.

CAMP GREENHOUSE
70 Wellington Street East
Aurora ON L4G 1H8
Telephone 905-751-1215
Website www.campgreenhouse.com

REFERRAL SERVICES

Kids Integrated Developmental Services

Kids Integrated Developmental Services, called K.I.D.S, is an important Toronto resource you should know about. One phone call connects you to the services of the 23 different agencies that belong to K.I.D.S. This group helps families with children 6 years old or younger who have developmental delays get the services they need.

K.I.D.S.
32 Heath St. West
Toronto ON M4V 1T3
Telephone 416-920-3515, Ext. 111
Contact Barb Hannah, Service Coordinator

DEVELOPMENTAL SERVICES

Surrey Place Centre

Surrey Place Centre is a community agency that helps all people, children, youth and adults with developmental disabilities and their families living in Toronto.

They offer many different kinds of services for people with complex needs, such as

- assessments
- counselling and therapy,
- support and educational services, and
- coordination of services

SURREY PLACE CENTRE
2 Surrey Place
Toronto ON M5S 2C2
Telephone 416-925-5141
Website www.surreyplace.on.ca

Community Living Ontario

Community Living Ontario provides a wide range of support and services to children, youth, and adults with developmental disabilities.

Support includes early childhood services for children 2 to 6 years of age, such as the services of consultants and resource teachers. Other services include respite services and home management programs for children and youth 2 to 21 years of age.

If you do not live in the Toronto area, you should call Community Living Ontario at 416-447-4348 to find the office that is closest to you.

COMMUNITY LIVING ONTARIO
20 Spadina Road
Toronto ON M5R 2S7
Telephone 416-968-0650
Website www.communitylivingontario.ca

AUTISM ORGANIZATIONS

Autism Society of Ontario

The Autism Society of Ontario and its chapters share common goals of providing information and education, supporting research, and advocating for programs and services for the ASD community.

AUTISM SOCIETY OF ONTARIO
1179A King Street West, Suite 004
Toronto ON M6K 3C5
Phone 416-246-9592
Website www.autismsociety.on.ca

Aspergers Society of Ontario

The Aspergers Society of Ontario provides education, resources, and support to people with Aspergers syndrome, their families, and the community at large.

THE ASPERGERS SOCIETY OF ONTARIO
293 Wychwood Avenue
Toronto ON M6C 2T6
Telephone 416-651-4037
Website www.aspergers.ca
Contact Margot Nelles, managing director and co-chair

Kerry's Place Autism Services

Kerry's Place Autism Services tries to improve the quality of life of people with ASD. They offer services such as live-in programs, community, and respite care.

They have many offices that offer service to different areas (for example, Peel/Halton/Dufferin, York/Simcoe/Durham, South East region, Guelph/Wellington and Toronto).

KERRY'S PLACE AUTISM SERVICES
Central Administration
34 Berczy Street, Suite 190
Aurora ON L4G 1W9
Telephone 905-841-6611, extension 302
Website www.kerrysplace.org

Geneva Centre for Autism

The Geneva Centre for Autism provides a wide range of services for children and youth 18 years old or younger who have ASD. They consult on child behaviour.

The Centre suggests methods of helping your child, such as

- educational programs,
- methods of communicating,
- ways of managing your child's behaviour, and
  ways of developing your child's social skills

GENEVA CENTRE FOR AUTISM
112 Merton Street
Toronto ON M4S 2Z8
Telephone 416-322-7877
Contact Intake social worker
Website www.autism.net

OTHER RESOURCES

C.O.T.A. Comprehensive Rehabilitation & Mental Health Services

C.O.T.A. Comprehensive Rehabilitation & Mental Health Services, helps people of all ages with physical, developmental, or mental health issues. C.O.T.A. does not require you to have a doctor or other health care worker send you to them.

If the services are offered through Community Care Access Centres or government funding, you will not have to pay for them. If the services are offered through private groups, you will have to pay for them.

C.O.T.A./COMPREHENSIVE REHABILITATION & MENTAL HEALTH SERVICES

Telephone	416-785-8797 (Client Service Centre) 1-888-785-2779 (free call from outside of Toronto)

Website www.cotarehab.ca

Toronto Public Health Department - Toronto Health Connection

The Toronto Health Connection is your link to information, counselling and referral to Public Health and community services. It is open Monday to Friday from 8:30 in the morning to 4:30 in the afternoon. Translation services are also available.

