

# Including Sensory Dysregulation in Every Diagnosis of FASD

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# Conflict of Interest

- None to declare

# Learning Objectives

- Recognizing the developmental variability of sensory difficulties in this population
- Recognizing that sensory dysregulation is found in almost all of those diagnosed under FASD
- Recognize that sensory difficulties are but one factor which directly influence behaviour
- Learn how to diagnose with or without specialized OT support

# What we know about brain development\*

- Brain development starts in utero and may be influenced by many factors such as:
  - Genetics, including structural abnormalities
  - Diet and health of the mother during pregnancy
  - Exposure to teratogens including, alcohol and drugs/medication and/or infections/viruses
  - Epigenetics (grades the response to the above factors)
- Brains are built from the bottom up-sensory and motor development mature 4 to 5 months after birth.
- Cognitive, social & emotional development are inextricably intertwined (emotional regulation)

\* Levitt, P. 2016

# What else do we know..

- Genes and experience together build brains
- Expansion of the cerebral cortex is what makes us human (10 billion neurons; 3 billion connections)
- The hippocampus can produce new neurons but otherwise the brain does not make new neurons after birth—only synaptic connections change.
- Maximum #of connections are formed by 3 yrs and stabilize by 7 to 10 yrs. These connections are pruned in adolescence (10 to 20 yrs).

# What we know about FASD and the brain structures it affects

- Cerebral Cortex: Includes functions of Sensory and Motor control; Cognition and abstract thought; Working Memory; Speech and Language; Visual and Hearing perception. \*Executive functioning which is dependent on working memory is associated with the pre-frontal cortex.
- Cerebellum: Controls motor skills, balance and co-ordination. Hasn't completed it's development at birth. It also helps provide cognitive processing, acquisition of language, task sequencing and time perception and estimation. Children with FASD are dysfunctional in each of these tasks.
- Caudate Nucleus: Part of the basal ganglia. Important role in motor function. Also important in cognitive function, motivation and executive function (ability to plan and execute specific tasks) \*\*Basal Ganglia + Cerebellum = Cognitive and Attention tasks

Zieff et al., 2016

# Other brain structures affected

- Corpus Callosum: Most consistent deficit with FASD. Important in timing tasks, motor tasks and co-ordination. MRI studies indicate that the damage to the corpus callosum is associated with verbal learning abilities.
- Hippocampus: responsible for learning and memory, along with the cerebral cortex.
- Attention- regulated by parietal cortex
- Judgment + Impulsiveness: orbofrontal Cortex
- Mood, anxiety and emotions: amygdala + cerebral cortex

Zieff et al., 2016

# The Brain and Sensory Dysregulation

- Recent studies in sensory processing disorders demonstrate:
  - Abnormalities in the white matter that contribute to perceiving, thinking and learning.
  - Primary areas involved are the back of the brain serving as connections for the auditory, visual and tactile systems.
  - Integrating information across multiple senses becomes challenging. (Owen et al., 2013)

“Top down” executive functioning skills need to balance the “Bottom up” sensory information coming in through the spinal cord. When the brain is compromised as in children with FASD it becomes challenging for them to regulate their responses to incoming information.



# New Canadian Guidelines

## *FASD with/without Sentinel Facial Features:*

Includes evidence of impairment in 3 or more of the following central nervous system (CNS) domain

- *Motor Skills*
- Neuroanatomy/neurophysiology
- Cognition
- Language
- Academic achievement
- Memory
- *Attention\**
- Executive functioning, including *Impulse Control\**
- *Affect Regulation\**
- *Adaptive Behaviour, Social Skills, or Social Communication*

