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Working with Neurodivergent Families: A Strength-Based Approach

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PHN-PREP Series

December 6, 2023

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“I am unique.
Why would
anyone think
just like me?”

AGENDA & Bottom Lines

1. Neurodiversity is DIVERSE
 - Understand some key cognitive & contextual domains
2. Neurodivergent parents' perspectives on healthcare, service delivery and parenting.
3. Create compassionate, trusting and strength-based models of parenting and family-centered care that are TAILORED for each neurodivergent client





#1 Neurodiversity

Understanding profiles and recognizing diversity

[illegible]

- [illegible]

[illegible]



What are Neurodiversity & Neurodivergence

- The term 'neurodiversity' was coined by Autistic sociologist Judy Singer in the late 1990s¹
- Refers to the idea that certain developmental disorders are normal variations in the brain.
 - They are not problems to be fixed, but more akin to differences to be accepted
 - Just because neurodivergent people think differently, does not mean that they do not face barriers in many aspects of society or otherwise need accommodation.
- Singer, 2017



Specific Neurodiversity Profiles

~ 15-20% of children have neurodevelopmental disability profile (U.S. Data)

- Autism/Autism Spectrum Disorder (ASD) :~ 2.0% adults
- ADHD: ~ 3% adults (8.6% children);
- Intellectual Disability: 0.5-1 %
- Specific Learning Disability: 5-10%
- Communication Disorders: 3-10%

• Antolini and Colizzi, 2023 (see for review); Cleaton and Kirby, 2018; Dietz et al. 2020; Espinet, S. D. et al., 2022; Frances et al, 2022; PHAC, 2022 ; Starck et al., 2016; Yang, Y., et al., 2022; Zhang et al., 2022

Remember

- 70% of conditions co-occur
- Symptoms can change over time
- Mental health problems commonly emerge more prominently
- Psychosocial stress more common than in neurotypically developing population

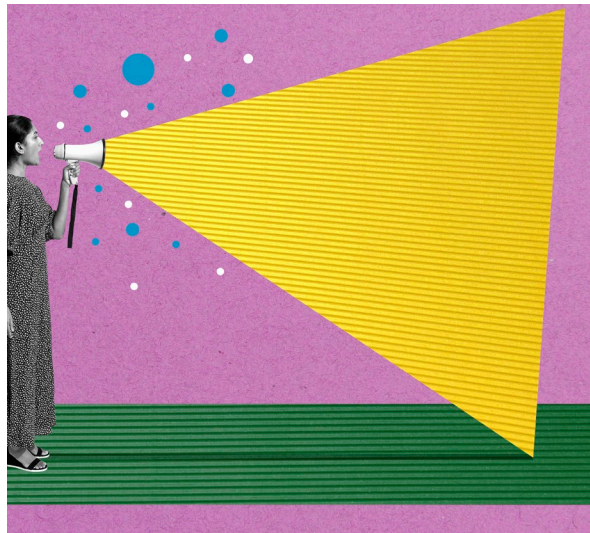
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Autism & SOCIAL COMMUNICATION



American Psychiatric Association, D. S. M. T. F., & American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders: DSM-5* (Vol. 5, No. 5). Washington, DC: American psychiatric association.



Autism: Sensory, Repetitive Behaviours, Routine, Interests

- American Psychiatric Association, 2013.

Autism & Co-Occurring Challenges

Language Impairment (50-70%)

Intellectual Disability (30-40%)

Mental health challenges (60-70%)

