

“Ask the Doctor”: Improving pathways to timely diagnosis of autism



AutismONTARIO



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Disclosures

- Research funding from Canadian Institutes of Health Research, Kids Brain Health Network, National Institutes of Health, Autism Speaks, Autism Science Foundation, Women's and Children's Health Institutes, Stollery Children's Hospital Foundation
- No industry funding
- I miss Ontario (and Ontarians!!)

Overview

- What are the earliest signs of autism?
- Can my pediatrician diagnose autism or does my child need to see a specialist?
- Why are some people diagnosed with autism earlier or later than others?
- What are the health care needs of autistic children?

Challenges...

- **Average age of diagnosis remains around 4 years**
 - Long wait lists
 - Variable access - disparities (e.g., related to ethnicity)
- **Autistic children less likely to have a ‘medical home’ than other children with additional health care needs**
- **Access/quality of care further compromised with transition to adulthood**

Autism Assessment Task Force

- **Early detection, diagnostic assessment, ongoing care**
- **Representation Included:**
 - CPS (community peds, dev peds, mental health)
 - College of Family Physicians of Canada
 - Canadian Academy of Child and Adolescent Psychiatry
 - Canadian Psychological Association
 - Autism Alliance of Canada, and other parent leaders



Paediatrics & Child Health, 2019, 424–432

doi: 10.1093/pch/pxz119

Position Statement

OXFORD

Position Statement

Early detection for autism spectrum disorder in young children

Lonnie Zwaigenbaum, Jessica A. Brian, Angie Ip



Key Points

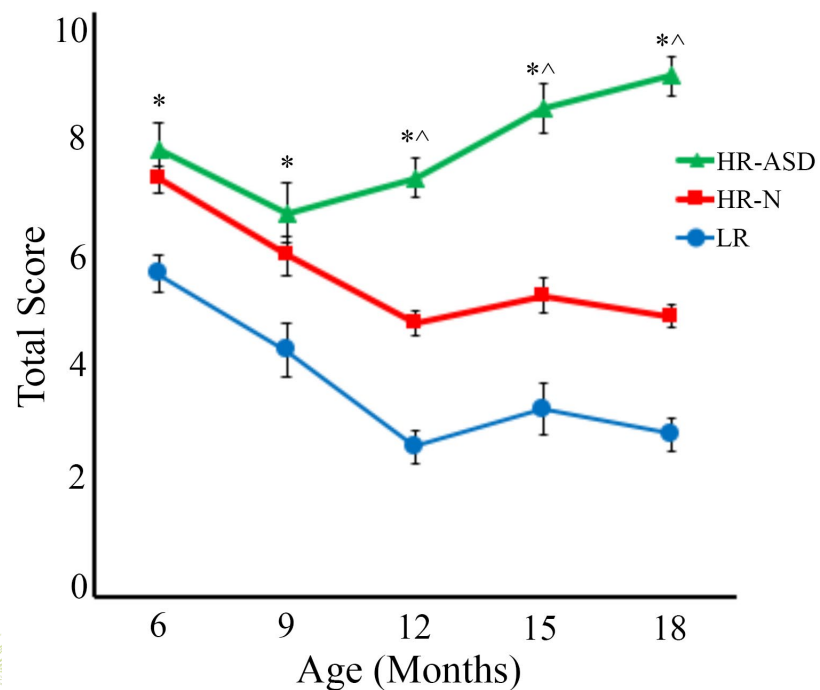
Early detection

- All Canadian children should be monitored for early behavioural signs of ASD as part of general developmental surveillance.
- Children identified as being at increased risk for ASD should receive an early, focused evaluation to determine need for further diagnostic assessment.

Autism by the 1st birthday

Based on 500 sibs and 180 LR infants followed to age 3

Autism Observation Scale for Infants (AOSI) Total scores



- **Behav signs of autism 9-12 mo**
 - Not responding to name
 - Reduced babbling
 - Reduced eye contact
 - Reduced shared positive emotion
 - Less social referencing
 - Difficulty with transitions
 - Insistence on particular object
 - Intense sensory-oriented play



**ASD
Detection**

**ASD
Diagnosis**

Early behavioural/biomarker research:
earlier diagnosis will follow earlier
detection

**ASD
Detection**

**ASD
Diagnosis**

Health system innovation,
community partnerships –aimed
at improving access



Paediatrics & Child Health, 2019, 444–451

doi: 10.1093/pch/pxz117

Position Statement

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Position Statement

Standards of diagnostic assessment for autism spectrum disorder

Jessica A. Brian, Lonnie Zwaigenbaum, Angie Ip



**Determine
definitive diagnosis**

Explore co-occurring conditions
(which may overlap with autism)

**Child- and family-
centered
& culturally safe**

**Determine adaptive function;
strengths, challenges, interests**

**Gather sufficient information
to inform treatment planning**

Multiple pathways to diagnosis

Community Model

Collaborative/'virtual team'

