Ask the Doctor

Wendy Roberts, MD, FRCPC
Developmental Paediatrics
Professor Emerita, Paediatrics, University of Toronto
Hospital for Sick Children

Autism ONTARIO
see the potential

Objectives

By the end of the session, participants should be able to discuss:

- Newly acquired knowledge related to early signs of Autism Spectrum Disorder (ASD)
- Early intervention principles
- Medical problems including Sleep, Nutrition, Gastrointestinal problems and Toileting
  - Autism Speaks, Autism Treatment Network (ATN)Toolkits for medical care
- Competence building at all ages
- Communication strategies

Early ASD Trajectories

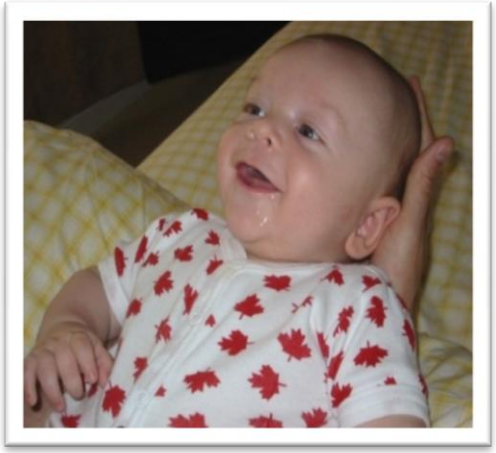
What do we see before 2?

‘Baby Sibs’ Studies in Autism

- Baby Siblings Research Consortium: 17 sites in Canada, US, Israel, UK
- Autism Speaks (and CIHR)
- Advantages of working with siblings
  - Higher risk = ++ascertainment
  - Can start observations in early infancy
  - Selection not based on clinical features
  - Highly committed families
  - Identification of ‘other’ learning needs in non-ASD sibs (language impairment, social anxiety)

CANADIAN 'INFANT SIB STUDY'

(ZWAIGENBAUM, BRYSON, ROBERTS, BRIAN, SMITH, SZATMARI)



- **Current participants**
  - 197 Controls enrolled to date
  - 552 Sibs enrolled to date
    - 377 Sibs seen at 3-yr "exit" assessment
    - 160 Sibs seen for 5-yr assessment
    - 40 Sibs seen for 8+-yr assessment
- **Assessed every 6 mo. to age 24 mo., independent diagnostic assessment at 3 yr (ADI, ADOS, DSM-IV) → 5yr → 8+ (blind Ax)**
- **Measures include:**
  - Behavioural signs: AOSI (6-18mos), ADOS (18mos+)
  - Language and cognition: Mullen, MacArthur CDI → WPPSI → WISC
  - Visual attention/ Temperament (Rothbart scales)

Pediatrics, Sept 1, 2011

- Ozonoff et al
- Recurrence risk for ASD: Baby Siblings Research Consortium Study
- N=664 siblings
- Overall recurrence risk **18.4%**
  - **25.9% in boys, 9.6% in girls**

ASD in Toddlers:
A Summary of findings from high-risk cohorts

- Social-communication/language
- Play interests and behaviour
- Visual attention
- Motor skills and behaviour

Social-Communication

- Atypical eye gaze
- Reduced social smiling
- Reduced social interest
- Reduced anticipatory responses
- Reduced joint attention behaviours
- Reduced expression of positive affect

[Bryson et al., 2007; Landa et al., 2007; Ozonoff et al., 2007; Presmanes et al., 2007; Zwaigenbaum et al., 2005]

Play

- Reduced imitation of actions
- Reduced interest in social play
- Repetitive actions with toys
  - e.g., spinning, rolling
- Prolonged/intense visual examination of toys and other objects

Bryson et al., 2007; Ozonoff et al., 2008; Wetherby et al., 2006; 2007; Zwaigenbaum et al., 2005

Motor Development

Delayed fine and gross motor skills

Landa et al., 2005; Zwaigenbaum et al., 2005, but also note Ozonoff et al., 2007

Repetitive/atypical motor behaviours and postures

Brian et al., 2008; Loh et al., 2007; Wetherby et al., 2006

ASD Red Flags at 6 Months

- **Subtle differences**
  - **Motor control**[2] (38%)
  - Reactivity[1] (34%)
  - Repetitive motor behaviours[1]
  - Atypical sensory behaviours[1]
  - Social interest/affect[1]
  - Eye contact (but 'typical' in 91%) [1]
- **But… most have <u>typical</u> social behaviours**
  - Reciprocal social smiling (95%)
  - Social interest and affect (90%)