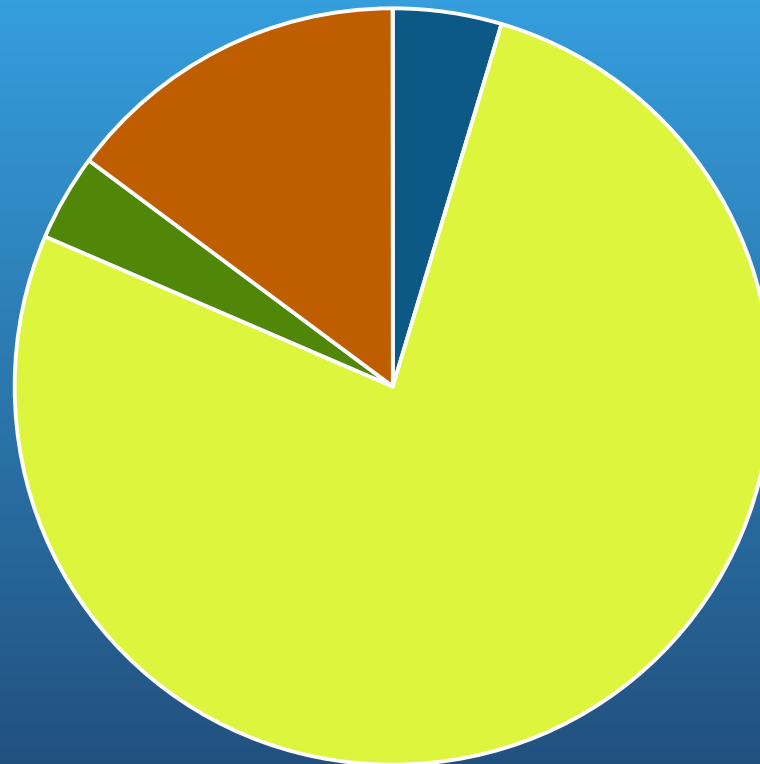
# 3 Ontario Diagnostic Clinics Criteria

- Inclusion criteria: confirmed PAE for two clinics
  - One has confirmed PAE or 3/3 facial features or MD specifies that lifestyle and presence or absence of features is sufficient to warrant a Dx.
- One clinic only sees children 7 years and under
- Two clinics see children from birth to under 19y
- All clinics have full multidisciplinary teams (OT, SLP, Psychometry, Paediatrician)
- Two clinics have Neuropsychology with Brain Injury diagnostic experience
- One clinic uses FASD Facial Analysis Software

# Sample Across 3 Ontario Diagnostic Clinics

- Original N (135) reduced due to unable to contact a number of families as well as no consent obtained from a few.
- Final sample for this project was N=108
- All 108 had confirmed PAE with 81.4% receiving a FASD Diagnosis
- Combination of old guidelines and new guidelines for diagnoses
- Only one clinic had significant number of no diagnosis given, one other had most of the Deferred Dx and other had 100% diagnostic rate

# FASD Diagnoses (81.4%)



□ FASD w SFF   □ FASD no SFF   □ Deferred   □ No Dx

# FASD without Sentinel Facial Features (SFF)

- Total = 83/108 (77%)
- pFAS = 12%
- ARND = 69.8%
- FASD without SFF = 18.2%

# Other diagnoses jointly given with FASD (10%)

- Intellectual Disability= 63%\* (7/108 or 6% of N)
  - Only one of this group with FAS
- ASD = 12.5%
- GDD = 12.5%
- TBI = 12.5%\* (only one clinic requests this data)

# Clinic with 100% Diagnostic rate

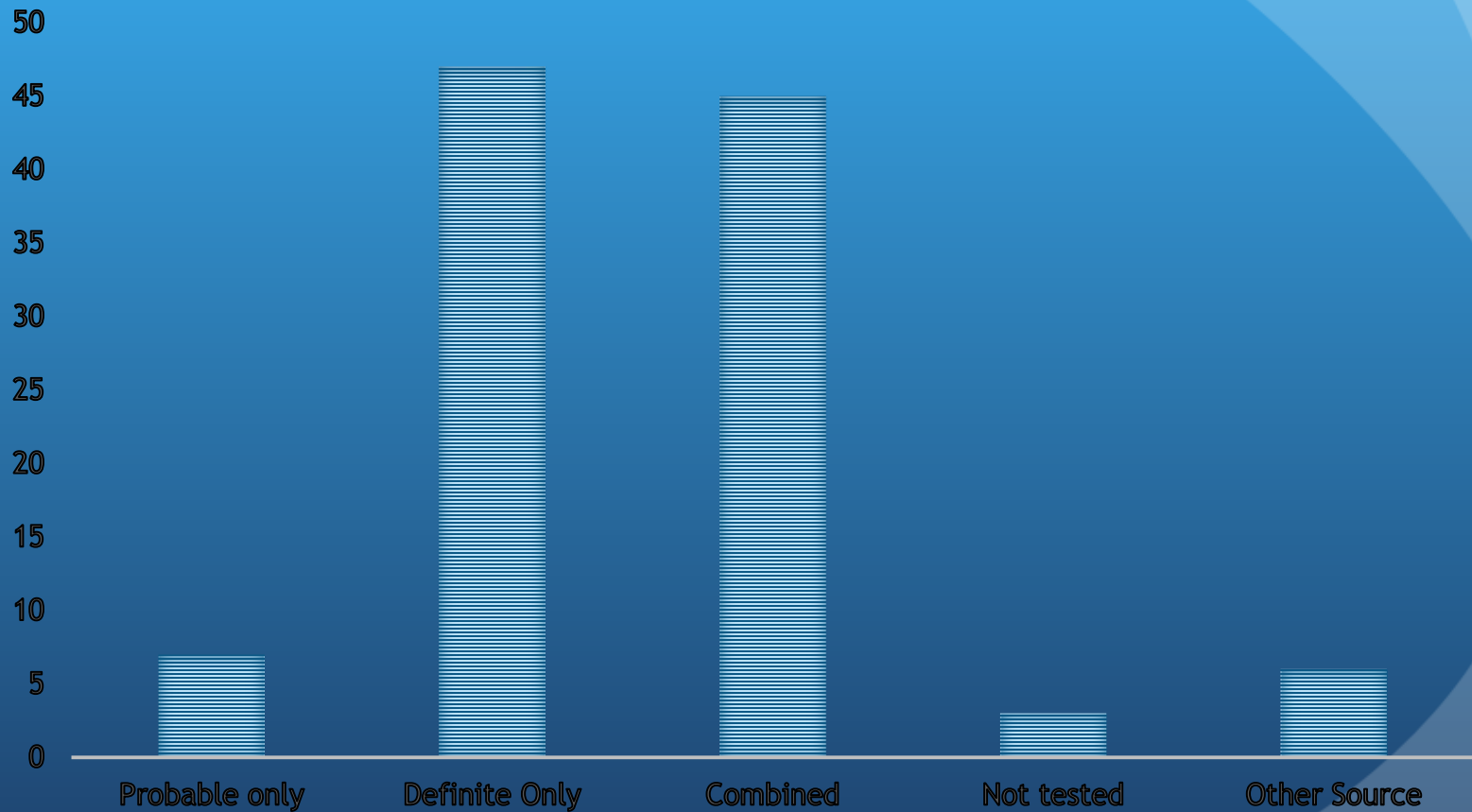
- N=43
- FASD with SFF = 5%
- FASD without SFF = 95%

