
SPECIAL EDUCATION ADVISORY COMMITTEE MEETING

Thursday, November 21, 2019

BOARDROOM

6:30 P.M. – 8:00 P.M.

Chairperson: Arlene Godby

Vice-chairperson: Melissa Gillespie

<p>TRUSTEES/MEMBERS WHO ARE UNABLE TO ATTEND THE MEETING ARE ASKED TO PLEASE NOTIFY THERESA GREAVETTE, (705) 748-4861 ext. 1213</p>
--

A. Call to Order:

1. Opening Prayer: Helen
2. We acknowledge that we are meeting on the traditional territory of the Mississauga Anishinaabe
3. Motion to Approve Agenda
4. Declarations of Conflicts of Interest
5. Motion for Excusal from Attendance
R.A. That, _____ be excused from attendance at the November 21, 2019 Special Education Advisory Committee meeting.
6. Motion for Approval of the Minutes of the October 17, 2019 Meeting.
7. Business Arising from the Minutes:
 - Action items that need to be implemented by SEAC as a result of the IPRC Process/IEP presentation.
 - Updates regarding the committee's recommendations following the IPRC Process/IEP presentation.

B. Recommended Actions/Presentations:

1. Remarks: Vice-Chairperson (*Melissa Gillespie*)
2. Remarks: Superintendent of Learning (*Laurie Corrigan, Superintendent of Learning/ Special Education*)
3. Update from Trustees:

4. [Self-Regulation in Schools](#) – Update (Jennifer Angelo)
5. School Based Autism Support Program Model of Delivery (*Steve O’Sullivan and Lisa Virtue*)

C. Discussion Items:

1. Next steps from presentation

D. Information Items:

1. Ontario Brain Injury Association (OBIA) Workshop - Nov. 25 (See D1 attached)
2. [OA Panel Report](#) (*Sharon Davenport*)

Reports from SEAC members:

Kelly Smigielski

Grandview Children’s Centre

- On Nov 1-2, Grandview held a job fair for numerous therapy positions such as: Speech Language Pathologists, Occupational Therapist, Physiotherapists, Behaviour Consultant, Autism Therapy Assistants and others. These positions have become available due to the recent change in contract between Grandview Children’s Centre and the Community School Based Therapy Program.
- As of Jan. 1, 2020, Grandview will be providing services for school needs, equipment and therapy in addition to the existing services Grandview provides. As a result of this change, Grandview requires more therapy staff to provide adequate services to their clients.

Shawna Belcourt

Community Living Trent Highlands

- Adapted Bike & Recreation Show – November 14th (see D2 Attached)
- FASD Parent/Caregiver Group (see D3 Attached) – Peterborough (see D3 Attached)
- FASD Parent Caregiver Group – Lindsay (see D4 Attached)
- FASD: Tools, Training and Discussion for Professionals, Parents and Caregivers (see D5 Attached)
- CICE Information Session – November 7 (see D6 Attached)
- Respite Now (see D7 Attached)
- PA Day Respite Supports (see D8 Attached)

Arlene Godby

Autism Ontario

- Forgotten: Ontario Adults with Autism and Adults with Aspergers
At this time, there is no consistent government policy regarding the need for supports and services for adults with Autism Spectrum Disorder (ASD), nor

agreement of which ministry/ministries should be involved in funding those services. Most, if not all individuals with autism, require some care, supervision or support through their entire lives; many require a great deal. With this discussion document (see D9 attached), Autism Ontario will illustrate why the recommendations put forth matter to all Ontarians.

E. Old Business:

F. New Business:

G. Next Meeting:

1. **Next Meeting:**

Thursday, January 16, 2020
Catholic Education Centre
6:30 – 8:00 p.m.

2. Agenda Items: PAAC Survey

3. Selection of Member for Opening/Closing Prayer:

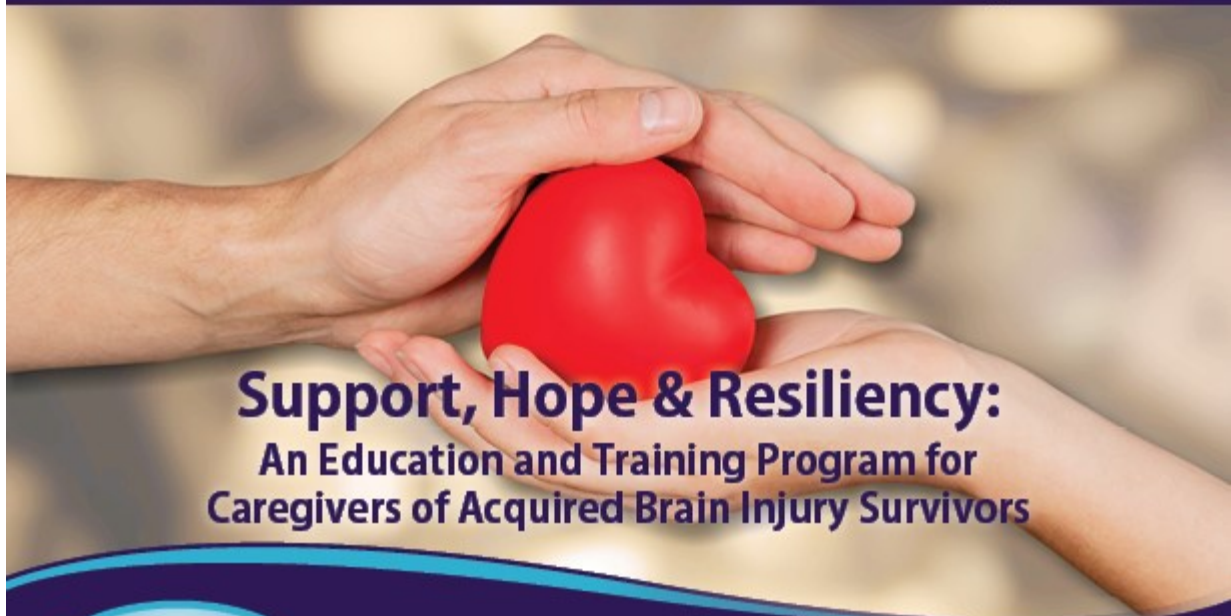
Future Meetings

Thursday, January 16, 2020
Thursday, February 20, 2020
Thursday, March 26, 2020
Thursday, April 16, 2020
Thursday, May 21, 2020
Thursday, June 18, 2020
Tour/PD To be determined

H. Conclusion:

1. Closing Prayer: Helen
2. Adjournment.

Pediatric Caregiver Education Workshop



Support, Hope & Resiliency:
An Education and Training Program for
Caregivers of Acquired Brain Injury Survivors

WHEN

Monday, November 25, 2019 from 10:00 a.m. - 2:00 p.m.

WHERE

Five Counties Children's Centre
872 Dutton Road, Peterborough, ON K9H 7G1

CONTACT

Nancy LaJoie, Caregiver Education Specialist, OBIA
Email: nlajoie@obia.on.ca 1-855-642-8877 ext. 248
-or- Marika Beaumont, Email: MBeaumont@fivecounties.on.ca

The Caregiver Workshops are completely FREE but require registration online.

Register at: www.obia.ca/caregiver-education-program/

A Project of the
Ontario Brain
Injury Association



In collaboration with:



Funding provided by:



Adapted Bike & Recreation Show



Thursday, November 14th 3:00pm to 7:00pm

at



Dr. Mary Thain Site
872 Dutton Road Peterborough, Ontario K9H 7G1
Phone: (705) 748-2221

Admission Free

Families of children/youth with disabilities, young adults with disabilities, community professionals and anyone interested in adaptive biking and recreation will benefit from attending this event.

Adapted bikes, trikes, sport-specific wheelchairs, hand cycles and special equipment available to try out! Bring your helmet!

Exhibitors including; Five Counties Children Centre, Align Home Health Care, Fishability, Challengers Baseball, Predator's sledge hockey and others.