[1]**ASD-Sibs > controls; p<.05;**

But: ASD-Sibs = Non-ASD Sibs

[2]**ASD > Non-ASD Sibs and ctrls**

ASD RED FLAGS AT 12 MONTHS[1]

- Social referencing (54%)
- Social babbling (44%)
- Reactivity (42%)
- Orient to name (41%)
- Atypical motor behaviour (38%)
- Social interest/ affect (37%)
- Eye contact (28%)
- Insistence (27%)
- Sensory (24%)
- Motor control (14%)

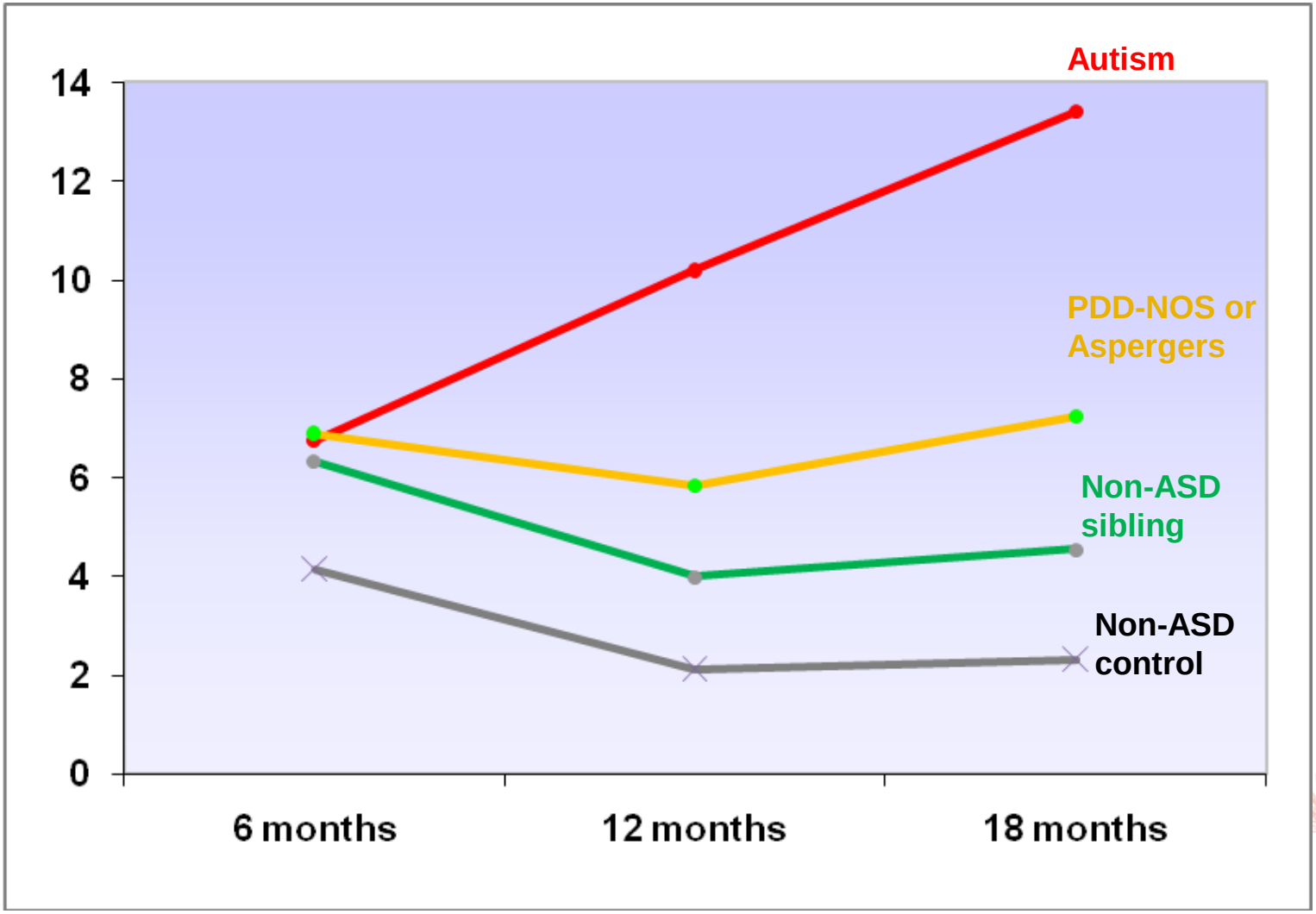
[1]ASD-Sibs>Non-ASD-Sibs and controls; p<.05