# Sensory deficits across 3 clinics

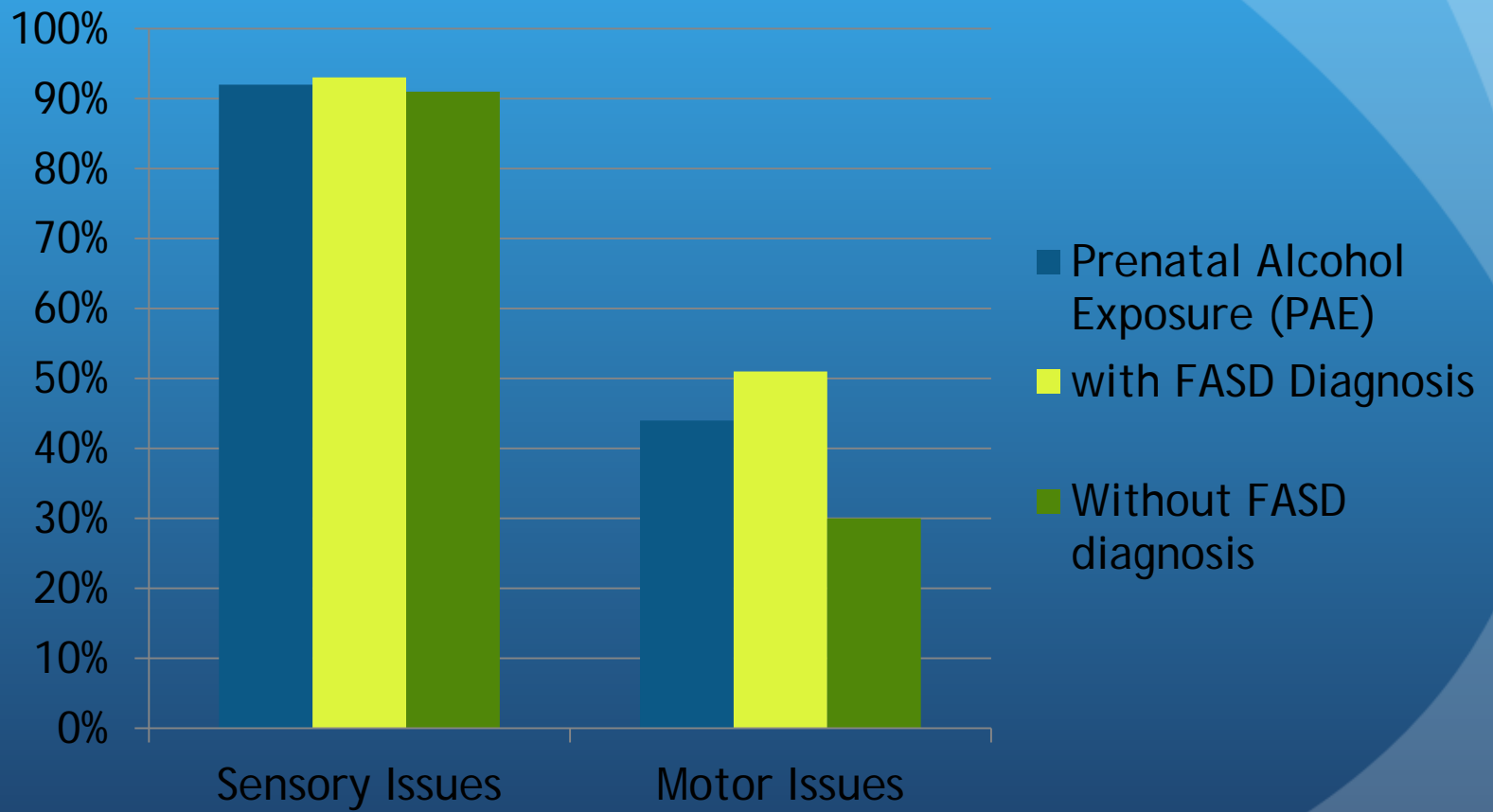
- Of entire sample 97.2 % had some sort of sensory deficit
- Of those 94.4% were assessed by an OT
- And 5.6% were diagnosed by Neuropsychologist independently of OT



# Sensory Deficits from all Clinics



# Results from Children Assessed through the Peel and Waterloo FASD Clinical Teams over the past 10 years (N=62)



# Dysregulation

- Definition of Self-Regulation:
  - The ability to stay calmly focused and alert. Allows us to integrate information coming in through our senses; assimilate it and sequence our thoughts and actions.