Displays featuring adapted sports and recreation equipment and funding information.

**This event is hosted by Five Counties Children's Centre and Community Living Trent Highlands
Sponsored by Align Home Health Care**

Questions? Contact FCCC Marika Beaumont 705-748-2221 or CLTH Lynn Wodzak 705-743-2412 x517





FASD Parent/ Caregiver Group

6 pm – 8 pm

Last Monday of the Month

September 30th is the first meeting

Come join us for an opportunity to connect with parents/caregivers whose lives are affected by FASD. You will share experiences, learn strategies and develop supports. Childcare will be provided.

Please call or email Kim Carson

705-876-9245 ext 231 or kcarson@tccss.org



Where: Five Counties Children's Centre
872 Dutton Rd, Ptbo



FASD Parent/Caregiver Group

Open to parents and caregivers of someone
with FASD diagnosed or suspected

Connect and Share Ideas
Facilitated Discussions
Guest Speakers

October 8, 2019, 6 to 8 p.m.

**Community Living Trent Highlands
205 McLaughlin Road, Lindsay, ON**

For more information or to RSVP

Contact: Janice Balfour

Email: klfasdgroup@cysc.ca

Phone: 705-328-3606

Future Meeting
Dates

November 12, 2019

January 14, 2020

March 10, 2020

May 12, 2020



FASD: TOOLS, TRAINING AND DISCUSSION FOR PROFESSIONALS, PARENTS AND CAREGIVERS

About the trainer

Sheila Burns: Sheila's background in children's mental health, justice, women's issues, and community development helped inform the emerging vision for FASD prevention and improved interventions. To build capacity, Sheila has developed tools to help guide practice; tools that help focus interventions and sharpen the use of resources while clarifying the needs of vulnerable children, youth and adults to their caregivers and professionals.

Sheila has held leadership roles to address individual and systemic issues related to FASD since 1998 including FASD Ontario Network of Expertise – chair and leads on the diagnostic and justice action groups, a fellowship with the Law Foundation of Ontario and is a member of the Ministry of Children, Community and Social Services FASD Expert Group.

R.J Formanek

R.J. is the founder and key-administrator for "Flying with Broken Wings". He is also the co-founder of Red Shoes Rock. Stop FASD, an international advocacy initiative to build awareness of the reality and needs of persons living with FASD.

Celebrations
35 Lindsay St N,
Lindsay ON

November 8, 2019 9:00 am - 3:30 pm

November 15, 2019 9:00 am - 3:30 pm

**** Must be available to attend both days.**

With Sheila Burns we will take a look at a fresh approach to FASD and training. The "My Kind of Mind" booklet and the "At A Glance" companion card are designed to explore multiple neurodevelopmental factors common in FASD. This helps the individual, caregivers and professionals build interventions that consider the diffuse brain injury and a pathway to reset expectations. For professionals, the FASD/ND Service Planning Guide is designed to help track relevant information that can inform diagnosis and enhance and direct therapeutic interventions, classroom placement, parenting, and plans of care.

Having obtained a diagnosis later in life, RJ Formanek has a number of unique insights about living with FASD. It is these nuggets of information, learned along the way, that he shares with others in hope of fostering a better understanding. RJ will talk about the developmental nature of FASD and what becoming an adult entails in today's society.

Registration Fee

\$50.00 for Professionals and Community Partners

Parents and Caregivers no fee.

Morning snack and lunch provided.

[Register Here](#)

www.eventbrite.com

Questions:

Contact Kim Carson
705-876-9245 Ext 231
kcarson@tccss.org



Fleming College

November 7th 2019
Information Session
7pm

The Community Integration through Co-operative Education (CICE) program is designed to strengthen essential skills for work, life and learning. This two-year program is open to adults with learning, intellectual, communication, physical and or multiple exceptionalities.

Julie Wilson

Faculty

705.749.5530 ext. 1257

1.866.353.6464 ext. 1257

julie.wilson@flamingcollege.ca

or

Patty Thompson

Program Coordinator

705.749.5530 ext. 1033

1.866.353.6464 ext. 1033

patty.thompson@flamingcollege.ca

Fleming College
Sutherland Campus

599 Brealey Drive
 Peterborough, Ontario
 K9J 7B1

flamingcollege.ca/cice

Please Join us for our Community Integration through Co-operative Education (CICE) Information Session Fleming College Trades Building Room D1129.1

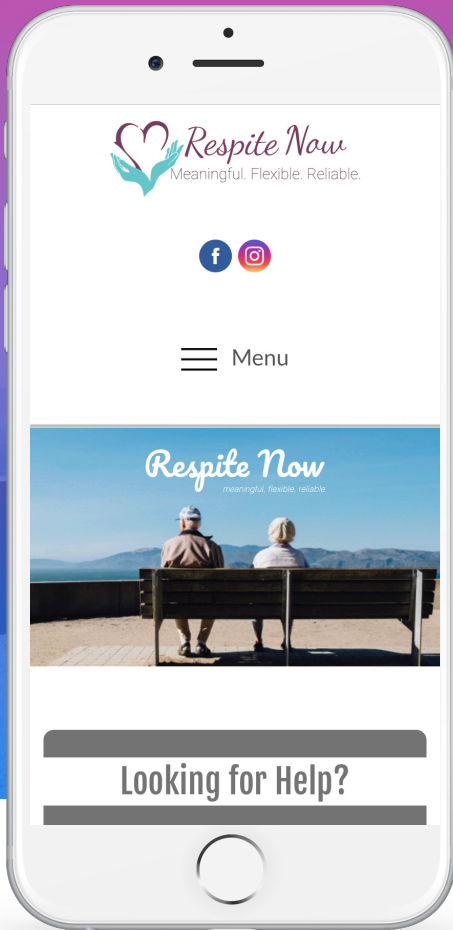


- Doors open at 6:30 pm
- Information Session starts at 7:00 pm
- Please park in Ash or Oak lots
- Enter via the main doors, our CICE Ambassadors will direct you
- Please RSVP to Julie Wilson or Patty Thompson
- Within your RSVP:
 - Include your license plate number for parking purposes

ABILITIES | INCLUSION | INDEPENDENCE



Respite Now
Meaningful. Flexible. Reliable.



BRAND | APP | WEBSITE LAUNCH

October 21 - Haliburton
October 23 - Lindsay
October 29 - Cobourg
October 30 - Peterborough

YOU'RE INVITED!

You're invited to the launch of our new Respite Now brand, mobile application, and website. Our new app is designed to connect families to respite care providers. Learn how this innovative new app can help your family and/or career!

HALIBURTON

A Point In Time
69 Eastern Ave,
Haliburton
Boardroom

OCTOBER 21ST
4:30PM-7PM

LINDSAY

Community Living Trent
Highlands
205 McLaughlin Rd
Lindsay

Large Boardroom

OCTOBER 23RD
4:30PM - 7PM

COBOURG

Community Living
West Northumberland
275 Cottesmore Ave,
Cobourg

Boardroom

OCTOBER 29TH
4:30PM-7PM

PETERBOROUGH

Community Living Trent
Highlands
223 Aylmer St,
Peterborough

Job Quest Boardroom

OCTOBER 30TH
4:30PM - 7PM

PA DAY RESPITE SUPPORTS

When: Friday October 25th

Time: 9:30 – 3:30

**Where: Ganaraska Forrest – drop off 223 Aylmer St
Peterborough**

What: Hike the trail at Ganaraska (4 KM)

Eat Lunch (bagged lunch only)

Carve Pumpkins at the main office

Cost: \$10 per person

Ages: 12 - 18

Join us for a fun day to celebrate Halloween in the forest! Scavenger hunt at Ganaraska, pumpkin carving and an opportunity to make friends. Limited spaces available. Payment due at time of registration. Please register with Bethany Sayles: bsayles@clth.ca

Registration begins Friday October 11th and closes Friday October 18th at 4pm

Kawartha Lakes
County
Suite 200, 205 McLaughlin Road
Street, Box 90
Lindsay, Ontario K9V 0K7
ON K0M 1S0
Tel: 705-328-0464 Fax: 705-328-0495
2626 Fax: 705-457-9287

Peterborough
223 Aylmer Street N.,
Peterborough, ON K9J 3K3
Tel: 705-743-2412 Fax: 705-743-3722

Haliburton
73 Victoria
Haliburton,
Tel: 705-457-

FORGOTTEN



Ontario Adults with Autism and Adults with Aspergers

PUBLISHED BY AUTISM ONTARIO, 2008

Autism Ontario has been the voice of people with Autism Spectrum Disorders (ASD) and their families since 1973, working to ensure that each individual with ASD is provided the means to achieve quality of life as a respected member of society. With thousands of members and supporters across the province, Autism Ontario is the largest collective voice for families whose teen and adult children struggle to receive necessary clinical and support services to meet their unique needs.