ASD RED FLAGS AT 18 MONTHS

- **COMMUNICATION**
  - Limited pointing, gestures
- **SOCIAL**
  - Reduced joint attention, social overtures, facial expressiveness, showing/giving, response to name
- **BEHAVIOUR**
  - Repetitive behaviours
  - Atypical sensory and motor behaviour
- **OTHER**
  - Transitions
  - Reactivity
  - Atypical motor control

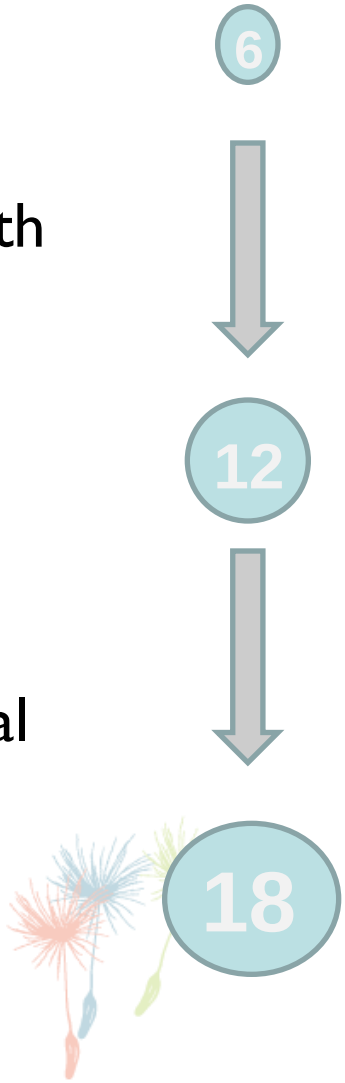
Sensory Interests

ASD SYMPTOM TRAJECTORIES (AOSI)



ASD Symptom Trajectories

- Difficult to identify behavioural differences specific to ASD at 6 months
  - Reduced motor control at 6 months associated with ASD *within high-risk group*
  - Sibs *as a group* > social-communication challenges than low-risk controls
- Differences emerge between 6 and 12 months
  - Eye contact, social interest/affect, reactivity, atypical motor and sensory behaviours
- Caveat: differences more subtle in children with PDDNOS and Aspergers; may be detected later



Challenges of Early Diagnosis

(Zwaigenbaum et al., *Pediatrics* 2009)

- **Limited clinical experience and research evidence base for reliability/stability of very early Diagnosis**

  Minimal data outside of highly specialized tertiary care setting (Chawarska et al., 2007)

  Outside of our 'comfort zone'

- **Minimum cognitive level needed to gauge typicality of critical developmental domains** (e.g., joint attention)
- **'Fuzzy boundaries' between ASD and other developmental disorders (especially in younger sibs)**
- **Experience to date suggests stability of early diagnosis is high, but sensitivity is low**

Diagnostic assessment for ASD: Challenges and Pitfalls

- Parents are the experts when it comes to their children, but they are not trained diagnosticians
  - Importance of eliciting detailed descriptions of the child's skills and behaviors rather than asking parents to make judgments about diagnostic criteria
- There is no *typical* case of ASD
- There is no symptom (or observation) that 'rules in' or 'rules out' a diagnosis
- Challenges at either end of the developmental continuum

Other Advances in Infant Studies of ASD

- **Neuroimaging studies**
  - Functional – ERP studies (e.g., Elsabaggh et al., 2008)
  - Structural – MRI/DTI studies (IBIS network, Piven)
- **Genetic and environmental risk factors**
  - **e.g., EARLI network, Newschaffer**
- **Early environment**
- **Links to intervention research**

