

Navigating the system after an autism diagnosis

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Autism ONTARIO
see the potential *voir le potentiel*

After this session:

- Participants will understand more about:
 - Coping with reactions to the diagnosis
 - Understanding the dimensions of ASD that will guide development of a management plan
 - What are reasonable components of the management plan in terms of available, affordable and manageable options
 - Access to internet information on reputable sites for a variety of information



After first hearing diagnosis

- Still the same child you loved yesterday
- Each of you as parents may feel very differently about what you have just heard
- Take time to get used to it!
- Then plan together
- Talk to someone you trust... Support from family and friends (or support group) will be critical going forward



Grieving the loss

Sudden versus suspected is more difficult.



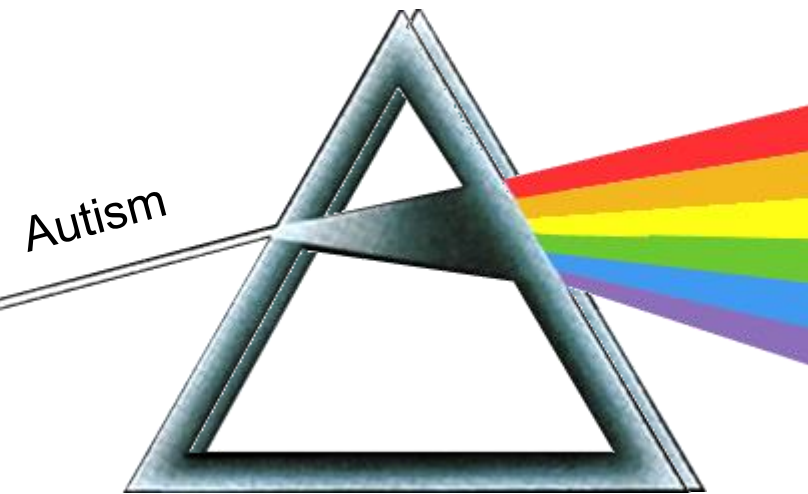
What you need to know

- How to go forward!
- Need to know
 - Something about child's spectrum dimensions
- How to set priorities
- Your region's services and funding sources... for you and your child
- Public versus privately available services





Spectrum Dimensions determine ability / challenge



Intelligence
Social reciprocity
Use of Language
Form of Language
Insistence on sameness
Stickiness/rigidity
Sensorimotor

Social Affect Sharing
Narrow interests including sensory and repetitive motor behaviors and mannerisms.

Lorna Wing, 1980
Georgiadis, Szatmari et al, 2012



Developmental History

Mental Health

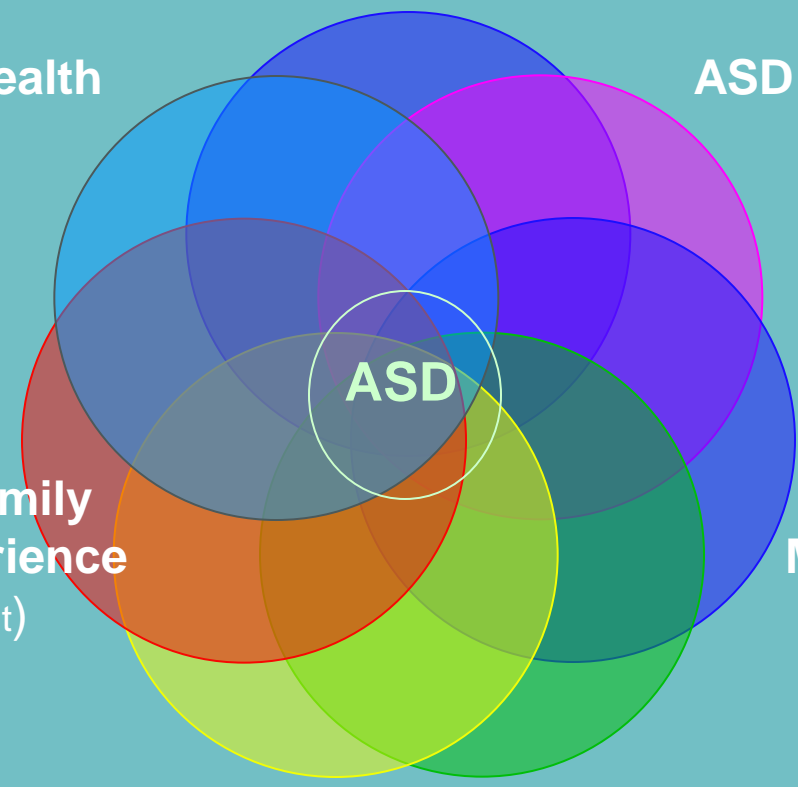
ASD symptoms

Individual and family
Differences/Experience
(e.g., temperament)