PHOTOS

Our thanks to our cover and report photo participants! Eric Beedham, Pam Newman Button, Tony Hill, Andrew Kyneston, Dwayne McLaughlin, Nadine McLaughlin, Marsha Serkin, Beth Waleski, Gary Waleski, and Jordan Weinroth.

COPYRIGHT

This document is in the public domain and may be used and reprinted without special permission, except for those copyrighted materials noted for which further reproduction is prohibited without the specific permission of copyright holders. Autism Ontario will appreciate citation as to source.

The suggested format for citation is: "Autism Ontario (2008). FORGOTTEN: Ontario Adults with Autism and Adults with Aspergers."

This report can be downloaded from www.autismontario.com

Autism Ontario

1179A King Street West
Toronto, ON M6K 3C5
416-246-9592

Table of Contents

ACKNOWLEDGEMENTS	4
COMMENTARY FROM DR. SUSAN BRYSON	5
EXECUTIVE SUMMARY & RECOMMENDATIONS	6
REPORT	10
What are Autism Spectrum Disorders?	10
Everyday Barriers	11
Impact of Increased Prevalence Rates for Adults	13
Current Supports/Services in Ontario and Challenges	13
A Service Delivery Model	17
Conclusion	19
Recommendations	20
REFERENCES	21
LITERATURE REVIEW	21
APPENDICES	22
A: Prevalence of Individuals with ASDs by Age Group	22
B: Range and Types of Impairment on the Autistic Spectrum	22
C: What Do Families and Self-Advocates Say They Need?	24
D: <i>“Our Most Vulnerable Citizens – A Report of the Adult Task Force”</i> 1991	25
E: How Services Have Developed in Ontario: The De-institutionalization Initiative	26

Acknowledgements

In 2006, the Ontario Partnership for Adults with Aspergers and Autism was formed with the direct support of Autism Ontario.

One priority of the group was to research and write a paper to inform current Ontario public policy on adolescents and adults with Autism Spectrum Disorders (ASDs). A subcommittee was formed, which included a diverse range of participants, and met during the winter/spring of 2008.

Membership included:

CO-CHAIRS

Patricia Gallin, Autism Ontario

Howard Weinroth, Autism Ontario

PARTICIPANTS

Lynda Beedham, Autism Ontario York Region

Ethel Berry, Autism Ontario

Robin Brennan, Woodview Manor

Eileen Cole, Autism Ontario

Jeanette Holden, PhD, Queen's University, ASD-CARC

Gail Jones, Kerry's Place Autism Services

Rick Ludkin, Woodview Manor

Peggy MacKenzie, Autism Ontario

Stephanie Moeser-Warren, Geneva Centre for Autism

Glenn Rampton, PhD, Kerry's Place Autism Services

Doug Reynolds, Autism Ontario

Margaret Spoelstra, Autism Ontario

Kevin Stoddart, PhD, The Redpath Centre

Kathleen White, The Redpath Centre, University of Toronto

The Working Group also thanks: Elizabeth Bloomfield, PhD, Bridges over Barriers and Ontario Adult Autism Research/ Support Network; Gerald Bloomfield, PhD, Guelph Services for Autism, Waterloo-Wellington Autism Services; Susan Bryson, PhD, Autism Research Unit, HSC and Autism Research Centre, IWK Health Centre; Pam Button, Self-advocate; Nancy Cherry, Autism Ontario Cambridge; Kerry Flynn, Self-advocate; J. Dale Munro, MSW, RSW, Regional Support Associates; Peter Szatmari, MD, Offord Centre for Child Studies/Child Psychiatry, McMaster University.

Throughout the process, the Working Group was grateful for the advice of staff from the Ministries of Education, Children and Youth Services and Community and Social Services. They also wish to thank the Ministry of Community and Social Services for additional support in the development of the document.

CONTEXT: Commentary

In 1990, I was invited to meet with a dedicated group of parents to discuss the current status of, and future outlook for, adults with autism in Ontario. This group, known as the Adult Task Force of Autism Society Ontario (now Autism Ontario), oversaw the 1991 publication of a document entitled “*Our Most Vulnerable Citizens: A Report of the Adult Task Force*” (Autism Society Ontario [ASO], 1991). This document had two main purposes: to provide data on the current status of 802 adults with autism in Ontario, and to identify key features of model services designed to meet their unique and individual needs.

To provide a context, the Adult Task Force was energized by the deinstitutionalization movement and the hope for a better, more humane and enriched future for individuals with autism and other disabilities. The last of the provincial institutions that had housed many of these individuals had been identified for closure, and there was a pressing need to invest in alternative, community-based services. Unfortunately, however, data provided in “*Our Most Vulnerable Citizens*” revealed that a great deal remained to be done—that we had only begun to address the diverse and often complex needs of Ontario’s adults with autism.

Now, more than 17 years later, as I read the present document, I once again feel hopeful. Progress has been made, although as outlined in what follows, some of the same as well as additional issues need to be confronted. Notably, we have become more aware of the various manifestations of autism, particularly

in those who are less severely affected by its associated language and cognitive challenges but who nonetheless require assistance. Even in these individuals, everyday problem-solving (adaptive) skills remain a significant challenge, and risk for additional psychiatric illness (particularly, depression and severe anxiety disorders) is high.

Recognition of the broader spectrum of individuals with autism, many of whom are diagnosed with Aspergers syndrome, has highlighted the critical need for a flexible continuum of services that addresses the needs of an even larger and more diverse population of adults. Other key issues that remain outstanding are the need for meaningful day (vocational and recreational) as well as residential programs, and, given the complexity of autism and its related conditions, for ongoing training and support of those working with these individuals, ideally through affiliations with university centers.

Finally, I am encouraged by the impressive team put together by Autism Ontario, by its leadership and by what hopefully will be a long and fruitful partnership with the Government of Ontario.

You are embarking on a critically important and long overdue task that promises to place Ontario at the forefront in providing caring, innovative opportunities for its most vulnerable citizens.

Susan E. Bryson, PhD

Craig Chair in Autism Research

Dalhousie University and IWK Health Centre

EXECUTIVE SUMMARY

“Autism itself is not the enemy... the barriers to development that are included with autism are the enemy.” – Frank Klein (*Klein, 2008*)

Why have adults with Autism Spectrum Disorder (ASD) been forgotten and how can we work together to help these individuals across the entire spectrum to have the best possible quality of life?

With this discussion document, Autism Ontario will illustrate why the recommendations put forth matter to all Ontarians.

At this time, there is no consistent government policy regarding the need for supports and services for adults with Autism Spectrum Disorder (ASD), nor agreement of which ministry / ministries should be involved in funding those services. Further, there is no “generic” system of adult services for those people with Aspergers to fall back on, unlike the developmental services sector that supports those with a cognitive impairment. Most, if not all individuals with autism, require some care, supervision or support through their entire lives; many require a great deal. Families and caregivers are not getting the help needed to plan for services and supports for a future when they are no longer here to be advocates for their loved ones.

