



REPORT

POLICY FORUM: AUTISM ACROSS A LIFESPAN

February 5 and 6, 2009
Opus Hotel, Montréal, Québec

Overview

The Centre of Excellence for Early Childhood Development (CEECD) and the Centre of Excellence for Children and Adolescents with Special Needs (CECASN) hosted a policy forum on autism February 5-6, 2009. This event was the second forum on autism spectrum disorders (ASD) organised by these two centres. The previous one, held in Montréal on November 17, 2007, brought together representatives responsible for the young children with autism portfolio. This year's forum differed from last year's by focussing on older children (above five years) and adults. The forum paid particular attention to transitions over a lifetime of autism. For the first time, professionals from this field were able to share knowledge in wide-ranging discussions. The forum had two main objectives.

- 1) to provide provincial/territorial policy advisors an opportunity to share best practices and lessons learned in a discussion of key issues, challenges and opportunities in the field of autism.
- 2) to open dialogue between policy advisors and researchers with a view of working together to develop better policies for the early identification of autism and intervention throughout life.

Participation in the forum was by invitation from the two Centres. Held in Montréal in early February, the event brought together representatives involved in program planning and service delivery from British Columbia, Québec, Manitoba, Ontario, Newfoundland and Labrador, Nova Scotia, New Brunswick, Saskatchewan, Alberta, as well as representatives from the two Centres, for a total of 18 participants.

The forum was chaired by Kim Kienapple, PhD, professor at Mount Saint-Vincent University and researcher at the CECASN.

After opening remarks by Kienapple, presentations were given by Georges Huard, who has first-hand experience with Asperger syndrome (AS), and Kevin Stoddart, PhD, Clinical Director of the Redpath Centre for Social and Emotional Development in Toronto and Adjunct Assistant Professor at the Factor-Inwentash Faculty of Social Work at the University of Toronto.



Living with Asperger's

Huard gave a personal and very interesting talk on what it means to live with Asperger syndrome, both as a child growing up and as an adult. He addressed its challenges and discussed strategies for coping. He also raised the need for making environments "Asperger friendly".

Huard is a member of the Advisory Board of the Autism Society of Canada.

Canadian Youth and Adults with ASD

Stoddart's keynote address focussed on Canadian youth and adults with autism spectrum disorders (ASD) and on the need for more inclusive services. He noted that there are over 150,000 Canadians, 15 years and over, with ASD. The presentation of ASDs varies widely in youth and adults, which makes it difficult to plan services and design policies. Current ASD services in Canada are piecemeal and not inclusive of the wide range of needs of adults with ASDs. Canada and its provinces are not prepared for the increasing prevalence of adults with ASDs; we are also in "catch-up" mode. Although there has been improved recognition of the need in some provinces, this approach is not informed by Canadian epidemiological or needs assessment research. Federal and provincial inter-ministerial cooperation and coordination are essential in meeting the needs of this group.

Furthermore, lack of diagnosis or misdiagnosis leads to inappropriate and uncoordinated services, which in turn bring about poor, long-term outcomes. For example, untreated children and youth with ASDs are at risk of school drop-out, depression, anxiety, and long-term psychosocial problems, while untreated adults with ASDs experience serious mental health problems (sometimes leading to suicide), isolation, addictions, unemployment, and ongoing dependence on aging families, social services, income support and (mental) health programs.

In conclusion, Stoddart called for more comprehensive services for all Canadians with ASDs, and made the following recommendations:

1. Coordinate Canadian research, policy and service efforts;
2. Develop closer partnerships with national and provincial advocacy groups;
3. Realize need for services across the spectrum and throughout life;
4. Foster Canadian research on lifelong ASD needs in a range of areas; and
5. Ensure effective knowledge exchange of best practices.



Panel Discussion: Voices from the Field

Representatives from the *Ministère de la Santé et des Services sociaux du Québec*, British Columbia's Ministry of Child and Family Development, and the Ontario Woodview Children's Centre and Autism Services, were invited to provide their overview of the situation regarding autism throughout life in their provinces, including the policies and programs available.

The panel discussion was divided into two parts:

1. Context: political and socioeconomic opportunities and challenges
2. What is being done to meet challenges and to take advantage of opportunities?

Each panellist was given 15 minutes to speak on both topics. After each section, the discussion was opened up to all participants.

