



# Exploring Why & Where Culture Matters In Working With Diverse Children And Youth With Autism And Their Families

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**Autism**ONTARIO

*see the potential*

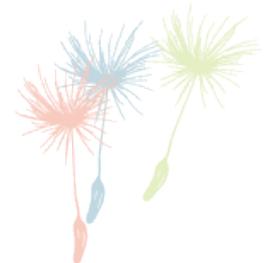
*voir le potentiel*

# Current Advocacy Work

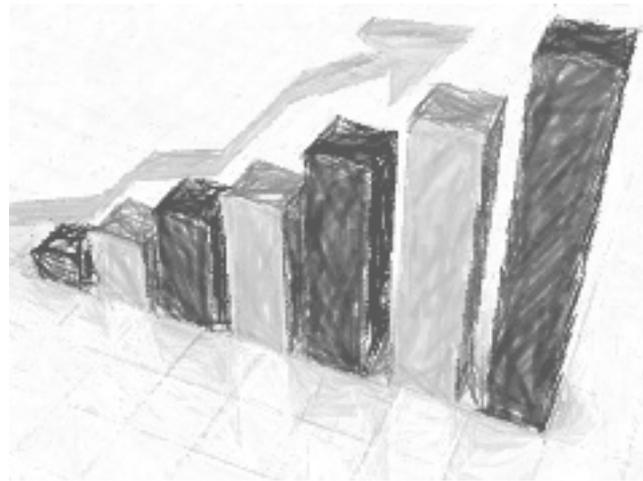
Board Member, SAAAC Autism Centre

Treasurer, PONDA Network

Executive, Developmental Pediatrics  
Section (Canadian Pediatric Society)



# Why Discussion And Reflection Matters On This Topic?



Disparities in access to diagnostic and treatment services for autism in low-income and ethnic minority families



# With Globalization...

There is an amplification of the movement of services, ideas and people across borders

Leads to diversification and standardization across many domains

Thinking about curricular and educational practices, along with training and delivery of service



# Engaging In Critical Reflection

**THEORETICAL CONSTRUCTS &  
ACADEMIC RESEARCH**

**APPLICATION OF  
INTERSECTIONALITY &  
REFLEXIVITY**

**DAY TO DAY  
PRACTICE**



# Situating Myself

I am an academic Developmental Pediatrician working in Hamilton, Ontario, with a primary focus on autism diagnosis and identification

I identify as a second-generation Canadian of immigrant parents from Pakistan and a Muslim

I spent part of my youth in the Middle East

I have lived in Oakville, Mississauga and Toronto

...