(Shanker, 2013)



# Dysregulation

- Foundation of regulated brain
- Sleep
- Sensory Processing
  - “Children with compromised sensory processing may be unable to learn efficiently; regulate their emotions or function at an expected level in daily activity” (Ayres, 1979)

# Dysregulated Brain

- Can't organize all incoming information
- Can't organize information once its in
- Can't organize information for output
- Leads to significant Frustration

# Dysregulation



# Sensory Dysregulation

- perceives all sensory stimuli as arriving with variable intensities
- no filters to selectively attend to some stimuli and ignore others
- So requires movement to think, and why can be so emotionally volatile.
- Analogy of Pig Pen = not surrounded by a cloud of dirt, rather a cloud of simultaneous variable intensity info on every sensory circuit
- results in a very confusing world to try to interpret

# Dysregulation

- Sensory dysregulation interferes with child's ability to access and apply strengths on demand
- BUT FASD = neurologically dysregulated in more than one area of brain function
- Therefore dependent upon the external environment to provide any regulation, especially when under stress.
- "External Brain" at all times and in all settings to ensure safety and success.
- Dysregulation also ensures that behaviour is more reactive than intentional.



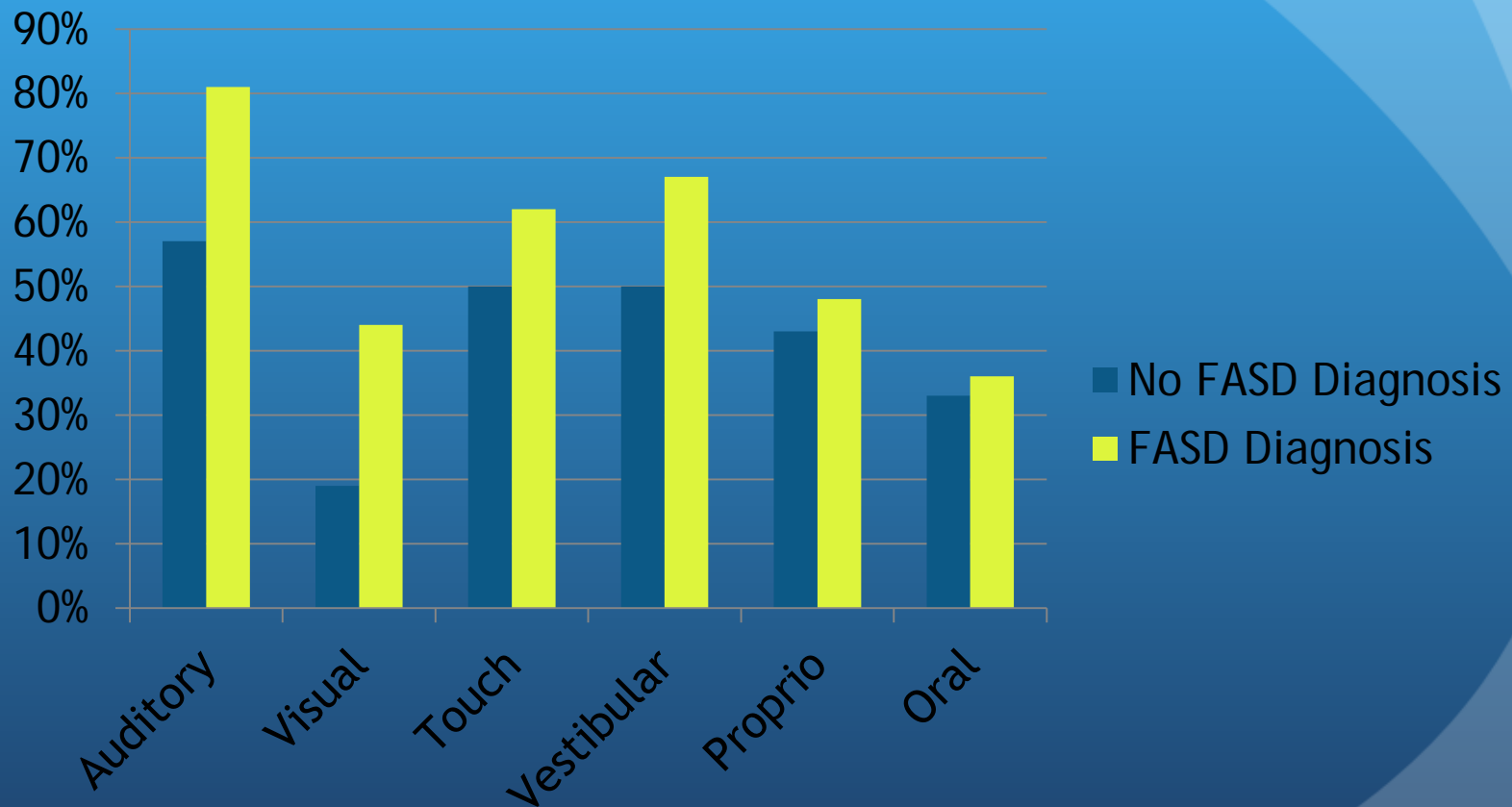
# Sensory → Self Dysregulation

- Sensory dysregulation underlies most of the reactive behaviours noted in FASD
- Including difficulties in broader area of Self regulation
- Long considered a core deficit in FASD due to deficits in regulating
  - Attention & Concentration
  - Emotion/affect/mood
  - Inhibition
  - Sleep (Hanlon-Dearman, et al, 2015)
  - 7 Senses (touch, hearing, vision, smell, taste, proprioception and vestibular)