Medical Issues

Behavior

Cognition, Language and
Learning Style



ASD

What you need to know

- How to go forward
- Need to know
 - Something about spectrum dimensions
 - Communication (SLP)
 - Social awareness
 - Motor speech
 - Other Developmental stages: motor, self help
 - Sensory aversions and interests (OT)
 - Developmental Services (Early Intervention, Infant Development}
 - Medical: Seizures, genetics, GI, diet, alternate



Services by Spectrum Dimension

- **SLP:** Speech and Language Pathologist provides communication intervention
- **OT:** Occupational Therapist, sensorimotor intervention
- Early Intervention, Infant Development provide general developmental intervention advice and guidance re preschool services. Some have parent coaching re communication or behaviour.



Beware of:

- Therapists who say:
- I don't see ASD here!
- SLP who says: I can't help your child until he or she can talk!!! (Run the other way!)
- “She is too young to assess speech”
- His motor skills are fine! (What about his sensory system?)
- You must do it my way!!



Behaviour Therapy

- What does the evidence say?
 - Longest term evidence supports structured, repetitive, behaviorally based intervention working on behaviors to give optimal learning.
 - Based on principles of Applied Behavioral Analysis:
 - Antecedent > Behavior > Consequence



BUT.....

- Many early studies are flawed in terms of huge variation in who was selected, children's age of onset of therapy, severity of autism spectrum disorder, etc.



Current Ontario Behaviour Therapy

- ABA: Applied Behavioral Analysis
 - Ontario services for short term blocks of teaching using ABA behavioral principles for 4 skill categories: behavior management, daily living, social/interpersonal and communication
- IBI: Intensive Behavioral Intervention
- <http://www.children.gov.on.ca/htdocs/English/topics/specialneeds/autism/agencies.aspx>



New Evidence

- Most recent evidence for preschool age children starting in infancy, strongly supports a different way of using behavioral principles.

Naturalistic Developmental Behavioural Interventions (NDBI)!!



NDBI: Shreibman

- **Naturalistic Developmental Behavioral Intervention**
 - Starting in infancy if possible when first signs seen
 - Before diagnosis given or even confirmable!
(bypass waitlists)!!

Naturalistic Developmental Behavioral Interventions: Empirically Validated Treatments for Autism Spectrum Disorder

Laura Schreibman, Geraldine Dawson, Aubyn C. Stahmer, Rebecca Landa, Sally J. Rogers, Gail G. McGee, Connie Kasari, Brooke Ingersoll, Ann P. Kaiser, Yvonne Bruinsma, Erin McNerney, Amy Wetherby, Alycia Halladay

Journal of Autism Developmental Disorders, March 2015



Four common components in effective interventions

- Parent involvement in intervention, including parent coaching focused on responsivity and sensitivity to child cues and on teaching families to provide the infant interventions
- Individualization to each infant's developmental profile
- Focusing on a broad rather than a narrow range of learning targets
- Temporal characteristics involving beginning as early as the risk is detected and providing greater intensity and duration of intervention

(Wallace & Rogers, 2010, pg. 1300)



Ontario pilot programs

12 weeks of “red flag” or diagnosis based Parent Coaching

Validated NDBI Treatments for Autism Spectrum Disorder

- Dr Connie Kasari using **Jasper** model (Joint Attention, Symbolic Play, Engagement and Regulation)
- Dr Laurie Vismara using Infant Start from of **ESDM** program (Early Start Denver Model)
- Dr Amy Wetherby using **ESI*** Early Social Intervention based on Social Communication, Emotional Regulation and Transactional Support Model (SCERTS)
- Dr Jessica Brian using Social ABC’s