PART 1 – CONTEXT: POLITICAL AND SOCIOECONOMIC OPPORTUNITIES AND CHALLENGES

Summary of presentation by Jocelyne Bélanger, Coordonnatrice en déficience intellectuelle, troubles envahissants du développement et dossiers intersectoriels, Ministère de la Santé et des Services sociaux du Québec

In Québec, support for people with ASDs and their families is moving in the right direction. A few years ago, the departments of health and social services, and education established an ASD network: *Le réseau national d'expertise en TED*. The objective was to develop an expertise in ASD. Clinical guidelines have also been developed.

Several effective programs and services are available, such as university level training for professionals working in the field, awareness raising and information programs for health and social services professionals, and support for parents and families. There is also a certain level of research that is ongoing in the field. However, several issues remain to be addressed. For example, services for children need to be consolidated; access, quality, and continuity of services for school-age children and adults needs to be improved; best practices need to be identified; and support for employment and housing must be put in place.

Summary of presentation by Karen D. Bopp, PhD, Senior Behaviour Consultant, Children and Youth with Special Needs Policy, Ministry of Child and Family Development, British Columbia

In British Columbia, we have identified the following challenges:

- Autism Funding: Under Age 6 and 6-18 years does not necessarily mean customized services specific to the child's individual needs.
- Allocation of funding is based on age rather than on a functional assessment of abilities (i.e., no sliding scale of funds to match a child's need).



- There is currently no mechanism to evaluate or re-assess if a treatment plan is effective.
- The quality of service provision is variable due to challenges with capacity, no standard guidelines of practice, and no regulatory body for behavioural consultants.
- The direct funding option has proven more challenging to administer than invoice payment.

In terms of transitions, the challenges are:

- When transitioning to the education system, a philosophical change occurs.
- Many families wish to continue ABA intervention in school – but there is a shortage of trained personnel and challenges with regards to hiring practices.
- Consistency across settings and systems is a challenge and a barrier for many families. For example, families are not able to use their MCFD autism funds towards augmenting the programs within the education system.
- There are increased difficulties for families in accessing services when a child enters school and when he or she leaves school or becomes an adult.
- The most significant transitional challenge is in the difference in eligibility criteria between adult disability programs and services for youth with special needs.
- There is a lack of dedicated services for adults with ASDs from assessment to intervention.

Summary of presentation by Rick Ludkin, Director of Autism Services Development, Woodview Children's Centre and Autism Services, Ontario

In Ontario, the overarching issue is the lack of a consistent government policy on the need for support and services for adults with ASD. Furthermore, there is no agreement regarding which government departments should be involved in funding.

High-functioning adults with ASD have no access to services. Current services for adults are designed for people with IQs under 70, yet most individuals with ASDs do not have an intellectual disability.

Comparing services for children vs adults with ASD, the lack of policy and services is clear. For children of all ages, demand exceeds resources; for adults with ASD, however, the problem is in the lack of services.

Studies show poor outcomes for adults with ASD in all areas: housing, level of independence, work, social well-being, networks, financial well-being, and quality of life. Higher IQ level is not an indicator of better outcome because social interaction issues become more prominent in the adult years.

Comments by other participants:

Major issues identified by the provinces were:

- Lack of services during transitional periods.



- Lack of services for high-functioning people or people with an IQ over 70 – this came up in more than one region.
- Assessment of people with ASD – review to include an evaluation of their strengths, as well as family and community strengths; move towards a needs-based rather than diagnostic model of assessment.
- Services – customize to the needs of individuals and their families (this follows from the strength-based or functional assessment practices).
- Call for more research in children over the age of six.
- Over all, a lack of resources. In all regions of the country, needs exceed resources.

**PART 2 – MEETING CHALLENGES, TAKING ADVANTAGE OF OPPORTUNITIES*****Summary of presentation by Jocelyne Bélanger, Coordonnatrice en déficience intellectuelle, troubles envahissants du développement et dossiers intersectoriels, Ministère de la Santé et des Services sociaux du Québec***

In Québec, organisational and clinical projects are being developed, as well as an access to service program for persons with ASD.

The departments of health and social services, and of education, have an agreement to provide services that complement each other.

Québec has established a provincial expertise network, as well as standards of practice.

Summary of presentation by Karen D. Bopp, PhD, Senior Behaviour Consultant, Children and Youth with Special Needs Policy, Ministry of Child and Family Development, British Columbia

The most recent opportunities have been:

- A new and revised Parent's Handbook to help families navigate services was released in May 2008.
- MCFD now contracts with ACT to provide a province-wide information and referral service created to support families of children with ASDs.
- ACT manages the Registry of Autism Service Providers (RASP). RASP ensures that service providers demonstrate education and experience that meets the qualification levels described by the ministry.
- In 2006, the BC Ministry of Education funding formula was expanded to align with MCFD.