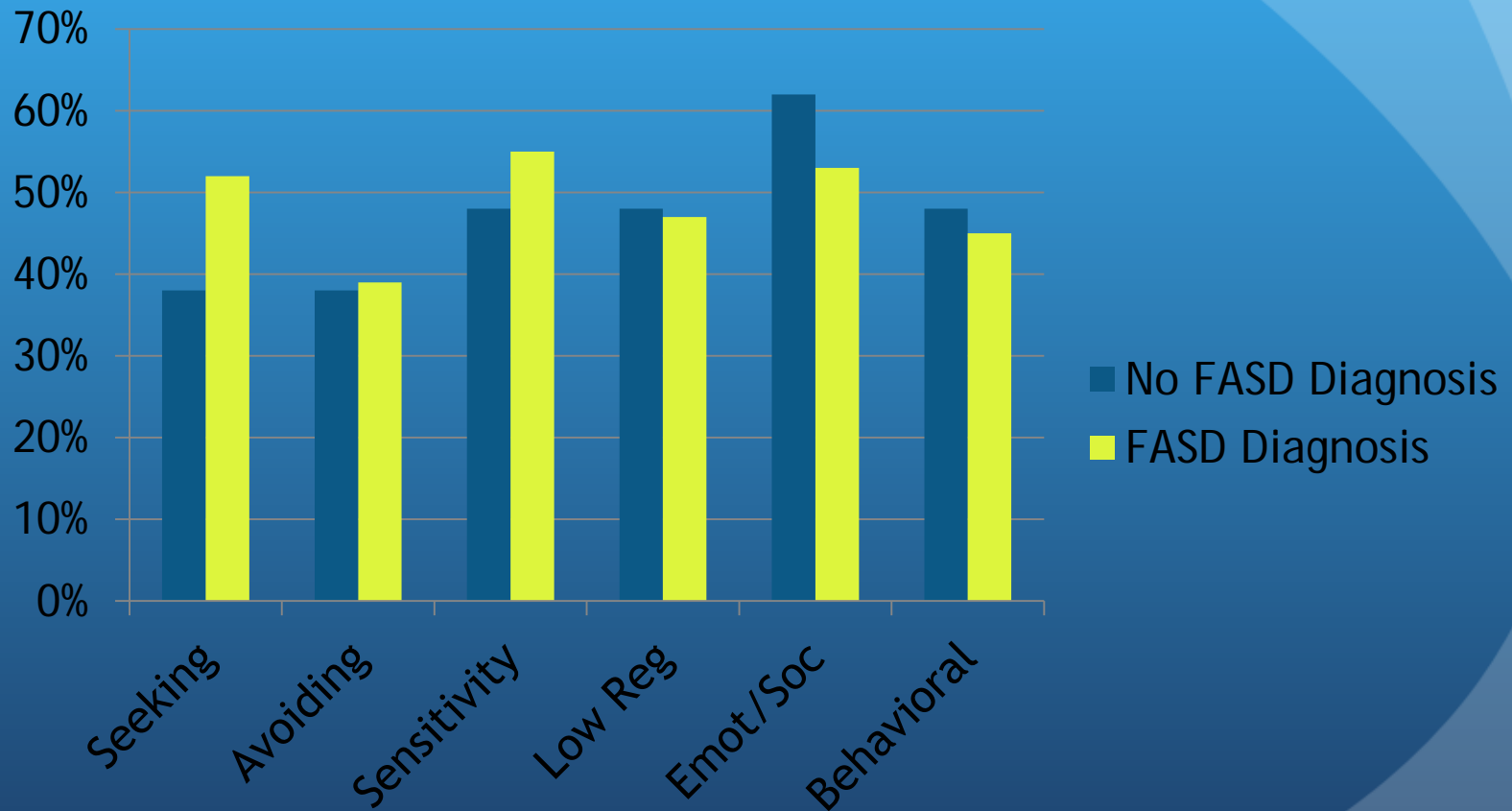
# Sensory Processing

- Areas typically measured by:
  - Five external senses; Auditory, Visual, Touch, Taste & Smell
  - Two internal senses; Vestibular and Proprioceptive
    - These internal senses help tell us our body position in space are the biggest contributors to motor planning and co-ordination of our movements.
    - To compensate for poor body awareness we often tend to overuse our visual sense.