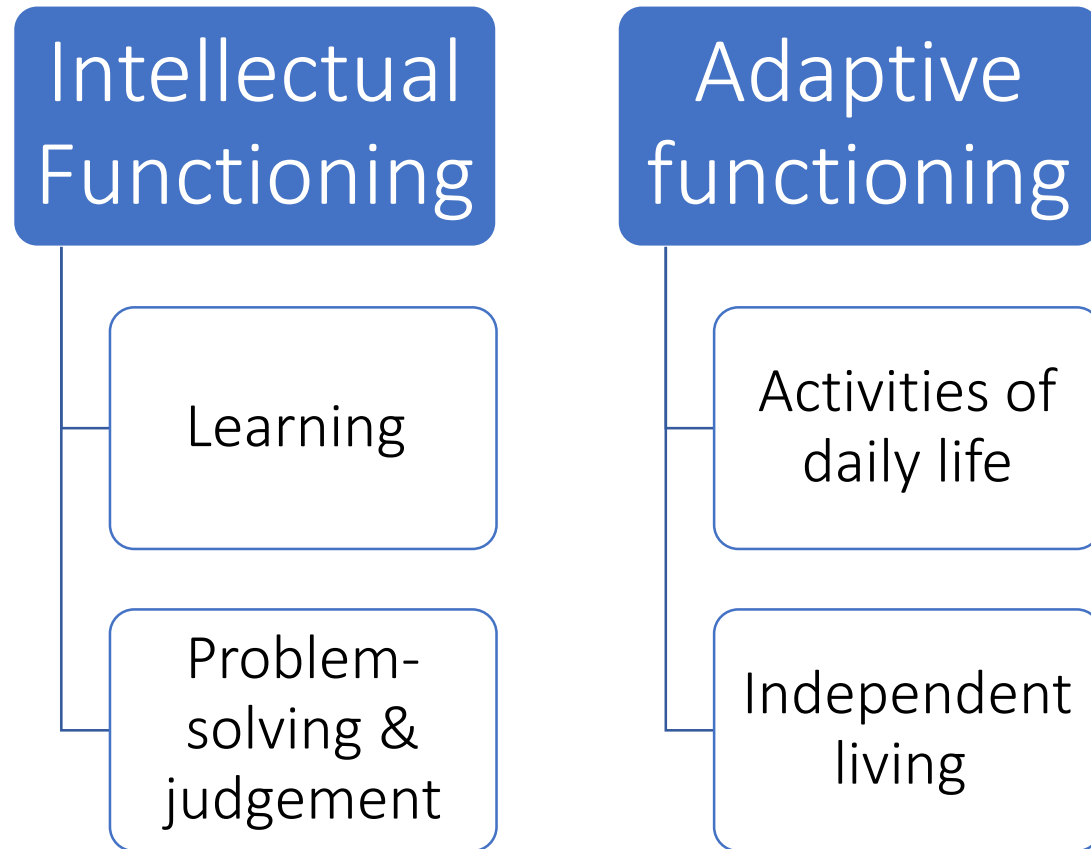
Daily living and adaptive skills

Executive functioning

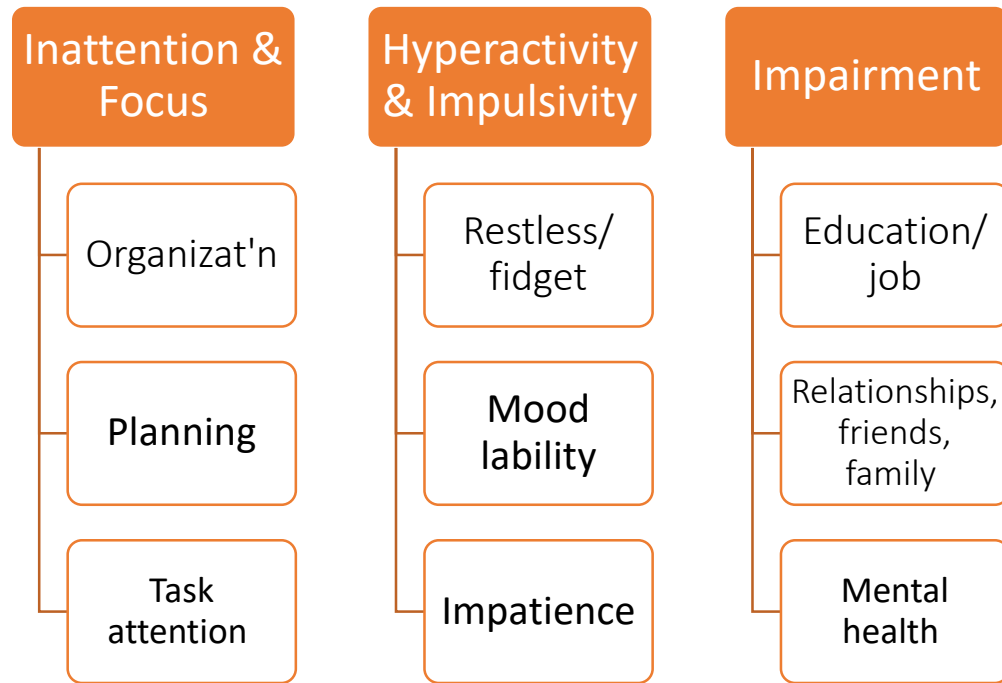


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Intellectual Disability



Attention Deficit/Hyperactivity "Disorder" (ADHD)



