

Closing the Gaps:

A Presentation to the
Select Committee for
Developmental
Services



AutismONTARIO
see the potential

About this submission: collaborators

- **Margaret Spoelstra** Executive Director, Autism Ontario
- **Kevin Stoddart** Director, The Redpath Centre
Adjunct Professor, Factor-Inwentash Faculty of Social Work, U of T
- **Sally Ginter** President & CEO, Kerry's Place Autism Services
- **Debbie Irish** CEO, Geneva Centre for Autism
- **Cindy I'Anson** ED, Woodview Mental Health & Autism Services
- **Robin Brennan** Director Autism Services, Woodview
- **Peter Szatmari** Chief, Child and Youth Mental Health Collaborative
CAMH & The Hospital for Sick Children; Director of the Division of
Child and Adolescent Psychiatry, U of T.
- Parent volunteers : **Elizabeth Hunter, Laurie Pearce, Howard Weinroth**

About this submission: our focus

- The supports and services for Autism Spectrum Disorder (ASD) are inadequate and fragmented, and fail to address needs across the entire lifespan.
- Despite some advances in social services for this group of Ontarians, the situation for many living with ASD remains dire.
- Early intervention and services for children are critical, but attention also needs to be given to the wide-ranging and overlooked needs of older youth and adults with ASD.

Acknowledging the work that has begun

- **Autism Intervention Program** (valuable intervention not accessible by most children with ASD)
- **ABA/School Support/Connections and Policy/Program Memorandum-140** (valuable services inconsistently applied, not easily accessed or well supported)
- **Clinical services** through key autism organizations
- Province-wide - **Potential Programme, Summer, March Break 1-1, ASD relevant websites**
- **Special Services at Home (SSAH)** funding – vital but depleted funding
- **Transition planning** from school to adulthood required, but to what?
- **Passport** (very few receiving, others ineligible)
- **Registered Disability Savings Plans** federal but grateful for no claw backs in Ontario

The unique challenges of ASD

- **A complex developmental disorder:** affects communication and social interaction, and involves repetitive behaviours and restricted interests.
- **Highly heterogeneous in nature:** Wide range in the presentation of the disorder and in the resulting impact on individuals and their families.



The unique challenges of ASD



- Problems with social understanding are central
- Can co-exist with Attention Deficit Disorder, learning disability, intellectual disability, and mental health disorders
- Can manifest as behavioural problems, self-injurious behaviour, addictions, aggression.



The unique challenges of ASD

- Severity of symptoms and co-occurring disorders change over time, as does individual need and family resources.
- Individuals to face *new* and *unanticipated* challenges throughout their adult years.
- These require responsive, integrated and informed services and supports for the individual and their family.

ASD and society: the promise of integration

- Accessibilities for Ontarians with Disabilities Act (AODA)
- Social Inclusion Act
- Realizing the Promise of Diversity: Ontario's Education and Diversity Strategy

ASD and society: the impact on families

- Cycle of poverty, feelings of isolation, loss of hope, fear for the future.
- “Live one day longer than your child.”
- Parents as caregivers, increasing responsibility as parents age and resources diminish.
- “Cured by adulthood”.
- Effect on siblings.
- Competition for scarce resources.

ASD and society: lost opportunities

- Numbers are not yet clear, but conservatively 1 – 2% of the population.
- Numbers are growing (Ministry of Education reporting since 2007- 7,000, 11,000 and currently 14,000 students with ASD).
- Unique to ASD – undiagnosed, diagnosed in adulthood.
- Lost opportunity to recoup investment in intervention and education, to leverage potential contributions to society.

The eligibility gap: if not this door, which one?

- Developmental Services Ontario (DSO) criteria discriminates against people on the basis of IQ: prevents access to services and funding.
- Regulation introduced criteria that is too narrow.
- Complex, subtle condition cannot be addressed with simplistic solutions.



The eligibility gap: if not this door, which one?

- Measurement tools do not reflect the challenges of those with ASD.
- People supported as children but not once 18.
- Self-selecting out of the process throws service numbers into question.



The services gap: inaccessible services

- Not enough funded services for all age and ability ranges: huge wait lists.
- Impossible to plan for future because wait time cannot be calculated.
- Services not always accessible in relation to language, geography, and culture.
- Availability, or lack, of funded and fee for service programs not communicated clearly to families and individuals.



The services gap: inappropriate services

- Generic services often not suited for those with ASD
- Duration or service needs to be appropriate and driven by objectives rather than time.
- Services need to lead to each other rather than stop-and-start.
- Crisis-driven services are ineffective for those with ASD.



The knowledge gap

- Specialized services require appropriately trained staff.
- Knowledge needs to extend to every type of professional.
- Need standards of care, best practices, and a system of monitoring and assessing knowledge of ASD.
- Need consistency: DSO itself applies rules differently across communities.

The coordination gap

- Transitions between Ministry responsibilities a challenge.
- Transitions forced by policy rather than need (loss of entitlement).
- Some processes in place (Intensive Behaviour Intervention (IBI) to school, new transition planning framework) but not enough.
- No apparent attempt to coordinate services or to share information about individual.

The direct funding gap: lack of funds

- Wait lists for funding: it is possible to age-out of Special Services at Home (SSAH) before receiving any funds.
- Disincentive to apply if no reasonable expectation of ever receiving funding.
- The Passport program needs to be expanded to include those who do not qualify for DSO

The direct funding gap: application processes

- Paperwork and processes complex, confusing , and stressful.
- Perceived requirement to paint the worst possible picture: painful for parents.
- Each process requires different information: time-consuming, costly.
- Some applications require cooperation of medical professionals, which may be difficult to solicit.

The direct funding gap:

- SSAH cut off at age 18, when loss of entitlement means families face greatest challenges and financial demands.
- Unreasonable restrictions placed on use of funds: parents are required to be caregivers (in absence of services) but not trusted to act responsibly with funds.

The program/service accountability gap

- Need independent program evaluation of services and supports.
- Need provincial standards of practice to be developed and adhered to.
- Need to be using scarce program funds wisely.
- Need to be engaged in “made in Ontario” program development and evaluation opportunities.

The applied research gap

- Research results are inconsistently used to inform public policy or to drive service delivery.
- Need a centralized, government-independent “Network of Excellence”.
- Clearinghouse of research to avoid research duplication, share knowledge, and promote new ideas.

In conclusion

- Without accurate numbers we cannot plan
- Without shared knowledge we cannot learn
- Without an inclusive society we cannot contribute
- Without services and supports we cannot thrive
- Without best practices we cannot succeed