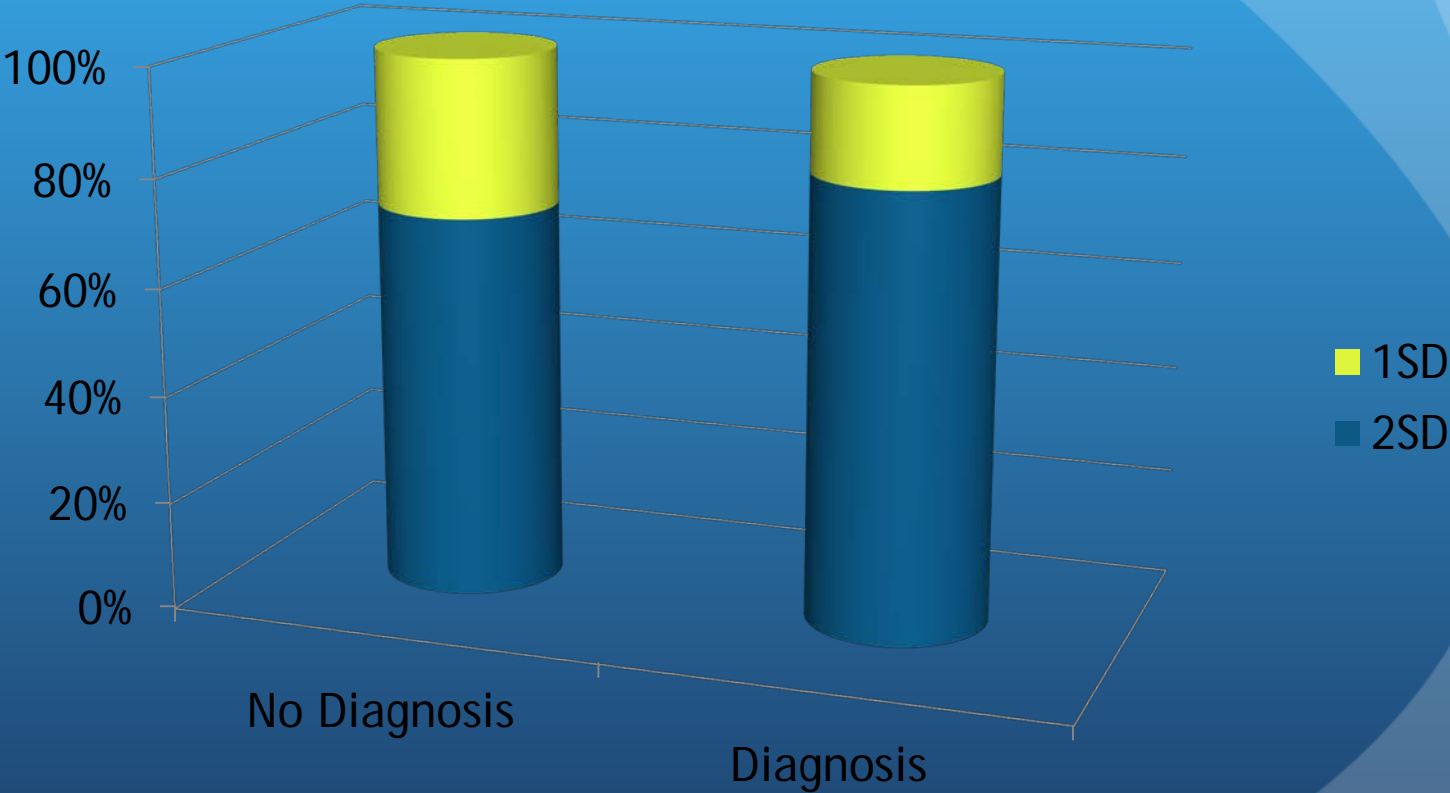
# Sensory issues reported in children assessed with PAE (N=94) over 10 years



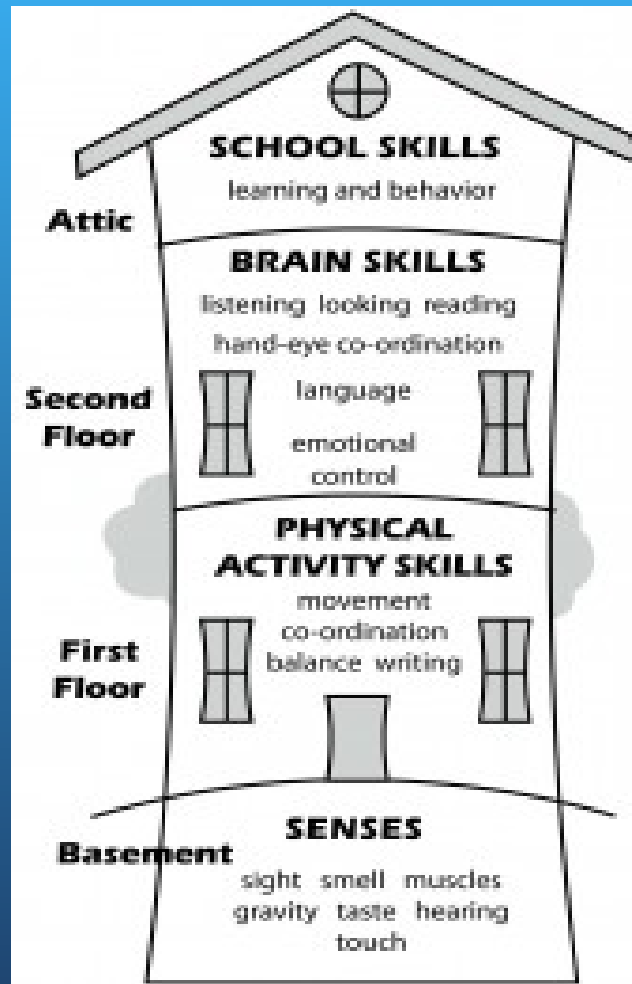
## Quadrants of sensory registration and behavioral factors reported in children assessed with PAE (N=49)



# Overall percentage of standard deviation from the norm for children with PAE reported as having sensory issues



# Building blocks for learning skills



# Assessing Sensory Processing

- Sensory Processing Measure (SPM): Available for children between ages 2 and 12 yrs. It is a standardized, integrated system of rating scales that enables the assessment of sensory processing issues, praxis and social participation in elementary age school children.
  - Benefits: Easy to complete and score; compares child's functioning in multiple domains (home, school and community); can be administered by itself as a screening tool or used together with other standardized tools to measure sensorimotor function.
  - Limitations: The assessor needs to have a firm understanding of sensory processing theories to interpret results effectively; Teacher needs to know child for at least one month before completing.