Summary of presentation by Rick Ludkin, Director of Autism Services Development, Woodview Children's Centre and Autism Services, Ontario

Woodview has developed a model of "seamless" services and supports for high-functioning people with ASD over their lifetime that is readily adaptable to other regions or provinces. To develop and deliver these services requires funding agencies and ministries to recognize the existence of a problem and the will to do something about it.

The Manor Personal deployment model (a program for adults with ASDs) has had good outcomes for adults with ASD in Ontario. Founded in 1994, it is a "social enterprise" or "consumer-driven business."

Manor Personal Deployment (MPD)

- Provides group activities instead of individual follow-up;
- Tries to integrate people in a work environment;
- Tries to make MPD a competitive business, emphasizing the importance of earning a wage;



- Creates huge mental and quality of life benefits for people involved;
- Includes adults with ASD, Asperger's, and schizophrenia.

Comments by other participants:

It is very important to train people who work with those who have ASD, and to train them to adapt to providing services and support over a lifetime.

A broader lifespan approach that includes transition from one program to another would be helpful.

The demand for services is overwhelming and leads to arbitrary or random decisions for access.

The various departments need to work better together. A provincial strategy and implementation plan is needed.

The department responsible for ASD varies – education, health, social services – from province to province.

Despite important differences across provinces, there is striking similarity regarding services for autism over a lifetime:

- Lack of funding
- Availability of services
- Need for new assessment criteria
- Need for research
- Few services for children, but even fewer for adults
- Emphasis on training professionals to provide services to school-age children and young adults.



BREAKOUT GROUPS

For the last part of the forum, participants worked in three breakout groups to address two themes: 1) policies currently available and policies needed, 2) contribution of research to policy development.

THEME 1 - REVIEW OF POLICIES AVAILABLE AND IDENTIFICATION OF POLICIES NEEDED

The following represents a list of policy recommendations for autism over a lifetime

1. Better coordination

- Create federal and provincial inter-ministerial cooperation and coordination.
- Establish a central office for autism policies (at the national and provincial levels)
- Identify a case mediator for all services provided for ASD / Case manager or service coordinator to coordinate the service planning (some jurisdictions already have something similar in place).

2. Continuity and consistency

- Ensure consistency over the years through protocols, interdepartmental committees and working groups, even when there is a change of government.

3. Research-based policies

- Base policies on research instead of pressure or lobbying to governments.

4. Provincial and national standards

- Define policies and protocols for service delivery.

5. Eligibility criteria and requirements for access to services

- Review eligibility criteria, especially the IQ eligibility criteria and its cut-off based on an IQ of 70.
- Transform services to address lifelong needs.
- Move towards a needs-based, risk assessment criteria.
- Survey eligibility criteria across provinces and territories.
- Establish consistency of eligibility criteria within provinces/territories and across Canada.
- Define successful outcomes for ASD treatments or redefine the criteria for discharging someone.

6. Accountability

- Make services and programs accountable.
- Develop measures to ensure the quality of services



7. Funding

- Fund services, programs, and service provider training, particularly for the transition between childhood and adulthood.
- Make more funding available for services for people with ASD once they leave the school system.

8. National action plan

- What do people with ASD need over a lifetime?
- What do we need to provide these services?

9. Research

- Coordinate and provide access to research.
- Create an autism knowledge centre.

THEME 2: CONTRIBUTION OF RESEARCH TO POLICY DEVELOPMENT

The following represents a list of recommendations for research on lifelong needs in autism

1. Co-ordinated research: program evaluation, outcomes, epidemiology
 - Global perspective on ASD (what is happening in other countries), more interdisciplinary approach.
2. Nationwide epidemiology studies to implement nationwide policies
3. Survey of adults with ASD
 - Needs assessment, environmental review epidemiology, type of services required or available.
4. Study of effective practices for transition
 - Best practices to provide support to school age children, adolescents and adults with ASD and Aspergers.
 - Approaches that are suitable and transferable across the lifespan.
 - Approaches that support social skills competency development
 - case studies.
 - Benchmark (current state of services and outcome).
5. A systematic review of evidence-based practices and programs
 - What is available, suitable and transferable throughout a life.
 - Select methods of instruction or teaching protocols that are more appropriate for a specific age group or ASD.



- Outcomes should be defined, evaluated, identified and measured.
6. A review of Canadian research on youth and adults with ASD
The range of ASD should be respected.
 7. Different model of research – move away from medical world into social, psychological – remove research from medical/health sector
A focus on strength-based supports and functional needs should be the agenda.
 8. Partnerships between universities and government for research
 - Research that bridges findings by researchers and service providers, and includes government input in final process.