Everyday Barriers

Individuals with ASD exhibit a wide range of behavioural challenges stemming from difficulty in verbalizing thoughts, managing anxiety, dealing with change, participating in group activities, disengaging from discussions on a specific topic—all leading to problems in coping with everyday activities. Not surprisingly, some individuals also have a diagnosis of mental illness. Autism Spectrum Disorder, developmental disability and psychiatric illness are separate conditions, yet much of the current service system is geared towards supporting individuals with an intellectual disability—leaving many adults with ASD without appropriate support.

Prevalence and Impact

The list of recommendations of policy and funding changes for adolescents and adults



with autism made in the 1991 report, *“Our Most Vulnerable Citizens”* are still valid today (ASO, 1991).

Sadly, people with autism remain among our most vulnerable and most poorly served citizens.

If we fail to address this issue, costs will be enormous. Using the figures from a US study (Ganz, 2007) the cost for a single generation in Canada could range from \$1.4 to \$8.4 billion CDN. This can be reduced substantially by providing appropriate and needed supports.

What is Autism?

Autism is a complex developmental disorder that affects the function of the brain.

The term autism spectrum disorders (ASDs) describes a group of disorders (Autism, Aspergers and atypical Autism or PDDNOS (Pervasive Developmental Disorder Not Otherwise Specified)) with the same symptoms: impaired communication and social interaction and repetitive behaviours and restricted interests. The range of disability resulting from these symptoms can be mild to extremely complex since the symptoms present in a variety of combinations. As a result, each person is affected uniquely. A combination of specialized supports is needed in social and communication skills, in carrying out daily living skills and in employment venues. (See Appendix B for ASD sub-types).

In Ontario, there are an estimated 70,000 people with ASD, 50,000 of whom are adults (*Autism and Developmental Disabilities Monitoring Network Surveillance [ADDMNS], 2002*).

The current framework and funding to support the specific needs of this population have barely begun to have an impact on the needs and numbers of the estimated 70,000 individuals affected in Ontario, 50,000 of whom are adults (*ADDMNS, 2002*).

Supports and Challenges

While families whose children are making the transition from teen to adulthood may expect to find similar levels of services in place for adults as were experienced with the school system, this is not the case. First, current services (i.e. developmental services) for adults are designed for people with an intellectual disability.

In some parts of the province, individuals with IQs greater than 70 are routinely excluded from such funding and supports. Secondly, developmental service providers often do not have the knowledge or training to deal with the unique, complex and highly individualized needs of adults with ASD.

Research and Best Practices

Unfortunately, there is a paucity of peer-reviewed literature discussing programs, education and counselling for adults with ASD. There remains a need for dedicated research on adults on the autism spectrum. The establishment of consolidated best practices “knowledge exchange centres” was recommended in the Standing Committee on Social Affairs, Science and Technology report, yet there has not yet been any forward action (*Standing Committee on Social Affairs, Science and Technology [SCSAST], 2007*).

RECOMMENDATIONS

The current framework of care does not match the complex, ongoing needs of adults with ASDs. This approach is piecemeal and out of date and, as a result, the services provided are not satisfactory. Both specialized services and enhanced community service capacity are needed to meet the service needs of the adult ASD population. Collaboration is needed to establish and champion an Ontario-wide policy

framework and coordinate the service delivery approach for adults with ASD.

Autism Ontario stands ready to provide provincial leadership in partnership with the Government of Ontario. We urge all Ontario Ministries to work together with us to make it happen.

These are our recommendations:

Recommendation One

Ensure sufficient and regulated services for adults with ASD in the adult/child mental health, social service, colleges/universities and developmental sectors through an Ontario-wide cross-sector policy framework and devoted funding based on a provincial needs assessment. Specifically, this policy framework would ensure:

- a) Financial supports which are not tied to “claw-backs” through ODSP, Registered Disability Savings, and welfare programs;*
- b) Day supports including vocational and employment, educational, social and recreational services/opportunities;*
- c) Programs devoted to monitoring the well-being and safety of adults with ASDs;*
- d) A range of supported living options; and*
- e) Professional supports including psychological, medical, and psychiatric assistance, dental care, person-centered planning, case coordination, respite care, crisis supports and legal assistance.*

Recommendation Two

Implement standard eligibility criteria to services for adults with ASD based on their functional needs rather than intellectual functioning through an Ontario-wide cross-sector policy framework.

Recommendation Three

Facilitate access to best practices education and research specific to adults with ASD across adult/child mental health, social service, colleges/universities and developmental sectors through a provincial knowledge exchange centre. This centre would:

- a) Lead a provincial needs assessment;*
- b) Guide or seed, translate and disseminate best practice research;*
- c) Provide information to specialized and generic or developmental service providers;*
- d) Provide information to families and individuals with ASDs; and*
- e) Track adult services available throughout the province.*

Next Steps

This report has focused on adults with autism and adults with Aspergers in Ontario: the economic impact, a review of existing supports and services, and a look at the state of research and best practices.

The facts are disconcerting—namely, that the growing costs to healthcare, social services and the education system, along with lost productivity of individuals with autism and their parents and siblings are substantial. There is a significant need for dedicated research and consolidation of best practices. The majority of adults with ASD do not have access to the specialized services and enhanced community services that they need. For example, people with ASD face a scarcity of available services and supports when they become adults.

Furthermore, their families and caregivers do not receive services and supports that they need to help plan for their child's future when they are no longer able to advocate for them.

Clearly, the current framework of care does not match the complex, ongoing needs of adults with ASD. Collaboration is needed to establish and champion an Ontario-wide policy framework. Now is the time to make the recommendations made in this document a reality.

(For an electronic copy of this report, or for more information on adults and ASD, visit: www.autismontario.com)



REPORT

WHAT ARE AUTISM SPECTRUM DISORDERS?

Autism Spectrum Disorders are a group of conditions that share common symptoms, including difficulties with: verbal and/or non-verbal communication, social interaction and engaging in reciprocal conversations or activities. These symptoms may be present in different combinations, and can range from mild to complex:

- Autistic Disorder with intellectual disability
- Autistic Disorder without intellectual disability
- PDD – NOS (Pervasive Developmental Disorder – Not Otherwise Specified)
- Aspergers Syndrome

However, an individual's profile is never that simple. The reality is that each individual's autism is unique, and until we look at this more closely, we risk making incorrect assumptions. While a person may have cognitive strengths, they may have serious support needs in the areas of social and communication skills, daily life skills and employment opportunities. Symptoms and characteristics often change over time.

● **There are estimated 70,000 people in Ontario with ASD, 50,000 of whom are adults.**
(ADDMNS, 2002)

EVERYDAY BARRIERS

Individuals with ASD exhibit commonalities but may differ in the number of symptoms or age of onset. Symptoms and characteristics can also change over time. Below is a list of common challenges:

a. Communication Difficulties

Adults on the autism spectrum have difficulty understanding nonverbal communication, verbalizing thoughts and feelings and processing verbal information. When there are two people talking too quickly or finishing one another's sentences, the person with ASD can have great difficulty switching focus from one person to another and cannot complete the sentences themselves. This can lead to frustration and socially disruptive behaviours, especially in those people who are unable to communicate verbally.

b. Socialization Challenges

Many people with ASD want to participate in social activities with others but their difficulties with understanding social rules and expectations make socializing challenging. Some adults on the autism spectrum need individual intervention or small groups. They may be overwhelmed by the presence of too many people (often even two to four others in a group) and/or by noise. They may be unable to concentrate sufficiently to learn new skills or to participate in group activities. All of the above can lead to misunderstandings, frustration and behavioural issues.

c. Anxiety

Many people with ASD have a generalized anxiety that may extend to all areas of their

lives. They may be unsure of expectations, including social expectations and be unclear of the meaning behind communication. Anxiety may also be caused by executive functioning deficits, especially problem solving and self organization.

d. Executive Function Deficits

Executive functioning can be a major cause of behavioural difficulties with individuals on the autism spectrum. Their difficulties with planning, organizing, decision-making and flexibility affects all facets of their lives. Problems in the ability to shift to a different thought or action according to changes in a situation can be a source of anxiety resulting in frustration and outbursts.

e. Difficulty with Change

Individuals with ASDs find it difficult to be in a "new environment" or have an unexpected person in their midst. Changes in routines and schedules can cause difficulties unless they are forewarned. They can feel very anxious and even feel frightened by the lack of predictability that change causes.