# Assessing Sensory Processing

- Sensory Profile-2: A standardized tool used to assess children from birth to adult (various tools available for different age ranges). 2<sup>nd</sup> edition has a score sheet combined with the questionnaire.
  - Benefits: Combination of sensory systems; behavioural and sensory patterns reported. Item consistency between forms. Can be completed on line or as a paper form. Assessment and planning report links findings from questionnaires to participation at home, school and community.
  - Limitations: Results can be misinterpreted without a strong understanding of the sensory integrative theories. New scoring needs to be explained to avoid "0" being used inappropriately.

## Sensory Profile-2 Child (Caregiver Questionnaire)

Scores one standard deviation or more from the mean are expressed as More Than Others or Less Than Others, respectively. Scores two standard deviations or more from the mean are expressed as Much More Than Others or Much Less Than Others, respectively.

		Raw Score Total	Percentile Range <sup>a</sup>	Much Less Than Others
Quadrants	Seeking/Seeker	51 /95		0----
	Avoiding/Avoider	61 /100		0----
	Sensitivity/Sensor	38 /95		0----
	Registration/Bystander	45 /110		0----
Sensory Sections	Auditory	28 /40		0----
	Visual	13 /30		0----
	Touch	17 /55		0----
	Movement	18 /40		0----
	Body Position	20 /40		0----
	Oral	22 /50		0----
Behavioral Sections	Conduct	21 /45		0----
	Social Emotional	49 /70		0----
	Attentional	21 /50		0----

<sup>a</sup> For percentile ranges, see Appendix A in the Sensory Profile 2 User's Manual.  
<sup>\*\*</sup> No scores are available for this range.

# Assessing Sensory Processing

- Questionnaires:
  - Analysis of Sensory Behaviour Inventory-Revised (ASBI-R), Morton & Wolford, 1994
  - Infant-Toddler Symptom Checklist: Long Version, DeGangi & Poisson, 2000
  - Sensorimotor History Questionnaire for Preschoolers, DeGangi & Poisson, 2000
  - Short Sensory Profile (SSP), Winnie Dunn, 1999
  - Building Bridges Through Sensory Integration (various questionnaires), Yack, Sutton & Aquilla, 2003

# Sensory Dysregulation and Adaptive Behaviours

Studies show correlation between sensory processing behaviours, sensory-motor performance and adaptive behaviours for kids with an FASD diagnosis.

- Significantly more problems with sensory modulation, poorer sensory motor and more soft neurological signs.
- Pattern of over-responsivity to tactile, auditory and visual stimuli, as well as patterns of under-responsivity, seeking behaviours and poor auditory filtering.

(Jirikowic et al., 2008)

# Clinical Observation as an Assessment Tool

(aka What to do with no OT)

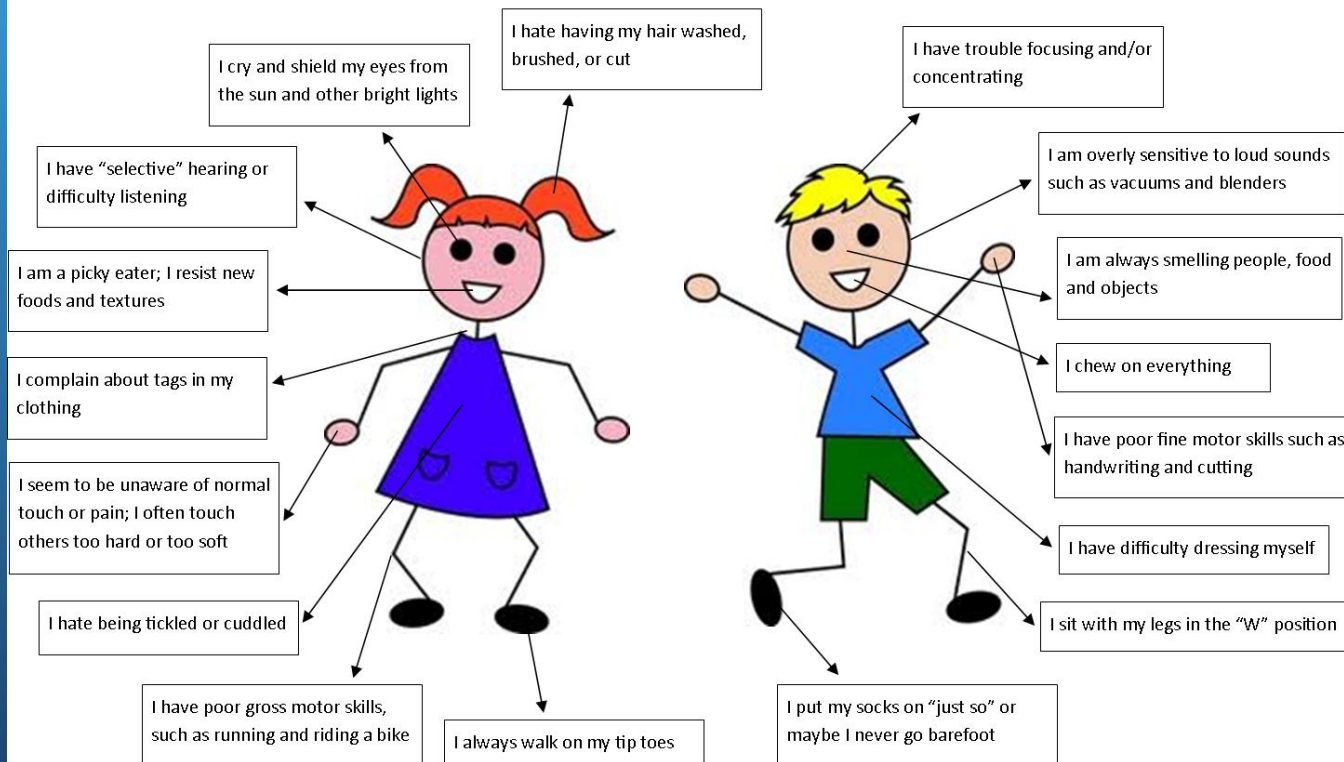
- When no OT videotape assessment sessions if possible to review and reflect on possible triggers for a child's behaviour.
- Take note of sitting posture; how child uses their vision; how do they respond to background noises and to verbal instructions.
- Movement- do they fidget, slouch in their seat, move stiffly, tend to use only one hand during fine motor tasks (i.e. forget about their helper hand).