*The Early Social Interaction (ESI) Project by Woods and Wetherby (2003) is a comprehensive early intervention approach developed for toddlers with ASD and their families by incorporating evidence-based active ingredients

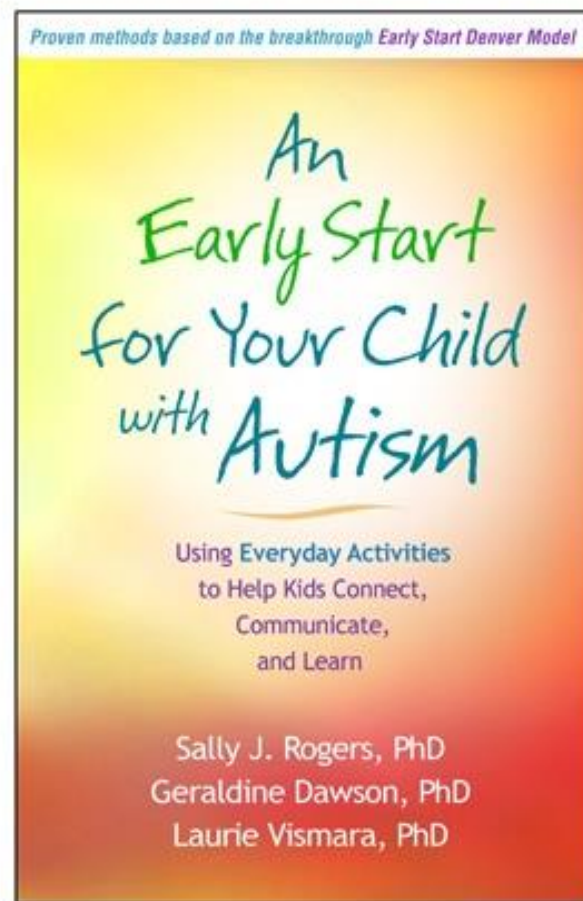
Starting in 2016



An Early Start

- Chapters 1-3: Coping with and understanding the diagnosis
- Chapters 4- 13: ESDM teaching topics
- Chapter 14: Putting it all together

- Rogers, Dawson and Vismara, 2012



Questions to ask a behavioral service provider

- Do you teach play skills?
- Do you coach parents to enjoy their child as the child learns how to play?
- How natural does your intervention appear? Does it look like play or table top teaching? If both, what proportion of each?
- How do you develop each curriculum to meet an individual child's needs?



Questions to ask a behavioral service provider

- How do you teach language?
- Does my child need to see an SLP and OT in addition to your programming?
- How does your team communicate with each other and with parents?
- For older child: How much of program is focused on daily living activities?



Sources of Potential Funding

- SSAH: Special Services at Home
- Assistance for Children with Severe Disabilities
- President's Choice Children's Charities
\$70000 cutoff. \$5000 every 5 years
- CRA Disability Tax Credit
- Jennifer Ashleigh no longer funds ASD



Sources of Information

- **Autism Ontario**...parent support, networks, regional chapters, networks and information about local services and funding
- **Autism Speaks**...Medical and Research links, Toolkits: e.g. toileting, sleep, gastrointestinal problems such as constipation and frequent stools, reflux etc.
- Government of Ontario Parent Resource Kit...publicly funded services available
- POND Research Network



When you understand local service picture:

- Prioritize your own child's needs
- Social communication is usually top priority
***unless there are severe behaviour and/or emotion regulation needs
- Do you understand sensory needs...if answer "No", get OT assessment
- If language seems further behind other skills, get knowledgeable SLP to assess communication and oral motor skills



When diagnosis is made at an older age:

- Good news if diagnosis could not be made until later age! May be positive dimensions that have changed developmental trajectory!
- More likely that social or generalized anxiety is now a significant factor:
 - May need treatment: CBT has most evidence
- Watch for bullying, academic challenges – it may look like anxiety or behaviour



Can my child recover?



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](#).

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Summing up

- Love your child for who they are.
- Intervention should help you enjoy your child more as well as communicate more, nonverbally as well as verbally.
- Get help to allow you and your partner to find time to talk each week, even over an undisturbed cup of coffee out of the house
- Get help with financial planning and accessing all the support you can!