What is Executive Function?

Executive function refers to a wide range of central control processes in the brain that activate, integrate, and manage other brain functions such as planning, working memory, impulse control, inhibition and mental flexibility, as well as for the initiation and monitoring of action.

f. Perseveration

Not only do individuals on the autism spectrum persevere (or fixate) on specific topics or processes, they have a need to complete tasks and can become very frustrated and upset if interrupted in their thoughts or activities. Perseveration can also alienate others. Often individuals with ASDs talk only about what they are interested in, assuming others have just as much interest in the topic. This can lead to others feeling uncomfortable and wanting to be free of the discussion and company.

g. Emotional Responses

As a result of frustration in any or all of the areas listed above there may be a variety of responses exhibited. Some people with ASD may withdraw and isolate themselves when frustrated, some may focus on an activity they can control, others may get angry. All demonstrate their frustrations in not being able to follow what is being said or done. Many people with ASD have difficulty with self-modulation so withdrawal can lead to extreme isolation and look like anti-social behaviour. Anger can lead to outbursts and rage which can unintentionally harm others. Such responses alienate others because they are interpreted as choices to be anti-social or to harm rather than a way to cope with frustration. Depression and mental health problems often develop, which are more challenging to alleviate.

The above responses are NOT common in individuals with intellectual disability alone.

ASD and Mental Illness

In a recent study (Sterling, Dawson, Estes & Greenson, 2008) 43% of adults with ASD who were administered a standardized psychiatric history interview expressed depressive symptoms. This is likely an underestimate of individuals affected, since many individuals with ASD are not able to use words to describe what they experience. Also to be considered is the impact of intensive behavioural intervention to shift the ASD population higher along the spectrum and the likelihood that there will be a greater need for mental health treatment (Barnard, Harvey, Potter, et al, 2001).

Unfortunately when mental health challenges are identified in this population, it is difficult to find designated service providers equipped to deal with dual-diagnosis issues, particularly in adults, leaving a serious health challenge for these people and their caregivers/families. Supporting someone successfully who has various combinations of these conditions is complicated because these conditions tend to



interact in their impact on a person's behaviour. Determining what intervention will be successful is extremely difficult. Much of the current service system for individuals with developmental disabilities is geared to supporting individuals with an intellectual disability (*Rampton, 2006*).

Misdiagnosis or No Diagnosis

Some individuals with ASDs slip through the cracks, and are either misdiagnosed or not diagnosed until their later teens, or even well into adulthood. Often, diagnosis comes after a period of aggression, anxiety or depression. Adults with ASDs who are not diagnosed in childhood, run a higher risk of being streamed into forensic or psychiatric units and subjected to inappropriate and even dangerous consequences or treatments. Those who do receive a diagnosis of ASD can suffer a similar fate within the criminal justice system or in rehabilitation treatment services within the community.

Individuals on the autism spectrum continuum who are more socially aware are more apt to recognize the differences between themselves and others, with anxiety and or mood disorders being the result.

IMPACT OF INCREASED PREVALENCE RATES FOR ADULTS

Based on a prevalence of 1 in 150 children, there are about 70,000 individuals on the spectrum in Ontario—with more than 50,000 of these being adults (*ADDMNS, 2002*). (See Appendix A for prevalence rates.)

Autism Spectrum Disorders have a significant economic impact, beginning in childhood and continuing through adulthood. If we fail to

provide the needed supports to adults on the autism spectrum, Ontarians will face major costs to healthcare, social services and the education system, along with lost productivity of these people and their families.

CURRENT SUPPORTS/SERVICES IN ONTARIO AND CHALLENGES

Families whose children are making the transition from teen to adulthood may expect to find similar levels of services in place for adults as they experienced within the school system. Unfortunately, this is not the case.

Current services for adults, funded through the developmental services system, are designed for people with an intellectual disability (IQ lower than 70). The *Diagnostic and Statistical Manual of Mental Disorders: Fourth Edition, (2000)* categorizes the diagnosis of ASD as a developmental disability.

Up to 50% of individuals with ASDs do not have an intellectual disability (ID), yet their needs for support are as great as those with ASD and ID.

I have spent every day

of Hayden's life worried about his future. Worried about what would happen to him if I died tomorrow.

– Heidi Penning, 2008
(*Spoelstra, 2008*)

Developmental service providers may be keen to provide service but need the training and knowledge to deal with the unique, complex and highly individualized needs of youth and adults with ASDs. The following discusses current support options and challenges.

Use of Transfer Payment Agencies

The Ministry of Community and Social Services (MCSS) supports a developmental service system for adults in Ontario through “a network of approximately 370 board-operated, community-based agencies” (*Ministry of Community and Social Services [MCSS], 2006, page 6*). These agencies have contracts with nine MCSS regional offices and are funded as transfer payment agencies.

The drive for new and specialized ASD services often comes from the grass roots level in response to local identified needs. Tailoring supports and services to local needs has been a valuable approach for customizing supports for people with ASDs in various regions.

Challenges

Grassroots responses to local needs has resulted in pockets of excellent service delivery for adults with ASDs and a consequent tremendous pressure for expansion into other geographic regions. Without funding or a formal structure for ASD service delivery, there are limited mechanisms to build on the successes of key programs. As a result, there is very little consistency in services for adults with ASDs across the province and there has been no ability to consistently apply best practices or standards for services. Often, a comprehensive customized plan for an individual goes unfulfilled as there are no resources or service providers available. Funding issues are compounded by no clear

existing structures to deliver even a minimum level of universally available service.

Community Networks of Specialized Care

With the transformation of the developmental services system, new and more specialized supports are developing that may greatly assist people with ASDs. Four Community Networks of Specialized Care have been established across Ontario to coordinate services for individuals who have very high support needs, particularly those with coexisting mental health or behavioural issues.

A goal of these Networks is to strengthen the entire specialized care community by providing training and sharing research findings with professionals and families. With the increased prevalence of ASDs and a dearth of research on adults, there is a significant opportunity at this time to leverage the involvement of the Networks. These Networks could be the focal point for a partnership with academic institutions to expand cutting edge research on ASDs. They are well-positioned to provide comprehensive multidisciplinary training regarding ASDs.

Challenges

Whether the Networks of Specialized Care meet the specific needs of all individuals with ASDs and their families will depend on whether these needs are understood and accommodated by the Networks. It is not clear whether this will be the case as this principle was not incorporated as a precondition in the establishment of the Networks. As well, there is inconsistency in eligibility for support by the Networks. In some regions the Network is available only for those

with a severe intellectual disability and acting out behaviour. Individuals with high-service needs, but without an intellectual disability, are left without support.

Passport Program

The Passport program is intended to provide opportunities for individuals with a developmental disability who are finished school and seek community participation supports, but may not be ready or able to pursue competitive employment. Emphasis on person-directed planning to support choice is a step in the right direction for people with ASDs who frequently do not fit into a developmental services program.

Challenges

Unfortunately, there are large waiting lists for this new MCSS program. Again, eligibility for Passport funding varies from region to region in Ontario with some regions only accepting applications if the adult has an intellectual disability of less than 70 IQ.

Individualized Funding

Given the uniqueness of adults with ASDs, one key to appropriate support is a flexible person-directed and person-centred plan with individualized funding. The system needs to be portable and responsive to ongoing changes in the lives of persons with ASDs as they move through adolescence, maturity and on to their senior years. Service gaps currently exist at many points in the life cycle of adults with ASDs.