APA, 2013 Beheshi et al., 2020;

Summary: Key Profiles in Neurodiversity

1. Some key domains of difference:
 - A. Social communication & language
 - B. Sensory sensitivity
 - C. Executive functioning, routine & need for sameness
 - D. Emotional regulation
2. Diversity is also the rule
3. Mental health problems co-occur
4. Psychosocial context matters – (even more)



A man with dark hair, wearing a grey long-sleeved shirt, is sitting on a light-colored couch. He is holding a baby in his arms. The baby is wearing a black and white striped onesie. A large, fluffy, light-brown dog is sitting next to the man, looking towards the baby. The background is a simple, bright interior space with a window visible on the left.

#2 PERSPECTIVES of NEURODIVERGENT PARENTS

Canadian Survey, Quality Improvement and Research Reports

Perspectives from Autistic Parents¹

- **Legal**

- "I'm trying to raise two autistic boys on my own who have been abused and the abuse continues because where in our family law system is there a checkbox that says one parent is autistic but still good, loving, capable, does all the work, all the drives, pays for it all, works two jobs? the moment I input a disability my abusive ex has control of the children in spite of his criminal history."
- "I have concerns I could compromise my ability to go to certain countries, or that it could be used against me in regards to parental rights"

- ¹All quotes in this section are from Salt et al., (2023), in preparation

- **Medical Discrimination**

- "When I accessed health care for other things (eg pregnancy and childbirth, dentistry) I am selective about disclosing autism because I don't want my agency to be diminished by an ignorant or biased practitioner."
- "I feel that the last psychiatrist I was seeing didn't listen to me - I struggled to communicate what was happening in my head, and felt dismissed and that their agenda was to get me onto a specific medication [that I was on in the past and] was no longer effective)."

Perspectives from Autistic Parents

- **Pregnancy**

- "My sensitivity to odours really made a huge negative impact on my when I was pregnant with my daughter and in the year following her birth; I became hyper-sensitive to smells and most would cause me to feel nauseous (and vomit) and take my appetite away... it contributed to my disordered eating, I had trouble during and after my pregnancy to eat enough to not lose weight when entering the 3rd trimester and while nursing my daughter."

- **General Parenting**

- "I need help coordinating our family life. I don't know how I am supposed to manage 3 neurodivergent children with a neurodivergent spouse. It feels like life is so chaotic and we can never keep up."
- "Parenting an autistic child as an autistic adult. It's more common than I realized, but there are limited resources on the topic."
- "How do we explain to our children that we have ASD?"

Perspectives from Autistic Parents

- **Domestic Help**

- "I tend to forget to make food, or not have the spoons¹ to cook food for myself, so having someone else cook for me is often required."

- ¹<https://www.washingtonpost.com/wellness/2023/01/14/spoon-theory-chronic-illness-spoonie/>

- **Respite**

- "As an autistic single parent of a neurotypical child, I need more support! I need breaks from parenting, so I can work but ALSO so I can have time to decompress and recover from overstimulation."

Perspectives from Autistic Parents

- **Feeling Left Behind**

- "We need to address giving support for the families of autistic children, especially as one of the parents has a high probability of being ASD too."
- "I have an autistic child for whom I am the main caregiver. He is recently diagnosed and I am on the slow path to getting support for him. However I fear that even with support for him, I will not have the support I need to be healthy. There are a lot of autistic parents with autistic kids and no supports for us as a dyad. I am fortunate to have a good job but my mental health is precarious."

- **Support for their Children**

- "My child requires support but is lacking a diagnosis. He has now basically aged out of the supports outside of the school system ... Since he does not have access to the support he needs, I am unable to meet any of my own needs and am barely functional. The realization that I am also autistic has helped me make sense of a lot of things I have struggled with throughout my life, but now I find myself in a position where I am unable to support my child and myself at the same time."

Tips for Giving Information to Autistic Adults

Listen!