TORONTO PUBLIC HEALTH DEPARTMENT

Telephone 416-338-7600
Website www.city.toronto.on.ca/health

SIBLING SUPPORT

Geneva Centre for Autism

The Geneva Centre for Autism offers support groups for the brothers and sisters, the siblings, of children with autism.

GENEVA CENTRE FOR AUTISM
112 Merton Street
Toronto ON M4S 2Z8
Telephone 416-322-7877
Contact Intake social worker
Website www.autism.net

Sibshops

Sibshops offers support groups for siblings of children with disabilities. Sibshops gives these siblings a chance to learn more about their sibling's disability in a relaxed fun setting with other children.

SIBSHOPS
Telephone 416-236-7621, extension 230
Contact Brenda Scott or Lori DelZotto

BOOKS AND VIDEOS

This list is a sample of the many books and videos available on ASD that you may find useful. These resources are not listed in any special order.

You may wish to buy these books or borrow them from a library. The Geneva Centre for Autism has many of these books and all of the videos in their library. The Centre will loan them to members. (To become a member, call the Geneva Centre at 416-322-7877.)

Many bookstores may also have these books. One bookstore called Parentbooks specializes in books about parenting. It has lists of books on ASD that you can print from their website.

Parentbooks

201 Harbord Street
Toronto ON M5S 1H6
Telephone 416-537-8334
1-800-209-9182
Website www.parentbooks.ca

BOOKS

Current Research and Theory

FRANCESCA HAPPÉ, AUTISM: AN INTRODUCTION TO PSYCHOLOGICAL THEORY

(ISBN# 0674053125)

Autism: An introduction to psychological theory gives a brief, readable introduction to current research and theory about autism.

Personal Accounts

TEMPLE GRANDIN, THINKING IN PICTURES AND OTHER REPORTS FROM MY LIFE WITH AUTISM

(ISBN# 0679772898, GENEVA CENTRE CODE #LB41A)

Temple Grandin is a great spokesperson for autism. Her second book about her life, *Thinking in Pictures and Other Reports from My Life with Autism,* has given many people hope and direction. She explains her life so far and comments on some current treatments for people who have autism.

LIANNE HOLLIDAY WILLEY. PRETENDING TO BE NORMAL: LIVING WITH ASPERGERS SYNDROME

(ISBN# 1853027499, GENEVA CENTRE CODE #LB79)

In her book *Pretending to be normal,* Lianne gives an excellent personal account about her experience growing up with ASD.

Aspergers Syndrome

TONY ATTWOOD, ASPERGERS SYNDROME: A GUIDE FOR PARENTS AND PROFESSIONALS

(ISBN# 1853025771, GENEVA CENTRE CODE #LB36A, B, C, D)

Tony Attwood's book, *Aspergers syndrome: A guide for parents and professionals,* has become a standard book about ASD because of all the information it has about Aspergers syndrome. This is a good book for both teachers and parents to read so they can understand this disorder.

BRENDA SMITH MYLES AND JACK SOUTHWICK, ASPERGERS SYNDROME AND DIFFICULT MOMENTS: PRACTICAL SOLUTIONS FOR TANTRUMS, RAGE AND MELTDOWNS

(ISBN# 0967251435, GENEVA CENTRE CODE #LB92)

Aspergers syndrome and difficult moments: Practical solutions for tantrums, rage and meltdowns provides useful information about treatments for behaviours, self-awareness, and self-management for people interested in Aspergers syndrome.

Intensive Behavioural Intervention

CATHERINE MAURICE, BEHAVIOURAL INTERVENTION FOR YOUNG CHILDREN WITH AUTISM: A MANUAL FOR PARENTS AND PROFESSIONALS

(ISBN# 0890796831, GENEVA CENTRE CODE #LB74A, B)

Behavioural intervention for young children with autism: A manual for parents and professionals is an excellent resource for parents looking into starting a behavioural treatment program with their child at home. It explains the process and provides programs.

S. HARRIS AND M. J. WEISS, RIGHT FROM THE START: BEHAVIOURAL INTERVENTION FOR YOUNG CHILDREN WITH AUTISM

(ISBN# 189062702X, GENEVA CENTRE CODE #LB66A)

Right from the start: Behavioural intervention for young children with autism is a good resource for parents looking for a behavioural treatment program for autism. The book compares programs done at home with programs offered at centres. It looks at what is taught and the qualities of a good program.