# Clinical Observation as an Assessment Tool

- Does child respond more quickly/accurately when moving around the room or when fidgeting?
- Does child report hearing background noises or report smells from background (e.g. clock ticking)?
- Does child touch you or desk or carpet and when does so can participate (i.e.: calmer)?
- Does child give crushing hugs, throw self on floor a few times before returning to testing?
- Does child verbally respond with innate rhythm?

# Signs of Sensory Dysregulation

## Signs of Sensory Processing Disorders:



# Case Study

## Background:

- 4 year old child with a history of PAE living with his grandmother since 4 months of age.
- Has attended 2 different pre-schools in the past 6 months- neither worked out due to aggressive behaviours reported towards peers and teachers.
- Concerns noted are: social communication delay; fine motor delay; trips a lot; picky eater; easily frustrated.



# Case Study

Observations during Motor Assessment (M-ABC-2):

- Constant fidgeting while seated
- Impulsive/ Overestimates ability
- Became angry (facial expression and pushing away) when hand over hand assistance attempted or verbal instructions provided once he had started the task.
- Needed reminders of the sequence of a task at times.
- Threw himself onto the floor frequently during the last three activities saying he was “too tired”.

# Case Study

## Strategies Tried during Assessment:

- Provided a visual marker (happy face on wall) during the static balance activity.
- Used pneumonics to increase success with following instructions (lace is a snake-not a clock).
- Activity breaks to help him re-focus on task completion
- Minimizing language when repeating instructions
- Keeping out of child's personal space

# Case Study

## Results of Assessment:

- Low Range (4<sup>th</sup> percentile) for Motor Co-ord on the VMI (compared with average range on the Visual Perception task and the free hand drawing task).
- At Risk range (9<sup>th</sup> percentile) for Manual Dexterity on the M-ABC-2 with the lowest score on the drawing within a trail task.
- Definite Difference in the areas of Touch, Conduct and Avoiding on the Sensory Profile-2
- Probable Difference in Auditory, Movement, Social Emotional & Attentional as well as Seeking, Sensitivity and Registration

# Case Study

## Recommendations:

- Work with an OT to improve manual dexterity and motor co-ordination.
- Sensory Diet throughout the day (wearing a weighted knapsack on outings; movement breaks; heavy work activities; using a “sit & move” cushion during seated activities)
- Support new preschool setting by helping staff to understand some of the triggers to behavioural outbursts (i.e. proximity of others; touch; noises).

# Take Home Message

- Identify particular sensory problems and re-evaluate over time
- Use OT to prepare current sensory diet
- Recognize that you may not always be able to identify a trigger
- Recognize that for child each moment is a brand new moment
- Be aware of own internal state as that can “feed” exposed child’s emotional state

# Dysregulated Brain

Dysregulated brain → Increased anxiety →

Less regulation → Reactive Behaviour

# Sensory Dysregulation for non-OTs

- Behaviour is always a symptom of brain function
- Dysregulation makes finding triggers difficult
- Try placing yourself in the situation



Look, smell, touch, listen by turning off own filters

- Look for the unexpected
- And realize can not always determine triggers but can still find solutions for today

# Sensory Dysregulation requires us to:

- Keep language to a minimum
- Use visual prompts/cues or signs
- Remember brief multiple choice questions (2 choices)
- Be aware of cognitive and physical fatigue
- Escalation of symptoms = dysregulation
- Back off and not engage in reactive behaviours
- Not set the child up to react strongly



# Summary

- Clear evidence that sensory issues are prevalent in majority of FASD
- Sensory can best determined by OT
- But can be determined by observation during other testing
- Sensory and sleep are foundations of a regulated brain

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# Thank you for listening!

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