Ask them what they need/how they best understand

Be willing to communicate using multiple/different mediums

Ask for understanding


Be willing to repeat or rephrase, possibly multiple times

Give them time to formulate responses / process

Be prepared for follow-up questions but be careful of pre-empting them

Understanding Accessibility of Mental Health Services for Parents with Intellectual or Developmental Disability (IDD): Clinical Quality Improvement (Raso & Bennett, 2022)

BARRIERS IDENTIFIED FOR PARENTS WITH IDD

- 
1. Difficulty understanding the process for accessing treatment for their child
 2. Feeling that intake processes were too long
 3. Difficulty understanding the content of family-focused treatment
 4. Difficulty sharing or defending new concepts to other adults in the child's life.


Themes from CQI

1. Tailoring the way content is delivered to parents with IDD
2. Providing these families with more individualized support
3. The clinician as advocate for the parents
4. Leveraging parents' own supports such as a grandparent or support person
5. Providing material support to parents where possible.



Tips for effective communication:

- Use role-playing
- Give specific examples
- Incorporate videos and visuals
- Keep sessions brief
- Simplify language
- Avoid relying too much on reading

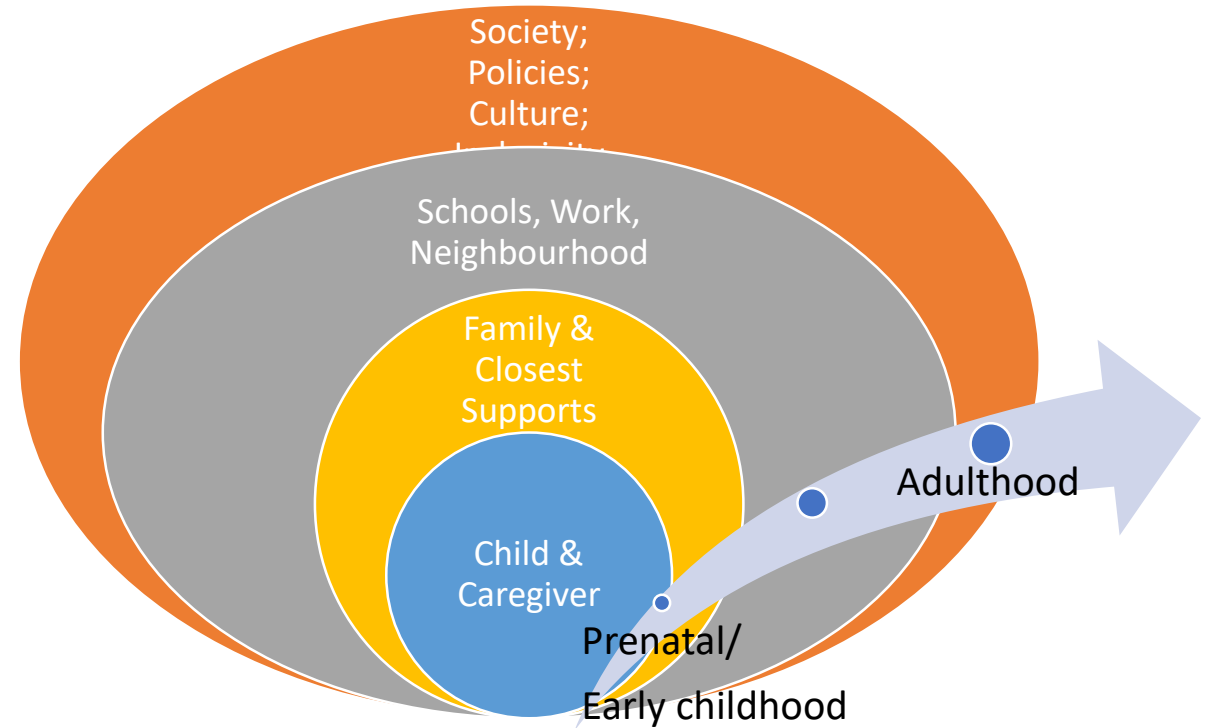
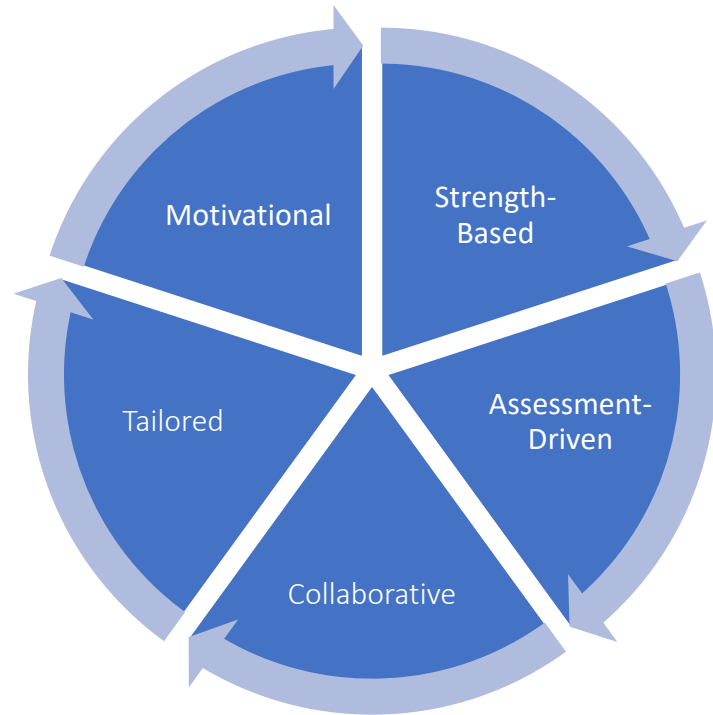