Less complexity

Ongoing mentorship

Specialty Team

Multi-disciplinary

More complexity

Consults as needed

Review Article

Xiaoning Guan, MD, Lonnie Zwaigenbaum, MD, Lyn Sonnenberg, MD

Building Capacity for Community Pediatric Autism Diagnosis: A Systematic Review of Physician Training Programs

- Five of 6 studies reported that training community MDs led to improved access, with 50% reduction in wait times.
- Very good agreement on ASD diagnosis between trained community MD and local expert team (71%– 100%).
- Community MDs reported increased comfort level discussing ASD diagnosis, increased use of screening
- One study: parental satisfaction rate 90%

‘ECHO Autism’ (Extension for Community Healthcare Outcomes): combines mentoring and case discussion to create a virtual learning network



Glenrose Community Stream: Training Model

Sonnenberg, Zwaigenbaum, Piedhayeki, Perrott, Mah, Demeriez and team

Initial training

Mentored
office
assessments

Mentoring and
Q&A via case
discussions

**Ongoing support and oversight by Central Intake
'Community of Practice' in Autism Diagnosis**



AutismONTARIO



- Stop Video
- Mute My Audio
- Pin Video
- Rename
- Hide Self View





AAPLES

**AUTISM ASSESSMENT FOR PRESCHOOLERS
WITH LANGUAGE ELEMENT SEQUENCE**

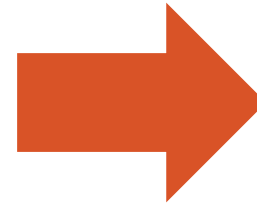
L Sonnenberg, L. Zwaigenbaum, M. Penner, J Brian

- Virtual assessment
- Parent-mediated
- Clinician coaches
- Elicits social, communication and play behaviour
- Informs ratings of DSM-5 defined features

Transitioning back to usual care...

- Some ambivalence among parents; prefer in-person
- Especially helpful for families living further from diagnostic centres, supported by local team
- Re-calibration of clinical 'barometer' with in-person assessments
- **Opportunity for hybrid model going forward?**





Medical Home



Paediatrics & Child Health, 2019, 461–468

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Post-diagnostic management and follow-up care for autism spectrum disorder

Angie Ip, Lonnie Zwaigenbaum, Jessica A. Brian

Canadian Paediatric Society, Autism Spectrum Disorder Guidelines Task Force, Ottawa, Ontario



Key Points

Post-diagnostic Management

- Paediatricians and other primary care providers are well-positioned to provide or coordinate ongoing medical and psychosocial care and support services for children with ASD.
- Managing ASD includes treating medical and psychiatric co-morbidities, behavioural and developmental interventions, and providing supportive social care services to enhance quality of life for affected children and families.

Common co-occurring conditions

Sleep

GI (e.g., constipation)

Seizures

Emotional-behavioural health

- (e.g., anxiety, attention, regulation)

Considerations in later childhood...

- **Groups that tend to be diagnosed later**
 - Milder symptoms, stronger language and intellectual skills
 - Girls ('social camouflaging')
- **Gender diversity**
 - Higher rates in ASD (and vice versa)
- **School challenges**
 - Emerging learning and mental health challenges
 - Safety and dignity
- **Transition to adult care system**
 - Establishing relationship with family physician
 - Building capacity in primary care



Central role of community physicians

**Early detection and
referral to intervention services**

Role in Autism diagnosis



**Liaise with pediatric specialties,
education and service system**

**Support and build capacity in
primary care, prepare for
transition to adult care**


Planning for transition to adulthood

- **Start early**
- **Involve youth in planning, decision making**
- **Plan for primary and specialty health care**
- **Plan for post-secondary education and vocation**
- **Lay groundwork for employment success**
 - Part-time work, volunteering, mentorship
- **Maintain social engagement; e.g., cultivate interests, and involvement in recreational activities**

ORIGINAL PAPER



“Best Things”: Parents Describe Their Children with Autism Spectrum Disorder Over Time

Katherine T. Cost¹ · Anat Zaidman-Zait² · Pat Mirenda³  · Eric Duku⁴ · Lonnie Zwaigenbaum⁵ · Isabel M. Smith⁶ · Wendy J. Ungar¹ · Connor Kerns³ · Theresa Bennett⁴ · Peter Szatmari⁷ · Stelios Georgiades⁴ · Charlotte Waddell⁸ · Mayada Elsabbagh⁹ · Tracy Vaillancourt¹⁰

Strengths based approach



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- Dev Peds, Comm Peds and GRH colleagues
 - Lyn Sonnenberg MD, Shannon Mah OT
 - AAPLES co-authors: Dr. Melanie Penner and Dr. Jessica Brian



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- Many wonderful children and families