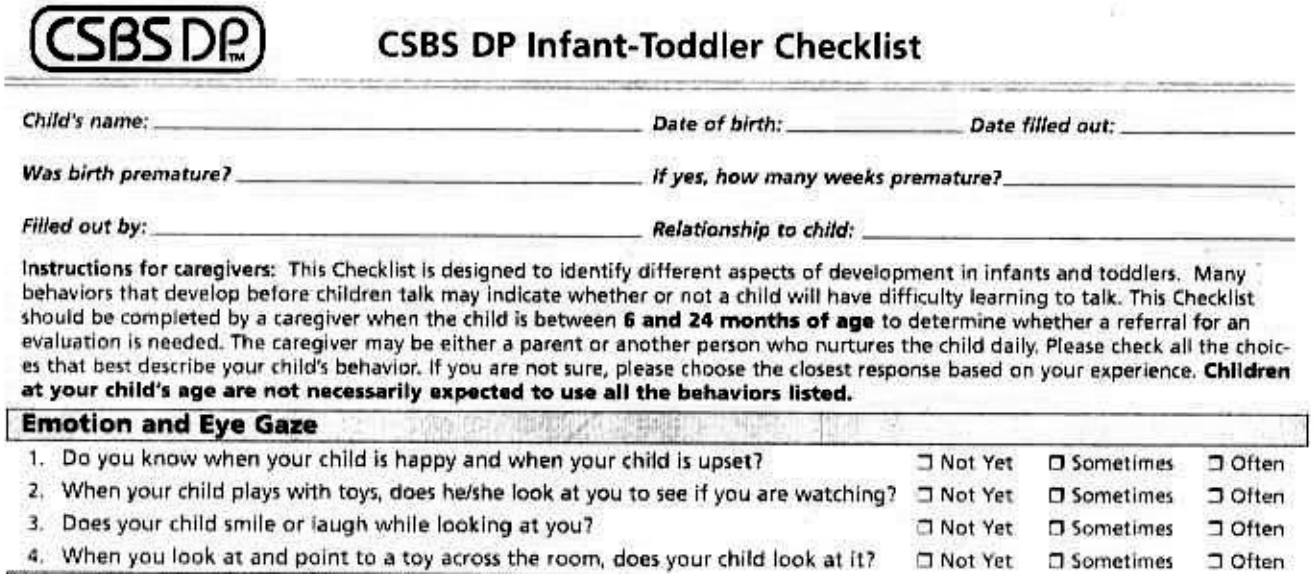
Early Identification

IF PREVALENCE is 1:88

Centre for Disease Control (2011)

- Everyone will be seeing more
- Enhanced 18 month visit in Ontario
  - Nipissing (NDDS) or ITC (Infant Toddler Checklist) from Amy Wetherby
  - Rourke Baby Record
  - MCHAT if ASD concerns
  - Play with child in standardized way

CDBS DP Infant-Toddler Checklist



CSBS DP™

CSBS DP Infant-Toddler Checklist

Child's name: _____ *Date of birth:* _____ *Date filled out:* _____

Was birth premature? _____ *If yes, how many weeks premature?* _____

Filled out by: _____ *Relationship to child:* _____

Instructions for caregivers: This Checklist is designed to identify different aspects of development in infants and toddlers. Many behaviors that develop before children talk may indicate whether or not a child will have difficulty learning to talk. This Checklist should be completed by a caregiver when the child is between **6 and 24 months of age** to determine whether a referral for an evaluation is needed. The caregiver may be either a parent or another person who nurtures the child daily. Please check all the choices that best describe your child's behavior. If you are not sure, please choose the closest response based on your experience. **Children at your child's age are not necessarily expected to use all the behaviors listed.**

Emotion and Eye Gaze

1.	Do you know when your child is happy and when your child is upset?	❒ Not Yet	❒ Sometimes	❒ Often
2.	When your child plays with toys, does he/she look at you to see if you are watching?	❒ Not Yet	❒ Sometimes	❒ Often
3.	Does your child smile or laugh while looking at you?	❒ Not Yet	❒ Sometimes	❒ Often
4.	When you look at and point to a toy across the room, does your child look at it?	❒ Not Yet	❒ Sometimes	❒ Often