#3 Building a Strength-Based, Trusting & Collaborative Relationship

Motivational Interviewing and the
Developmental-Ecological Model of
Care



Towards Developmental-Ecological Models of Care





Motivational Interviewing: The Skills of OARS

OARS (Open-ended questions; Affirmation; Reflection; Summary)

- **Open-ended Questions** (*with Follow-Up as Needed*)
 - Draw out and explore the person's experiences, perspectives, and ideas
 - **ELICIT:** first explores what the person already knows
 - **PROVIDE:** then *seeks permission* to offer what the practitioner knows
 - **ELICIT:** then explore the person's response to the information provided



-
- **E:** *"You mentioned that you sometimes find it hard to read others' emotions. How have you found this with little Frankie? "*
 - **P:** *"that's a worry a lot of us can have with our first babies... Can I share a tip? "*
 - **E:** *"What would it be like for you to try this with Frankie? "*



The Skills of OARS

- **Affirmation**
 - Help notice parent strengths, efforts, collaboration, past successes
 - Help to build the person's hope and confidence in their ability to change
 - *Remind ourselves as clinicians to look for the strengths of neurodivergence in child-rearing*





"I appreciate that you are willing to meet with me today. That took some real trust given your past experiences. "

"You are clearly connecting with Jeremy's need to be his own person! "

"You learned, sometimes the hard way, about "camouflaging" as an autistic person... and you want to help your kids be proud of their uniqueness."

"You reached out for help, even though that has been hard for you in the past."



The Skills of OARS

- **Reflections**

- Based on careful listening
- Trying to understand what the person is saying, repeating, rephrasing or offering a deeper guess about what the person is trying to communicate
- Foundational to how we express empathy
- ****Tailor** this to the relationship – be mindful of how reflections “land” with different people, be humble and careful, repair clearly if you miss the mark*

-
- ***It sounds like ...****you want help from your mother, but you also want her to respect that you're a Mom too now and you want to feel in charge.*
 - ***So you feel *...****you're a bit overwhelmed with all these people giving different directions!*
 - ***You're wondering if *...****You can let people know this without pushing them away...*