Speech and Language

FERN SUSSMAN, MORE THAN WORDS, HELPING PARENTS PROMOTE COMMUNICATION AND SOCIAL SKILLS IN CHILDREN WITH AUTISM SPECTRUM DISORDER

(ISBN# 0921145144, GENEVA CENTRE CODE #LB85)

More than words, helping parents promote communication and social skills in children with autism spectrum disorder is an excellent resource for understanding the different levels of communication based on the Hanen Program. It provides clear goals for each level of communication. It suggests activities to try and ways to encourage interaction with children. This book is for children in the early stages of language development.

SABRINA FREEMAN AND LORELEI DAKE, TEACH ME LANGUAGE

(ISBN# 0968098509, GENEVA CENTRE CODE# LB42A)

Teach me language is a book of activities for teaching children with autism. These activities cover everything from social skills to the academic skills children with autism need in the classroom. The book provides an overview of why these skills should be taught to children with autism. It comes with a workbook.

KATHLEEN ANN QUILL, DO, WATCH, LISTEN, SAY
(ISBN #1557664536)
Do, watch, listen, say is a complete guide to assessment and treatment. It has hundreds of creative ideas you can use to promote your child's social and communication skills. It also has information about how to plan and use treatments at home or in school.

Sensory Difficulties

E. YACK, S. SUTTON, AND P. AQUILLA, BUILDING BRIDGES THROUGH SENSORY INTEGRATION
(ISBN# 0968537502, GENEVA CENTRE CODE #LB70A)
Building bridges through sensory integration is very easy to read. It helps the reader understand sensory problems. It is very practical and provides many tips that you can use with a person with autism.

Education

KATHLEEN ANN QUILL, TEACHING CHILDREN WITH AUTISM: STRATEGIES TO ENHANCE COMMUNICATION AND SOCIALIZATION
(ISBN# 0827362692, GENEVA CENTRE CODE #LB19A, B, C, D)

Teaching children with autism: Strategies to enhance communication and socialization is an excellent resource for parents and teachers. It provides information from personal, parental, and professional viewpoints. It offers many tips that have been effective for people with autism.

AUTISM SOCIETY OF ONTARIO, NAVIGATING THE SPECIAL EDUCATION SYSTEM IN ONTARIO: A HANDBOOK FOR PARENTS OF CHILDREN WITH AUTISM SPECTRUM DISORDER
Navigating the Special Education System in Ontario: A handbook for parents of children with Autism Spectrum Disorder is a detailed handbook for parents of school aged children. It provides information about special education in Ontario and tips on how to communicate with your child's school. It also includes many

personal accounts. This handbook can be purchased through the Autism Society of Ontario (416) 246-9592.

LINDA HODGDON, VISUAL STRATEGIES FOR IMPROVING COMMUNICATION: VOLUME 1 AND VOLUME 2 - PRACTICAL SUPPORTS FOR SCHOOL AND HOME

(ISBN# 0961678615, GENEVA CENTRE CODE# LB24A)

Visual strategies for improving communication is an excellent resource for tips about communication that are essential for many people with autism. The book offers many examples of using visuals at home, in school, or in the community.

Resource Manuals

AUTISM SOCIETY OF ONTARIO, CHILDREN DIAGNOSED WITH AUTISM - WHAT TO EXPECT AND WHERE TO GET HELP: STRATEGIES AND INFORMATION FOR ONTARIO FAMILIES AND CARE PROVIDERS

Children Diagnosed with Autism - What to Expect and Where to Get Help: Strategies and Information for Ontario Families and Care Providers is an excellent resource for parents and care providers. It provides extensive information about autism. The manual includes information on topics such as getting a diagnosis and dealing with emotions, intervention strategies for behaviour and learning, speech, language and communication, and financial resources. This handbook can be purchased through the Autism Society of Ontario (416) 246-9592.

Siblings

SANDRA L. HARRIS, SIBLINGS OF CHILDREN WITH AUTISM: A GUIDE FOR FAMILIES

(ISBN# 0933149719, GENEVA CENTRE CODE #LB50A, B)

Siblings of children with autism: A guide for families explains autism to other children in the family. Parents should find the chapter "Balancing Act" particularly helpful.