Amy Wetherby, www.firstsigns.org

M-CHAT

- Modified Checklist for Autism in Toddlers
  (DL Robbins, 1999, 2008; www2.gsu.edu/~psydlr)
  - 16 months to 30 months (+)
- 23 item parent questionnaire
  - 6 critical items for autism: 2,7,9,13-15
  - Fail: 2 critical items or any 3 items
- Follow-up interview re: failed items **unless>8**
- Positive predictive value 0.57-0.65 for ASD
    - Higher for general developmental delay

M-CHAT™ Information

Robins, Fein, & Barton, 1999

Download iApp store: iAutism

www.mchatscreen.com

Best Practice Approach

- Screening/surveillance for early signs of ASD at all points of entry to health/developmental services
- Early referral for children with suspected ASD (but recognize that assessment may be inconclusive in children ≤ 24 months)
- Early initiation of child- and family-centred interventions targeted at specific functional concerns (*in parallel to diagnostic asst).

Acting on Red Flags

Best evidence to date:

– *Early Start Denver Model*

- *Dawson, G. Randomized controlled trial for toddlers with autism: The Early Start Denver Model. Pediatrics 125:No 1 Jan. 2010*

- *An Early Start for Your Child with Autism.* Sally Rogers, PhD, GeraldineDawson PhD, and Laurie Vismara, PhD

Very Early Intervention

- **Pivotal Response Treatment (PRT):**
  - Koegel, LK (2000). Interventions to facilitate communication in autism [Special Issue: Treatments for People with autism and other PDDs: Research Perpectives]. *JADD, 30*, 383-391.

Very Very Early Intervention Study:

Current Research: Bryson and Brian funded by Autism Speaks

- PRT principles (R. and L. Koegel):
  - Capitalize on child's **motivation**
  - Follow **child's lead**
  - Capture child's **attention**
  - Provide clear (communication) **opportunities**
  - Intersperse easier and harder tasks
  - **Reinforce all good (communication) attempts**
  - **Natural**, immediate and contingent **reinforcement**

Communication

- Communication can positively impact difficult behaviour
- Improved communication increases the likelihood that the child will participate in an interaction
- **Ensure** that the child has a way to intentionally communicate for basic reasons
  - Asking for things
  - Telling others to do things
  - Protesting
  - Commenting on things

Communication: *problems*

- **Frustration** – child uses behaviour instead of communication
  - Replace behaviour with communication
    - E.g., throwing toy/food → replace with "all done" gesture or word
- **No communicative attempts**
  - Parents should take an inventory of the most motivating snacks and activities → set up opportunities for requests or protests
- Child **loses interest** in communicating during an activity
  - Activity may be too difficult, language and communication demands may be too high

Social Play Skills

- Social Play includes any enjoyable interaction between people (without toys)
- Important part is to maximize time in face-to face interactions
  - Can be during daily activities (bathing, diaper changing, meal time, etc.)
  - Can be in parent initiated social games (pat-a-cake, peek-a-boo, songs)
- Success with early social games is important in the development of games with toys and later conversation

Social Play Skills: *Strategies*

- Parents should identify activities that are enjoyable to the child
  - **Persistence is the key -** the child needs time to learn how it works
- The child may need many examples at first
  - Start the activity → Wait for child to respond (looks at you, smiles, laughs, moves body, reaches)
  - Immediately continue the activity → wait again
- Promote imitation (e.g., action songs)

Social Play Skills: *Troubleshooting*

- Child is **not interested** in activity
  - Shorten the activity
  - Decrease the language
  - Repeat, repeat, repeat using the same order and the same language
  - Wait, wait, wait
  - TRY not to "teach"
- Child wants to do the activity on his/her **own agenda**
  - Participate in activity with only one change toward the end → then allow child to return to their agenda

Toy Play Skills

- Toy play is important in the development of symbolic language
- Knowing how to play with many different toys allows children to participate in play with children in other environments (childcare, school)
- Problem solving with toys is important in the development of some cognitive abilities
- Toy play follows a broad developmental course
- Avoid excessive contact with TV/video games, etc.