Funding for services should flow to families, individuals or agencies to enable them to have/ provide supports when they are needed, with the

proviso that they can be reduced, increased or re-allocated as the needs of the individual change.

Challenges

Currently, because this flexibility does not exist, family members are placed in a position where they alone must advocate for services for their adult children. They are also put into a position where they need to be the case managers for services for their adult children. Families must relive the same advocacy and case management roles that they took on when their son/ daughter was first diagnosed. And, most importantly, individualized funding is extremely difficult to obtain, with lengthy wait lists and insufficient funding.

Autism is a spectrum

disorder and people with autism are a diverse culture. As with any culture, we have social norms, unwritten rules and a thought perspective all our own. That people with autism have to exist within a different culture on a day to day basis in order to survive—one that often blindly insists on conformity rather than respecting our cultural diversity—makes functioning in the world around us exceedingly difficult, often depressing and continually anxiety-laden.

– Temple Grandin & Sean Barron
(Grandin & Barron, 2005)

The flexibility should include the ability to partner with an agency to support the family / individual as they make their choices, and potentially, for the agency to directly provide the needed services. A provincial policy for adults with Aspergers and autism is needed, along with funding sources to support delivery and a mechanism for applying this type of service.

It is important to note that with any individualized funding model, a formalized assessment of levels of need will likely be used to assess the level of funding. It is extremely important that staff doing the assessments are well-trained and qualified to understand the uniqueness and specific requirements of people with ASDs.

Generic vs. Specialized Services

Individuals with ASDs do not perceive the world in the same way as “neurotypical” individuals or people with an intellectual disability do.

Often, “universally” accepted best practices, interventions or service delivery approaches are not what the person with ASD needs. An effective and compassionate approach to service delivery may even counter the “Golden Rule -- do unto others...” For example, “neurotypical” individuals like to be complimented and be the centre of attention when they do something well. In contrast, those on the autism spectrum often find this type of attention painful.

Service delivery approaches need to tailor the environment to the strengths of the individual. Given the unique requirements of people with ASDs, specialized services are needed. Approaches that are holistic, seamless and integrated are necessary to provide a range of individually tailored services.

Challenges

In Ontario a few services have been developed specifically to serve the ASD community. As previously noted, these resources are geographically scattered, poorly funded and unable to meet the current and growing demand.

Services tend to be located in southern Ontario. Supports and services for adults with ASDs in Eastern, Northern and North-eastern regions of Ontario are rudimentary at best. Best practices that have been effective in one part of the province are not always known or adopted in other parts of the province.

The few specialized programs for adults with ASDs that do exist have experienced a significant increase in referrals. Individuals often require long-term support throughout their life and rarely move ‘out’ of their support system. As well, there are limited support structures in generic services once individuals are ready to move towards more independence (e.g. lack of affordable housing, lack of funding for



continuing education, etc.). Often the level of need makes adults with ASD poor candidates for generic services.

It is imperative that generic service providers work together with specialized service providers in providing services for youth and adults; there is too much to be done by specialized providers alone.

Best Practices in Ontario

Establishing best practices for “what is effective and what works” with adults on the autism spectrum is in its infancy, and few peer-reviewed papers have been published. There is a lack of funding in Ontario to scientifically investigate and assess the effectiveness of current practices. However, clinical experience indicates that supports and services need to be:

- Provided by individuals with specialized training and experience
- Delivered within the context of an integrated system of support
- Provided by individuals who the person with ASD trusts, and with whom a relationship has been built
- Supported by case management in order to navigate the myriad of services providers within the services system

Challenges

With little scientific evidence on which to base program and support recommendations, care providers rely on the experiences of existing service providers, parents, siblings and self-advocates to provide what works best in supporting them.

Limited Understanding of the Needs of Adults with ASDs

The MCSS developmental services system has staff that, with specialized training, can be called upon to provide supports for people with ASDs who also have an intellectual disability.

Challenges

There is very little infrastructure established for services to people with ASDs who do not have an intellectual disability, leaving them without services or services to meet their needs.

A SERVICE DELIVERY MODEL

Current Supports and Services

Establishing a best practices service delivery model for individuals on the autism spectrum that is within the current framework will serve only those individuals who have concurrent intellectual disabilities and will not meet their specialized needs. Thus, both specialized services and enhanced community service capacity are needed to meet the service needs of the entire adult ASD population.

In a funding climate of limited resources, the existing network of specialized ASD services could be directed to work in a partnership to provide comprehensive training, and current knowledge and consultation support for other agencies that provide services. It requires capacity building for both specialized and generic services.

Organizations with specialized ASD services can provide leadership and best practice research to support generic agencies. Research is needed to

validate best practices and establish mechanisms for quality assurance in service delivery.

Integrating Research and Best Practices

The 2007 report *“Pay Now or Pay Later, Autism Families in Crisis”* (SCSAST, 2007) makes several recommendations based on extensive public deputations from individuals, family members, healthcare and social agencies, researchers, sector organizations and other levels of government.

There was agreement about the need for consolidated best practices knowledge exchange across disciplines. The report also documented the need for:

- Supports/funding
- Human resource strategy
- Public awareness
- Research on autism

The Committee further recommended that a National ASD Strategy be developed in collaboration with the provinces and territories.

It should be noted that research findings about the autism spectrum can not be generalized across the spectrum, but rather, studies must target different groups for analysis and recommendations (e.g. higher functioning individuals; those with an intellectual disability).

Clear Policies on Service Eligibility Are Needed

Current eligibility for MCSS-funded services continues to be defined under the *Developmental Services Act*, (R.S.O., D11.1990) and includes only “conditions of mental impairment present or occurring in a person’s formative years that are associated with limitations in adaptive behaviour” (*DSA Definitions Section 1*). The Ministry notes that the developmental services community has asked that eligibility criteria for supports and services that are funded by MCSS be “more clearly identified and be consistent within and across regions” (*page 33*).

This current inconsistency is especially true in service delivery for individuals on the autism spectrum without an intellectual disability (ID) (an IQ >70).

While adults with an Aspergers diagnosis are considered eligible for funded supports in some



MCSS regions, they are not eligible in others. It is, however, recognized that all individuals with Aspergers Syndrome have problems with non-verbal communication and social interaction and have a developmental disability. In Ontario narrow definitions of developmental disabilities have excluded adults with Aspergers, yet most Community Living agencies in Ontario have always supported some adults with Aspergers.

At this time, there is no consistent government policy regarding the need for supports and services for adults with Aspergers, nor which ministry / ministries should be involved in funding those services. Further, there is no existing “generic” system of adult services for these people to fall back on that could be enriched with ASD training, unlike the developmental services sector that supports those with cognitive impairment.

Since the release of “*Opportunities and Actions*” (MCSS, 2006), the Ministry has begun discussions to clarify eligibility criteria. The eligibility criteria will likely be the level of required support or support intensity rather than IQ level. As described, debilitating limitations in adaptive behaviour, life skills and executive function place some individuals with a high IQ in greater need of support than developmentally delayed individuals with a significantly lower IQ but adequate adaptive skills.

Co-ordination and Leadership

Adults with ASDs urgently require consistent and integrated service delivery within MCSS and between provincial ministries.

Close co-ordination and information sharing between social service and healthcare policy

makers is essential. Planning and co-ordination among service providers is especially needed in the area of mental health services, and needs to include active collaboration from the Ministry of Health and Long-Term Care to support comprehensive ASD service policy development.

Collaboration on public policy development to support the needs of adults with ASDs is needed in several different areas including: transition from high schools, higher education, housing, daily living skills, healthcare / clinical supports, justice and correctional services, employment, transportation, social assistance, recreational / day programs, respite care, and emergency and legal resources.

For such an approach to work, a lead agency and Ministry are needed to establish and champion an Ontario-wide policy framework to coordinate an appropriate service delivery approach for adults with ASDs. Autism Ontario can provide provincial leadership in this endeavour in partnership with the Government to champion an Ontario-wide intra-ministerial policy framework.