VIDEOS

All of the videos in this list are available at The Geneva Centre's Resource Library. If you want to borrow a video, call the Geneva Centre at 416-322-7877. (You must be a member at the Geneva Centre to borrow books and videos.)

A IS FOR AUTISM (12 MINUTES, 1998)

Distributed by Films for the Humanities and Sciences, P.O. Box 2053, Princeton N.J. 08543-3767
Telephone 1-800-257-5126

A is for Autism offers a short, but deep look into the world of autism through the words, drawings, and music of people with autism. It includes a wonderful animation of the drawings of a 9-year-old who is a train-lover.

Temple Grandin does some of the narration. She and several others describe their unique sensory differences.

AUTISM: LITTLE VICTORIES (28 MINUTES, 1992)

Distributed by Autism Society of British Columbia, 1584 Rand Avenue, Vancouver BC V6P 3G2
Telephone 1-604-261-8888

Autism: Little victories is a good introduction to autism. This video talks about the main characteristics that result in a diagnosis of ASD. Professionals give their views. Parents share their experiences about discovering that their child has autism and learning how to help. Children of different ages in different environments are highlighted in this film.

GREAT EXPECTATIONS: LIVING WITH MORE ABLE LEVELS OF PERVASIVE DEVELOPMENTAL DISORDER (35 MINUTES, 1996)

Distributed by Geneva Centre for Autism, 112 Merton Street,
Toronto ON M4S 2Z8
Telephone 416-322-7877

Temple Grandin gives her personal account of living with autism. She offers tips to others struggling at more able levels of autism and Aspergers syndrome. This video includes the opinions and understanding of more able persons with autism or Aspergers syndrome and their families.

Teachers and service providers offer families, educators, and others practical tips for helping people with ASD learn, live, and work in their schools, homes, and communities.

PARENT'S GUIDE TO AUTISM TREATMENT (20 MINUTES, 1998)

Distributed by Outreach Education, 702 N. Blackhawk Avenue,
Suite 215, Madison WI 53705-3357
Telephone 1-608-263-6510

Parent's guide to autism treatment is part of a series called Picture of Health, produced by the University of Wisconsin. Dr Christina Iyana, a developmental pediatrician in Madison, Wisconsin, talks about

- the characteristics of autism
- the supports a family needs when they get the diagnosis,
- the importance of early treatment, and
- several approaches to treatment.

This tape also briefly shows a family who is using an intensive behavioural program with their son.

STRAIGHT TALK ABOUT AUTISM WITH PARENTS AND KIDS: CHILDHOOD ISSUES (41 MINUTES, 1999)

Distributed by Attainment Company
Telephone 1-800-327-4269

Straight talk about autism with parents and kids: Childhood issues uses interviews with adolescents with autism and their parents to provide an overview of autism. They talk about topics such as first signs, first diagnosis, things not to worry about, wrong diagnosis, grief and relief, sensory hypersensitivity, splinter skills, arcane interests, and support groups. The parents offer frank, honest views about their experiences and understanding. And the adolescents talk about their experiences.

AUTISM SPECTRUM DISORDER:
appendices

Phone Contact Record

Contact Name & Organization

Tel Fax

Date & Time

Notes

Email

Contact Name & Organization

Tel Fax

Date & Time

Notes

Email

Contact Name & Organization

Tel Fax

Date & Time

Notes

Email

Phone Contact Record

Contact Name & Organization

Tel

Fax

Date & Time

Notes

Email

Contact Name & Organization

Tel

Fax

Date & Time

Notes

Email

Contact Name & Organization

Tel

Fax

Date & Time

Notes

Email

Health Contacts

	Name, Agency, Address	Telephone Fax Email
Family Doctor		
Paediatrician		
Speech-Language Pathologist		
Psychologist		
Social Worker		
Nurse		
Occupational Therapist		
Physiotherapist		
Others		

For copies or permission to reproduce this information, please contact

CENTRE FOR HEALTH INFORMATION AND PROMOTION

The Hospital for Sick Children
555 University Avenue
Toronto, Ontario M5G 1X8
Canada
Phone: 416-813-5819

Prepared by Child Development Centre,
The Hospital for Sick Children, Freight Design, Toronto Ontario.

Edited by Sharon Nancekivell, plain language consultant, Guelph, Ontario.

Designed and Printed by The Graphics Centre, HSC.