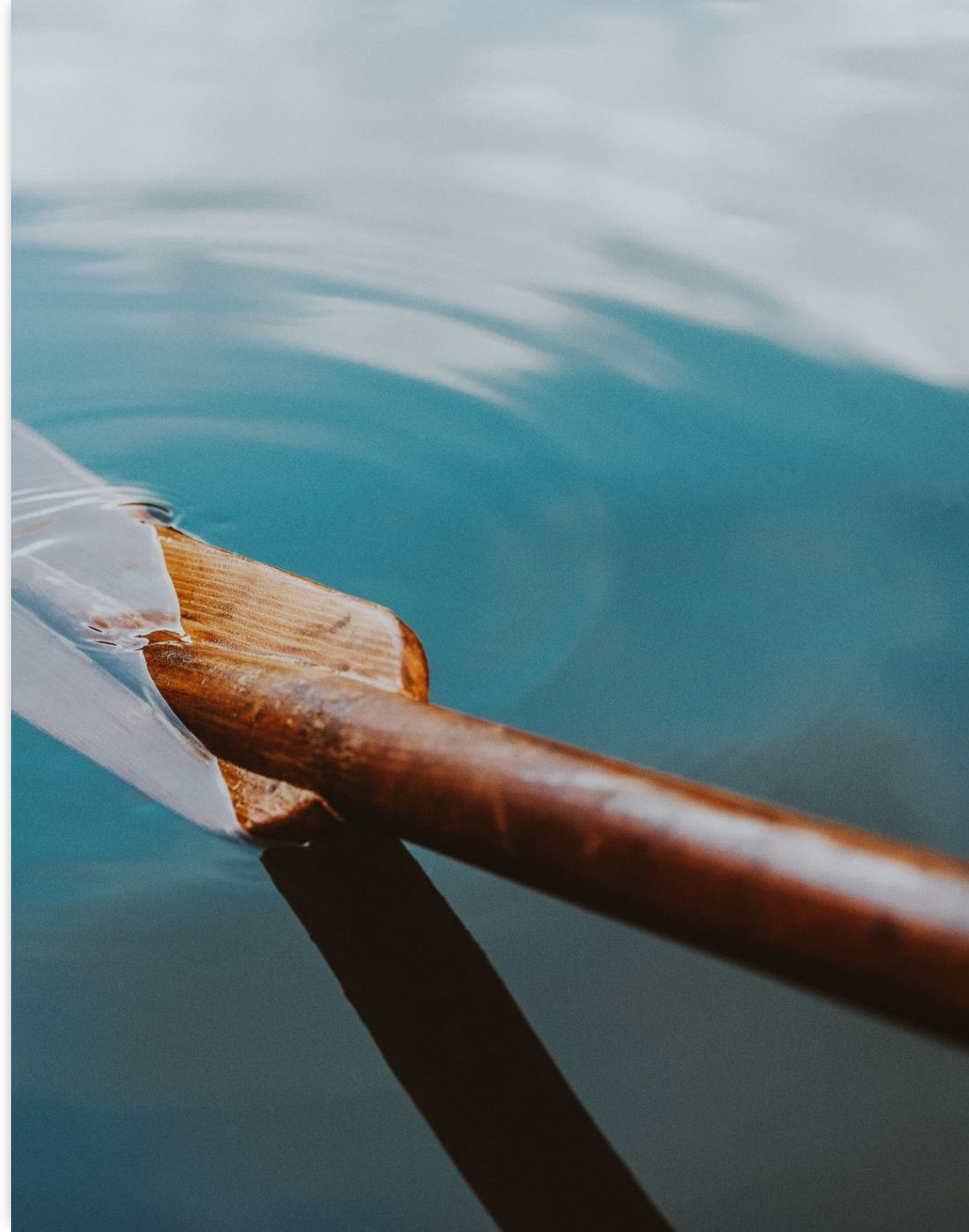


The Skills of OARS

- **Summarizing**

- Ensures shared understanding and reinforces points made by the client
- *Consider building in multiple media, leaving summary sheets*

- *Let me see if I understand so far.....*
- *Here is what I've heard. Tell me if I've missed anything.....*