Conclusion

Clearly, the current framework of care does not match the complex, ongoing needs of adults on the autism spectrum. Collaboration is needed to establish and champion an Ontario-wide policy framework. Now is the time to make the recommendations in this document a reality.

RECOMMENDATIONS

Recommendation One

Ensure sufficient and regulated services for adults with ASD in the adult/child mental health, social service, colleges/universities and developmental sectors through an Ontario-wide cross-sector policy framework and devoted funding based on a provincial needs assessment. Specifically, this policy framework would ensure:

- a) Financial supports which are not tied to “claw-backs” through ODSP, Registered Disability Savings, and welfare programs;*
- b) Day supports including vocational and employment, educational, social and recreational services/opportunities;*
- c) Programs devoted to monitoring the well-being and safety of adults with ASDs;*
- d) A range of supported living options; and*
- e) Professional supports including psychological, medical, and psychiatric assistance, dental care, person-centered planning, case coordination, respite care, crisis supports and legal assistance.*

Recommendation Two

Implement standard eligibility criteria to services for adults with ASD based on their functional needs rather than intellectual functioning through an Ontario-wide cross-sector policy framework.

Recommendation Three

Facilitate access to best practices education and research specific to adults with ASD across adult/child mental health, social service, colleges/universities and developmental sectors through a provincial knowledge exchange centre. This centre would:

- a) Lead a provincial needs assessment;*
- b) Guide or seed, translate and disseminate best practice research;*
- c) Provide information to specialized and generic or developmental service providers;*
- d) Provide information to families and individuals with ASDs; and*
- e) Track adult services available throughout the province.*

References

Autism and Developmental Disabilities Monitoring Network Surveillance, Principal Investigators. (2007). Prevalence of autism spectrum disorders – Autism and Developmental Disabilities Monitoring Network, 14 sites, United States, 2002. *Centers for Disease Control Morbidity and Weekly Report* 2007, 56, 12-28.

Autism Society Canada. (2007). *Report of the Advisory Committee of Adults with Autism Spectrum Disorders*. Available: autismsocietycanada.ca/general_info/download_resources/index_e.html

Autism Society Ontario. (1991). *Our Most Vulnerable Citizens: A Report of the Adult Task Force*. Toronto, ON. Susan E. Bryson, Autism Society Ontario. Available: [www.autismontario.com/Client/ASO/AO.nsf/object/Our+Vulnerable+Citizens/\\$file/Our+Vulnerable+Citizens.pdf](http://www.autismontario.com/Client/ASO/AO.nsf/object/Our+Vulnerable+Citizens/$file/Our+Vulnerable+Citizens.pdf).

Barnard, J., Harvey, V., Potter, D. & Prior, A. (2001). *The reality for adults with autism spectrum disorders*. London, National Autistic Society.

Bloomfield, E. (2003). *Adults with Autism Spectrum Disorders in Wellington County, Ontario*. OAARSN and Guelph Services for the Autistic.

Developmental Services Act, R.S.O., c. D11. (1990). Available: www.e-laws.gov.on.ca/html/statutes/english/elaws_statutes_90d11_e.htm

Developmental Services Act. (1974). Available: www.mcass.gov.on.ca/NR/MCFCF/developmental/DSreport_En.pdf

The Diagnostic and Statistical Manual of Mental Disorders (4th ed. – rev.). (2000). American Psychiatric Publishing, Inc. Washington, D.C.

Ganz, M.L. (2007). The Lifetime Distribution of the Incremental Societal Costs of Autism. *Archives Pediatric Adolescent Medicine*, 161, 343-349.

Grandin, T. & Barron, S. (2005). *The Unwritten Rules of Social Relationships: Decoding Social Mysteries Through the Unique Perspectives of Autism*. Arlington, TX. Future Horizons, Inc.

Jones, G. (2008). Protecting Vulnerable Adults. *Autism Matters*, 5:2, 4.

Klein, F. (2008). Odd One Out. Available: <http://lastcrazyhorn.wordpress.com>

Ministry of Community and Social Services. (2006). *Opportunities and Action, Transforming Supports in Ontario for People who Have a Developmental Disability*. Toronto, ON. Author.

Ministry of Education. (2007). *Making a Difference: From Evidence to Action*. Available: <http://www.edu.gov.on.ca/eng/document/nr/07.02/autismFeb07.pdf>.

Ministry of Education. (2007). *Policy/Program Memorandum, No. 140*. Available: www.edu.gov.on.ca/extra/eng/ppm/140.html

Rampton, G.M. (2006). Autism Spectrum Disorder – Developmental Disabilities with Distinctive Support Needs. *Living with Autism, Spring* 10-11.

Szatmair, P. (2008). *Understanding ASD Sub-types*. Personal Communication.

Spoelstra, M. (2008). Safety, Security, Wellbeing. *Autism Matters*, 5:2, 12.

Standing Committee on Social Affairs, Science and Technology. (2007). *Pay Now or Pay Later: Autism Families in Crisis*. Available: parl.c.ca/39/.../commbus/senate/com-e/soci-e/rep-e/repfinmar07-e.htm

Sterling, L., Dawson, G., Estes, A., and Greenson, J. (2008). *Characteristics Associated with Presence of Depressive Symptoms in Adults with Autism Spectrum Disorder*, *Journal of Autism & Developmental Disorders* 38:6, 1011-1018.

Literature Review

A comprehensive search of electronic databases of the peer-reviewed academic literature was undertaken using keywords related to twelve areas of interest. The focus of the search was youth and adults with ASDs, all levels of functioning, their characteristics and service/treatment needs.

Search Categories	Studies Included
Adult Outcome and Quality of Life	12
Advocacy	7
ASD Characteristics and Service Needs	47
Employment Training	8
Family Needs and Services	10
Housing and Residential Needs	5
Issues Related to Aging	10
Policy	14
Post-Secondary Education	4
Prevalence and Epidemiology	14
Reviews on Treatment	7
Transition Planning	4
Total Papers Reviewed	142

Search notes:

- It was difficult to find programs for adults with ASDs that are well-described and scientifically evaluated
- Emerging areas such as parenting by persons with an ASD, post-secondary education, couples counselling for adults with ASDs, and older individuals with ASDs (over 40) are rarely addressed
- Only two unpublished studies and two brief reports on adults with ASDs/dual diagnosis originated from Ontario/Canada in the area of service needs
- The National Autistic Society (UK) has provided current and compelling documentation and research about the service needs of adults with ASDs

Appendices

A. Prevalence of Individuals with ASDs by Age Group

Age Group	"Classic Autism"	ASD Rate
	1 in 2,222 ¹ (2003)	1 in 150 Children ² (2007)
0 – 4 years	302	4,473
5 – 14 years	702	10,407
15-19 years	346	5,127
20-24 years	323	4,787
25-44 years	1,583	23,453
45-54 years	736	10,900
55-64 years	479	7,093
65 + years	662	9,813
Children (0-19)	1,351	20,007
Adults (20+)	3,784	56,060

¹ "Adults with Autism Spectrum Disorders in Wellington County, Ontario" Elizabeth Bloomfield for OAARSN and Guelph Services for the Autistic, August 2003

² ADDMNS, 2002

B: Range and Types of Impairments in Individuals on the Autistic Spectrum*

Areas of difference/ Impairment	Range and Types of Impairments in Individuals on the Autistic Spectrum
Communication	<ul style="list-style-type: none"> Some are non-verbal, while others have superior articulation and fluency Echolalia (repeating what one hears) Extreme difficulty with pragmatic and social language
Social	<ul style="list-style-type: none"> Difficulty in understanding the thoughts and feelings of others, social norms, facial expressions and body language Some are very socially motivated yet lack the skills or social understanding to be successful Difficulty with activities of daily living Limited range of interests, but often deep knowledge in one or two areas
Sensory	<ul style="list-style-type: none"> Many have unusual sensory experiences: hyper- or hypo-sensitivity "Self-stimulatory" behaviours (e.g. hand-flapping, rocking, jumping) Can present with self-injurious behaviour For some, sensory differences can make it more difficult to do well in typical developmental service congregate care settings without the required environmental adaptations
Cognitive/ Neurological	<ul style="list-style-type: none"> Some are also intellectually disabled, may also have Obsessive Compulsive Disorder, tics, rage behaviours, seizures, or anxiety disorders Difficulty with change and transitions
Physical	<ul style="list-style-type: none"> Some are poorly coordinated, have poor fine and/or gross motor skills; some have low muscle tone; many have difficulty with proprioception (self- regulation of posture and movement)