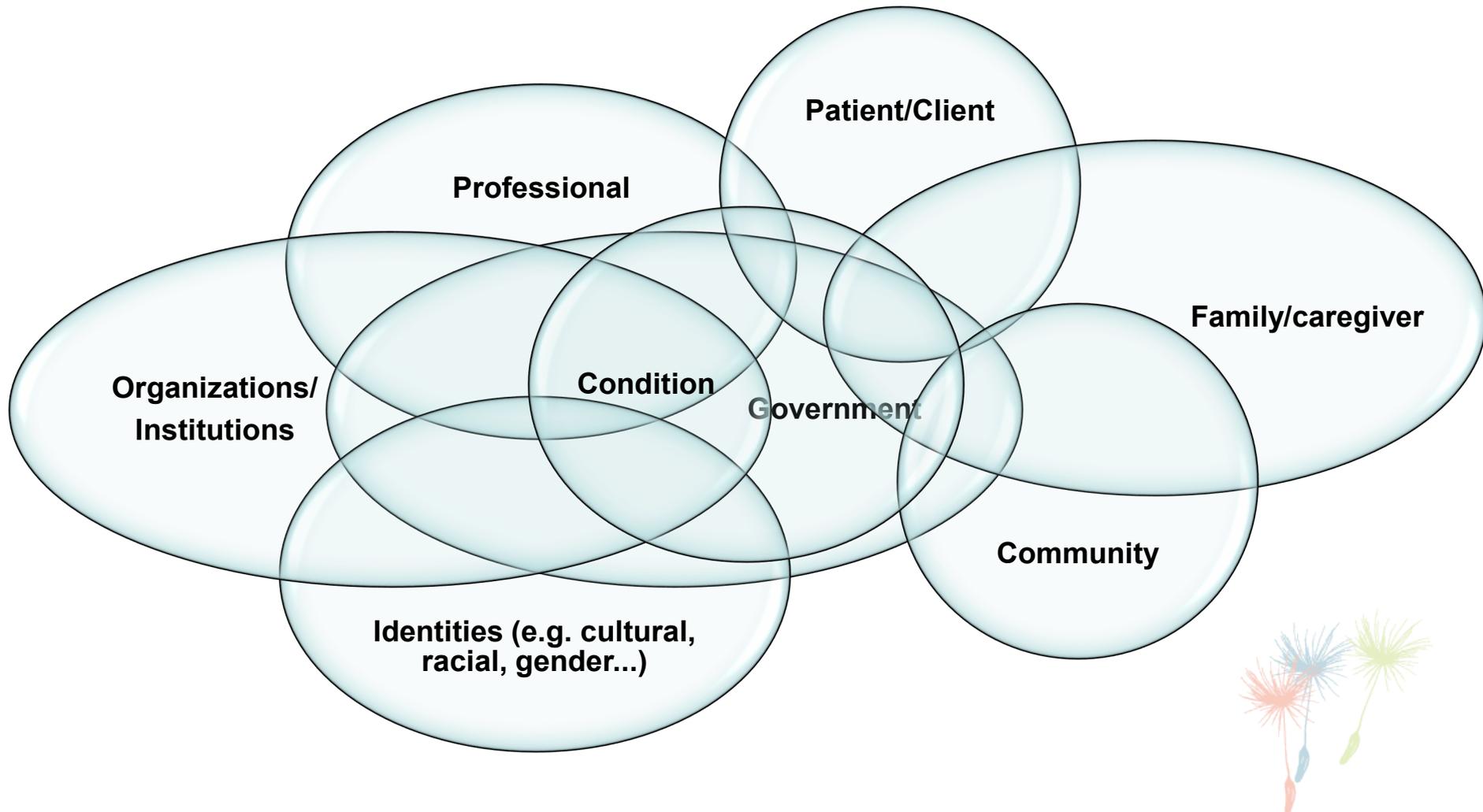


# As I Started Sharing With Parents And Caregivers...

I often wondered what families did with the information I was giving them during a clinical visit, including my explanation of how I had come to a diagnosis of autism



# A Complex Web



# Encounters with Culture in Day To Day Practice

How we think about our professional encounters with diverse children and youth with autism and their families/caregivers?

**A Cultural Encounter vs.  
All Encounters as Cultural**



# Visible vs. Invisible Elements of Culture

The term 'culture' encompasses many elements

Visible elements may include: our accents, our outward appearance and dress, our names

I've identified some parts of myself, including my story (history), which may suggest but not confirm my values, beliefs, experiences and practices (invisible elements)



# Cultural...

How can we begin to explore and become more aware of the invisible elements of culture, and their relationship to our day to day practice?

**Cultural Sensitivity**

**Cultural Humility**

**Cultural Competency**

**Cultural Safety**

**Culturally and Linguistically Appropriate Healthcare**

...Others?



# Challenges & Gaps

(Lindsay et al, 2012; 2014)

Specifically among pediatric providers:

Language barriers & use of interpreters

Discrepancy between cultural orientations

Gender & generational differences

Lack of resource knowledge

Difficulty building rapport and trust



# The Language We Use & How It May Be Interpreted

How we talk about 'typical' or 'normal' development?

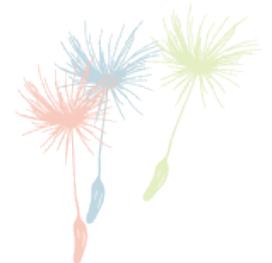
How we talk about areas of development such as:

- Social communication

- Restricted/repetitive behaviors and interests

- Adaptive functioning

- Cognitive capabilities



# Example: Pragmatic Language Abilities (Carter et al, 2005)

“Discourse rules, such as turn taking, interrupting, appropriate topic choices, use of eye contact and other nonverbal strategies for maintaining interaction, use of humor, and the ability to question and challenge communication partners, are largely determined by cultural rules and the child’s relationship with his or her interlocutor.”



# Example: Values Around Development

(Norbury & Sparks, 2013)

“The degree to which an outcome is disvalued by a culture may be gauged by the extent to which caregivers feel compelled to intervene and assist a child in developing a particular skill.”

“Practitioners need to start from the family’s point of view and try to discover what, if anything, family members are worried about and what they value and disvalue about child language, behavior, and education.”





# Where, When And By Whom?

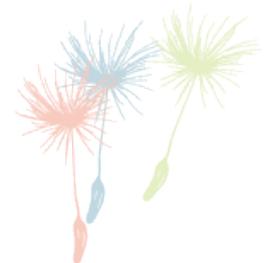
Context & process

Interview style

Assessment tools and their development

Therapeutic techniques

Biases in identification process



# Helping Families Digest Information

Who has the responsibility to help families digest information?

I have recently been humbled by one particular experience

Thinking about the process on a continuum

Describing vs. labeling





# Learning & Best Possible Collaborations

Consistency across different environments, including home, school and assessment/therapy services

E.g. in the US among Somali families thinking about school-based autism treatments (Sweeney, 2018):

Who provides intervention?

How a proper education is conceived?

How to help prepare for the future?

Recognizing child's strengths?

Communication between providers?

Options for treatment?

Experience of racism or discrimination?

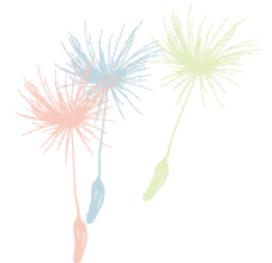
Trust?



# Some Of My Research Findings

(Work In Progress)

1. We don't go there, so let's try going there (individually and institutionally)
2. Conflicts often shine light, so shine the light before the conflict
3. Narratives matter, so go "off-script" with your client



# Professional Factors

Personal experiences

Training (& training contexts, including diversity of staff)

Awareness of biases

Communication skills

Diagnosis as priority (biomedical knowledge & gold standards)



# Context And Discursive Factors

Institutional practices

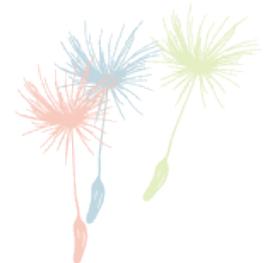
Patient and/or person-centred care

Multiculturalism

Patient safety and ethics

Socio-political events

Patterns of movement of people globally





# Final Thoughts: Addressing Barriers

(Nowell et al, 2015)

“Focusing recruitment efforts such that persons of diverse backgrounds are encouraged to study/train in the area of ASD is vital for the field.”

In addition to addressing:

- Financial concerns
- Transportation issues
- Time constraints
- Cultural mismatch between families and providers
- Access to trained providers



# Thank you

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