Conclusion

Kim Kienapple thanked speakers and participants for their contribution to making the forum a productive and informative event.

Participants were pleased with the opportunity to exchange information about ASD programs, services, and research. They agreed to distribute a list of resources available in their provinces, and to keep in contact.



Resources

Centre of Excellence for Children and Adolescents with Special Needs

<http://www.coespecialneeds.ca/>

Centre d'excellence pour les enfants et adolescents avec des besoins spéciaux

<http://www.coespecialneeds.ca/fr/?display=home>

SNIS Online

An information & resource service for children with special needs and the families and professionals who care for them

<http://www.snis.ca>

Centre of Excellence for Early Childhood Development

<http://www.excellence-earlychildhood.ca/home.asp?lang=EN>

Centre d'excellence pour le développement des jeunes enfants

<http://www.excellence-earlychildhood.ca/home.asp?lang=FR>

Encyclopedia on Early Childhood Development

<http://www.child-encyclopedia.com>

Encyclopédie sur le développement des jeunes enfants

<http://www.enfant-encyclopedie.com>



British Columbia

Cross-Ministry Children and Youth with Special Needs Framework for Action

http://www.mcf.gov.bc.ca/spec_needs/

Transition Planning

http://www.mcf.gov.bc.ca/spec_needs/transition.htm

Your Future Now

A Transition Planning and Resource Guide
For Youth with Special Needs and their Families

http://www.mcf.gov.bc.ca/spec_needs/pdf/your_future_now.pdf

Ton avenir t'appartient

Guide de planification de transition et répertoire de ressources
À l'usage des jeunes ayant des besoins particuliers et de leur famille

http://www.mcf.gov.bc.ca/spec_needs/pdf/your_future_now_french.pdf

Transition Planning for Youth with Special Needs

A Community Support Guide

http://www.mcf.gov.bc.ca/spec_needs/pdf/support_guide.pdf

Planification de transition pour les jeunes ayant des besoins particuliers

Guide de soutien communautaire

http://www.mcf.gov.bc.ca/spec_needs/pdf/support_guide_french.pdf

Early Intensive Behavioural Intervention Clinical Standards

http://www.mcf.gov.bc.ca/autism/pdf/eibi_clinical_standards.pdf

Customized Employment Demonstration Project

http://communitylivingbc.ca/what_we_do/employment/employment_overview.htm

A Parent's Handbook: Your Guide to Autism Programs

http://www.mcf.gov.bc.ca/autism/pdf/autism_handbook_web.pdf

Service Provider Qualifications

Application for registry of autism services

http://www.mcf.gov.bc.ca/autism/pdf/CF0901FILL_AUG08.pdf

UBC Research Update

Autism and Developmental Disabilities webcasts (2008)

http://setbc.org/setbc/topics/autism_dev_dis.html



Alberta

Alberta Programs and Services

<http://www.programs.alberta.ca/Living/651.aspx?N=770+175>.

Family Support for Children with Disabilities Program (FSCD).

The FSCD Program supports children ages 0-18 who have a developmental, physical, mental health, sensory or disabling health conditions by providing a range of services and supports based on each child's individual needs.

<http://www.child.alberta.ca/disabilities>.

Alberta Education

Early childhood special education programming to preschool age children and special education supports to students.

<http://www.education.alberta.ca/admin/special/ecs.aspx>.

Alberta Health and Wellness

Services to children with autism including diagnostic and some health therapy services.

<http://www.health.alberta.ca/services/health-regions.html>

Alberta Seniors and Community Supports - Persons with Developmental Disabilities (PDD)

Support and services to adults with developmental disabilities including ASD.

<http://www.pdd.org/default.shtml>

Alberta Seniors and Community Supports - Assured Income for the Severely Handicapped (AISH)

<http://www.seniors.gov.ab.ca/AISH/index.asp>

Alberta Seniors and Community Supports - Alberta Employment and Immigration Disability Related Employment Supports

<http://employment.alberta.ca/cps/rde/xchg/hre/hs.xsl/3159.html>

Distinct but Linked

Government of Alberta Services for Preschool Children with Special Needs.

http://www.child.alberta.ca/home/documents/childrenwithdisabilities/Distinct_But_Linked.pdf



Saskatchewan

Intensive Supports

Students with Intensive Needs: Impact Assessment Profile Documents

<http://www.education.gov.sk.ca/IntensiveSupports>

Framework and Action Plan for Autism Spectrum Disorders Services in Saskatchewan

<http://www.health.gov.sk.ca/autism-strategic-direction>

The Saskatchewan Cognitive Disabilities Strategy

<http://www.health.gov.sk.ca/cognitive-disabilities-strategy>



Manitoba

Supporting Inclusive Schools: A Handbook for Developing and Implementing Programming for Students with Autism Spectrum Disorder

Distributed to all school divisions and First Nations schools in the province.