* Chart adapted from presentation "The Myth of the Autistic Spectrum" by Kathryn Everest, Autism Society Ontario – York Region Hockley Highlands Symposium, October 2003

Understanding ASD Sub-types

	Social- Communication Deficits	Repetitive Sensory-motor Behaviour	Inflexible Language & Behaviour	Significant Language Impairment (grammar/ vocabulary)	Intellectual Disability
“Complex” Autism (Autism WITH an Intellectual Disability)	+	+	-	+	+
“High- functioning” Autism (Autism WITHOUT an Intellectual Disability)	+	+	-	+	-
Aspergers	+	-	+	-	-
Pervasive Development Disorder not Otherwise Specified	+	-	-	+	-

Source: Adapted from P. Szatmari (personal communication, 2008).

Note: The plus and minus symbols under each category refer to more or less in comparison to other forms of ASD. All of these traits are more common in ASD than in the general population.

C: What Do Families and Self-Advocates Say They need?

1. The Report of the Advisory Committee of Adults with Autism Spectrum Disorders (2007) recommended that the following supports be available to individuals on the autism spectrum throughout their lifespan:

- Psychological services: assessment and diagnosis services
- Counselling: individual, couple and family counselling
- Educational and support groups and workshops (e.g. self-care, social skills, mental health, sexuality and sensory issues)
- Appropriate and safe housing: group homes and supported housing options
- Life skills training: budgeting, organizational skills, work skills
- Social and recreational opportunities
- Legal aid and other legal resources
- Mental health resources: counselling, medication and advocacy
- Post-secondary education and supports
- Employment opportunities: assessment and training

The report indicated that adults on the autism spectrum who are parents require financial supports, education about child development and non-verbal communication, individualized and specialized assessments of their parenting capacity, genetic counseling, parenting skills counseling and respite.

The report also recommended education of both the public and a wide range of professionals. It pointed out that the needs of seniors on the autism spectrum need to be addressed, and that employers should be educated about issues with ASDs.

2. At the 2006 Woodview Manor/Offord Centre for Child Studies conference *Stages of Autism: Adolescence and Beyond*, 300 individuals were surveyed in order to identify and set priorities on the needs of adults on the autism spectrum.

The following is a summary of the range of services identified and prioritized by the conference delegates in 2006 from the most to the least important:

- a. Services should be delivered within the context of an integrated system of support
 - b. Clinical supports—psychiatry/psychology; assessment/diagnosis; speech and language; behaviour management; occupational therapy; individual and family therapy, case management
 - c. Range of school support programs (e.g. fully included in a regular academic setting, self-contained units)
 - d. Day supports—recreation, life skills
 - e. Transition planning and supports
 - f. Vocational training and support options
 - g. Housing options
 - h. Respite
 - i. Public awareness, information, advocacy
 - j. Special Services At Home funds
 - k. Support groups—individual, parent, siblings, family
3. Over the past several years a number of needs analysis studies and satisfaction surveys have been conducted in various parts of the province by Kerry's Place Autism Services, to identify the kinds and levels of supports and services that individuals on the autism spectrum and their families are looking for.

Community Supports:

- Crisis intervention
- Respite
- Employment, recreational and meaningful day supports

- Consultation support to individuals, families and the community
- Workshops
- Social groups
- Family support groups
- Sibling support
- Intensive behavioural intervention (only in Central West area of the province)

Clinical Services:

- Environmental assessment
- Psychiatric and psychological assessments/ consultations
- Family supports
- Applied Behaviour Analysis
- Workshops/ training
- Occupational therapy
- Specialized communications support
- Medical support
- Abuse prevention (Jones, 2008)

Accommodation Supports:

- Creative accommodation options based on the particular needs of the individual
- Supported independent living
- Home-sharing options
- Employment supports
- Recreation and other day supports

The above list of supports and services is not unique to individuals on the autism spectrum. However, these survey respondents were clear that supports and services need to be provided by individuals with special training and experience in working with individuals on the autism spectrum. Further, they much prefer that these supports and services continue to be provided by individuals with whom they have built a relationship, and in whom they trust. It should be noted that they generally are not able to access multiple service providers for various aspects of support.

D: “Our Most Vulnerable Citizens— A Report of the Adult Task Force” 1991

“Our Most Vulnerable Citizens” (ASO, 1991) grew out of an increased awareness of the lack of services available to individuals with autism/Pervasive Developmental Disorder once they reach adulthood. The report includes an extensive review of the literature on their needs and existing service models, as well as the results of a survey that involved responses from 802 adults and older adolescents with autism/PDD in Ontario. The survey looked at the current status of these citizens vis-a-vis a broad range of issues. The main objective of the report was to identify the ingredients deemed necessary to ensure reasonable quality of life for severely handicapped individuals.



E: How Services Have Developed in Ontario: The De-institutionalization Initiative

In 1977 the Ministry of Community and Social Services began implementing plans to create community living opportunities for individuals living in provincially operated institutions. Institutions were closed, others downsized and the Ministry began to invest in community-based supports and services.

The *Developmental Services Act* (1974) provides authority for funding of a wide range of community-based services. This Act contains regulation-making powers regarding eligibility for service. Changes to the regulations have been made over the years.

In May 2006, the Ministry of Community and Social Services published a new policy discussion paper *“Opportunities and Action—Transforming Support in Ontario for People Who have a Developmental Disability”*. This paper reinforced the notion that the transformation of services should be based on the overarching principles that: “People with developmental disabilities are people first” and delivery of supports should focus on “independence, dignity and self-reliance” (page 14). The paper further states that they should be supported to live as independently as possible, fully included in all aspects of society, with the type of supports, and in the setting, that they choose.

The stated goal in *“Opportunities and Action”* was to “create a fair, accessible and sustainable system”. It envisioned that “funding and supports be more flexible and individually tailored” and “go with the person if she/he moves to another community”. The paper further states that “People with similar needs in similar circumstances receive similar supports across the province” (MCSS, 2006).

Education Reform in the 1980s

During the 1980s children with ASDs and other exceptionalities were integrated into their local schools when the approach to special education was

completely overhauled. Almost overnight special schools disappeared and children with a range of exceptionalities moved into local schools, and often into regular classrooms. This approach is now taken for granted, and many cannot even remember a time when it was not this way. Having welcomed exceptional children into regular schools, it seemed natural that the next step would be to find better ways to help them live in within the community.

Following the release of a report from the Ministry of Education’s Reference Group on ASDs (*Making A Difference: From Evidence to Action*, 2007), the Ministry issued a Policy / Program Memorandum (PPM 140) (May 17, 2007) providing direction to individual school boards in Ontario. Memorandum 140 not only directed the school boards on what to provide, but gives specific instructions on how to provide it.

“School boards must offer students with ASD special education programs and services including, where appropriate, special education programs using ABA (Applied Behavioural Analysis) methods” (PPM, 140 page 3).

However, while transition plans for youth with ASDs leaving the school system may be formulated (if the student has been identified and if there is an individual education plan), specialized service providers report that the lack of funding to provide resources for transition or a place in which to transition, renders these plans useless. As well, individuals with Aspergers often do not have the benefit of even the development of a transition plan. Either scenario leaves adults with Aspergers little or no support system despite the fact that many face debilitating daily living problems.