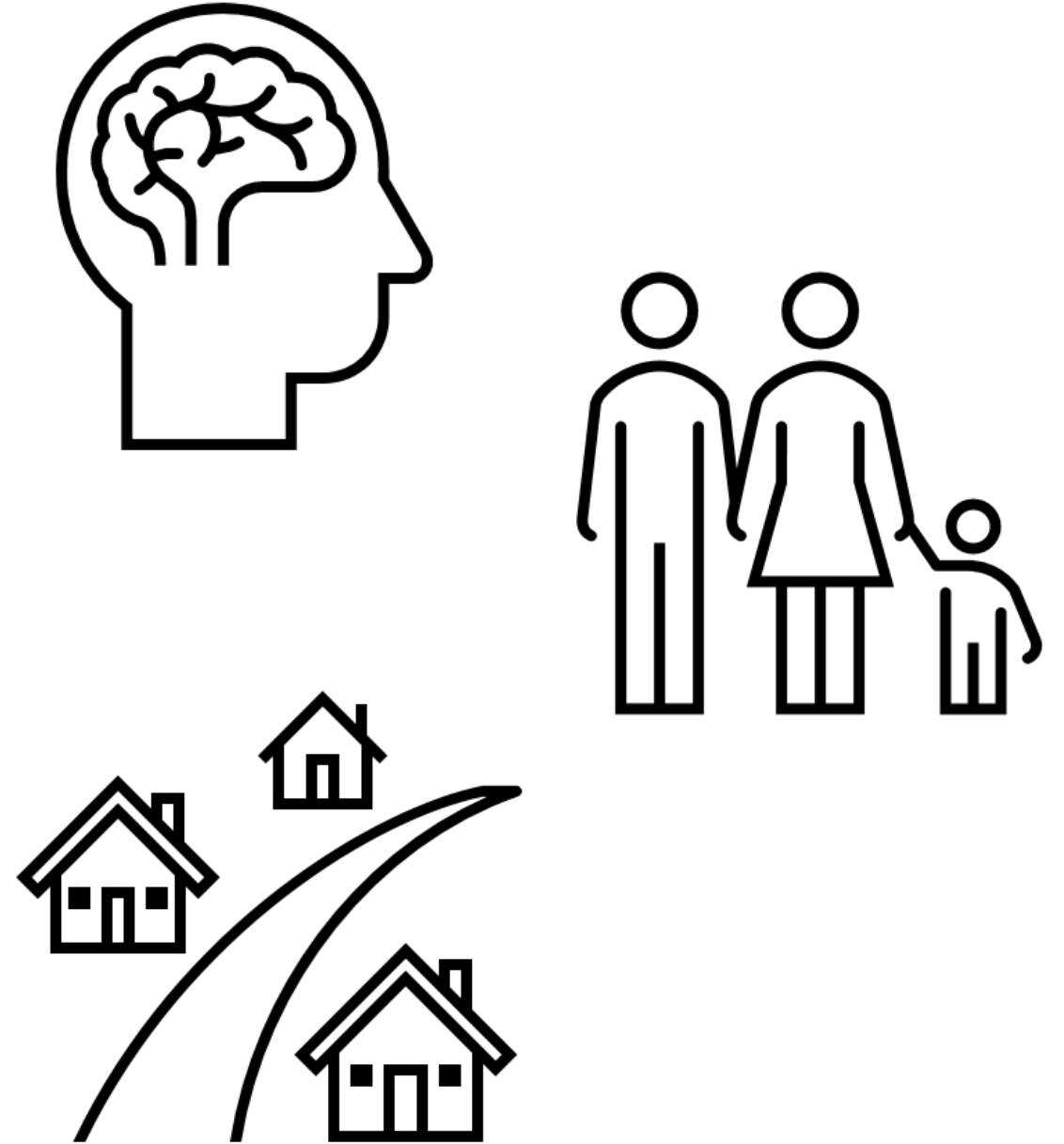


Pulling it all Together: Tailoring Family Support for Neurodivergence

PERSON (neurodivergent
profile, mental health)

RELATIONSHIPS & SUPPORTS
& PARENTING

PSYCHOSOCIAL CONTEXT,
BARRIERS, SOCIAL
INCLUSION





Bottom Lines

1. Remember: Neurodiversity is DIVERSE
2. Understand some key cognitive & contextual domains
3. Ask about neurodivergent parents' perspectives on healthcare, service delivery and parenting.
4. "Bake" an open, trusting and strength-based model into your everyday practice
5. Tailor and deepen the tools you have

THANK YOU!

- **Our FACT Family Advisory Committee and RJCHC Family Advisors**
- **Family Check-Up and Mental Health clinicians**
- **Our participating families**
- **Ron Joyce Children's Health Centre Leadership**
- **Our clinical research co-investigator teams**
- **Our Funders:**
 - **Kids Brain Health Network**
 - **HHS Foundation**
 - **Autism Alliance of Canada**
 - **Laidlaw Chair in Patient-Centered Care**
 - **Physician Services Incorporated (PSI) Foundation**



Advancing autism care through meaningful research



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