<http://www.edu.gov.mb.ca/k12/specedu/aut/index.html>

Appropriate Educational Programming: Standards for Student Services

The standards provide school divisions with a framework to use in developing a local policy for appropriate educational programming.

http://www.edu.gov.mb.ca/k12/specedu/aep/pdf/Standards_for_Student_Services.pdf

Appropriate Educational Programming: A Formal Dispute Resolution Process

The document provides information relating to the formal dispute resolution process in Manitoba.

http://www.edu.gov.mb.ca/k12/specedu/aep/pdf/Formal_DR_Process.pdf

Working Together: A Parent's Guide to Formal Dispute Resolution

This guide outlines the formal review process, describes the issues that qualify for a formal review, and poses some questions to consider when deciding whether a formal review might be appropriate for your situation.

<http://www.edu.gov.mb.ca/k12/docs/parents/dr/index.html>

Appropriate Educational Programming: A Handbook for Student Services

Appropriate Educational Programming: A Handbook for Student Services is a reference guide containing information that supports appropriate educational programming in Manitoba.

http://www.edu.gov.mb.ca/k12/specedu/aep/handbook_ss/index.html

Individual Education Planning: A Handbook for Developing and Implementing IEP's

This handbook is intended to provide student service administrators, principals, classroom and resource teachers, and other professionals with an effective process for deciding which students require IEPs. It is also designed to assist educators in developing, implementing and evaluating these Individual Educational Plans.

<http://www.edu.gov.mb.ca/k12/specedu/iep/index.html>

Student Services website

Manitoba Education, Citizenship and Youth

<http://www.edu.gov.mb.ca/k12/specedu/index.html>



Ontario

Autism Ontario website

<http://www.autismontario.com/>

Forgotten: Ontario Adults with Autism and Adults with Asperger's

<http://www.autismontario.com/client/aso/ao.nsf/Adults/Case+for+Support?OpenDocument>

Current issues for more able adults with Autism Spectrum Disorder:

An examination of quality of life, mental health, and physical well being

Colleen Mousseau, Rick Ludkin, Peter Szatmari, Susan E. Bryson

For a copy write to cmousseau@autism-woodview.com



Québec

Entente de complémentarité entre les Ministères de l'Éducation, du Loisir et du Sport et le Ministère de la Santé et des Services Sociaux du Québec

<http://www.mels.gouv.qc.ca/lancement/ententeMEQ-MSSS/index.htm>

Two Networks, One Objective: Guide for developing a memorandum of understanding on the joint provision of services to young people by the educative and health and social services networks

<http://www.mels.gouv.qc.ca/lancement/ententeMEQ-MSSS/index.htm>

Two Networks, One Objective: The Development of Youth

Agreement for the complementarity of services between the health and social services network and the education network

<http://www.mels.gouv.qc.ca/lancement/ententeMEQ-MSSS/index.htm>

Parcours de formation réalisé au MELS pour les jeunes en difficulté (in French only)

<http://www.mels.gouv.qc.ca/sections/parcoursFormation/>

Plan d'accès aux services pour les personnes ayant une déficience (in French only)

<http://msssa4.msss.gouv.qc.ca/fr/document/publication.nsf/fb143c75e0c27b69852566aa0064b01c/271f7db81d6ae81d85257464006ca8e6?OpenDocument&Highlight=0,d%C3%A9ficience>

Un geste porteur d'avenir (in French only)

Des services aux personnes présentant un trouble envahissant du développement, à leurs familles et à leurs proches

<http://msssa4.msss.gouv.qc.ca/fr/document/publication.nsf/fb143c75e0c27b69852566aa0064b01c/1c06f58f0eff1f2785256cd40050d0ce?OpenDocument&Highlight=0,avenir>

Bilan de la mise en œuvre 2004-2005 du plan d'action (in French only)

Les services aux personnes présentant un trouble envahissant du développement, à leurs familles et à leurs proches

<http://msssa4.msss.gouv.qc.ca/fr/document/publication.nsf/fb143c75e0c27b69852566aa0064b01c/764c077bc7106b6a8525722d00518534?OpenDocument&Highlight=0,envahissant>