Toy Play Skills

- Identify enjoyable toys → remember many objects can be toys but encourage interaction
- Learning to play with toys is still *learning*
  - Begin with cause and effect toys
  - Toys with lots of action or music (spinning tops, bubbles, push cars)
  - Add conventional toys (e.g., shape sorters, ring stackers, puzzles, books)

- To teach pretend play → begin with child participating in "real life" versions of the activities then follow with "pretend" version

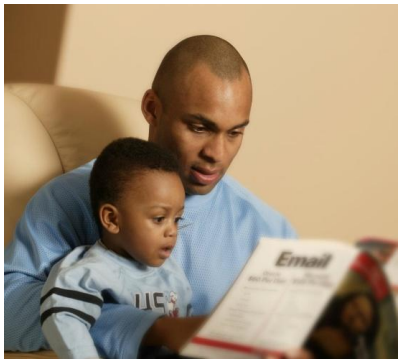
Toy Play Skills

Books

Parents can:

- "Share" a book rather than "read" a book with their child
- Begin with turning pages and being excited about what is next
- Use flap books and model "open" or "who is it?"
- Identify one particular object or character per page rather than many items with lots of language

Repetitive language/theme is usually good (e.g., that's not Maisy)



ABA in Autism:
RECOMMENDED PRACTICE

- Continue to refer to provincial IBI and ABA-based programs for children with ASD.
- Consider eligibility for IBI programming and varying wait times for other ABA-based programming.
- Push for "immediate" access to non-IBI options
  - Infant Development: Early Intervention services
  - Speech and Language Pathology
    - (eg Hanen: *More Than Words*)
  - OT, Play-based strategies (CCAC in school)
  - Play based programs with experienced clinicians

Parent and family group supports are often in Early Years Centres.

Autism Treatment Network by Autism Speaks

- Database
- Network of academic centres and community sites for autism care
- Mission:
  - to improve medical care for children and adolescents with autism spectrum disorder (ASD) and to standardize the care those individuals receive.

www.autismspeaks.org/atn

Recognize Medical Complexity

Areas:

- Gastrointestinal
  - GERD (Gastro-Esophageal Reflux Disorder)
  - Constipation
- Sleep
- Epilepsy
- Nutrition
- ***Genetic***

Autism Speaks

- Home » Family Services » Tool Kits

- **Based on QI INITIATIVES across ATN**
  - **CONSTIPATION**
  - **Toileting**
  - **GERD**
  - **AIMS FOR NEUROLEPTICS**
  - **Challenging Behaviors**
  - **Dentist office visits**

http://www.autismspeaks.org/science/science-news/pediatrics-supplement-autism-and-other-neurodevelopmental-disorders

www.autismspeaks.org/atn

Competence Building Over the Years

- One weekly activity outside the home
- Always add a new skill every few weeks or months that young person is aware they have gained
  - Self care, exercise and hygiene
  - Household support
  - Food preparation…one food > one meal
  - Time
  - Money
  - Community skills/safety

Increase independence gradually

Helt, Kelley, Kinsbourne, Pandey, Boorstein, Herbert, & Fein. Neuropsychol Rev (Dec 2008) 18:339-366.

1: Neuropsychol Rev. 2008 Dec;18(4):339-66. Epub 2008 Nov 14.

Can children with autism recover? If so, how?

Helt M, Kelley E, Kinsbourne M, Pandey J, Boorstein H, Herbert M, Fein D.

Department of Psychology, University of Connecticut, Storrs, CT 06268, USA. molly.helt@uconn.edu

Conclusions

- Prospective studies of ASD with high-risk infants have been informative for early behaviours and *patterns of development* predictive of ASD.
- Translation into clinical practice must take into account broader health systems issues
- Progress in early detection must be accompanied by efforts to establish developmentally appropriate and evidence-based interventions
- Promise of integrating behavioural and neurobiological studies to better understand early development in ASD, how to treat it and how to provide a continuum of care throughout the lifespan.

Resources

Autism Spectrum Disorder: Information for Parents: SickKids website

www.aboutkidshealth.ca/ResourceCentres.aspx

Autism Speaks

www.autismspeaks.ca (100 Day Toolkit)

An Early Start for Your Child with Autism. Sally Rogers, PhD, Geraldine Dawson PhD, and Laurie Vismara, PhD

Advances in the Early Detection of Autism

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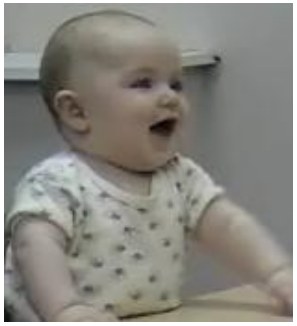

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