

### Allen Specter Center for Public Service Knowledge Exchange Talk - January 2018

### Supporting Full Participation Among Individuals With Autism Spectrum Disorder

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# 1 in 68



3 to 6 boys = 1 girl



# Family, Friends, etc.



<u>Source</u>

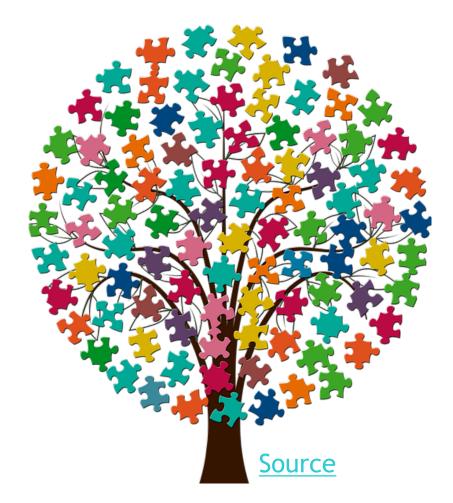


# So, ... what is autism?



# Autism is...

- A condition with multiple causes (e.g., genetic, environmental)
  - changes in multiple parts of the brain
  - changes occur before birth (mostly)
- A condition with many symptoms (i.e., communication, social interactions & sensory processing)
  - The degree of expression of each symptom varies between people
  - "Unique"



# **Diagnosis Criteria:**

### Social Communication & Social Interaction

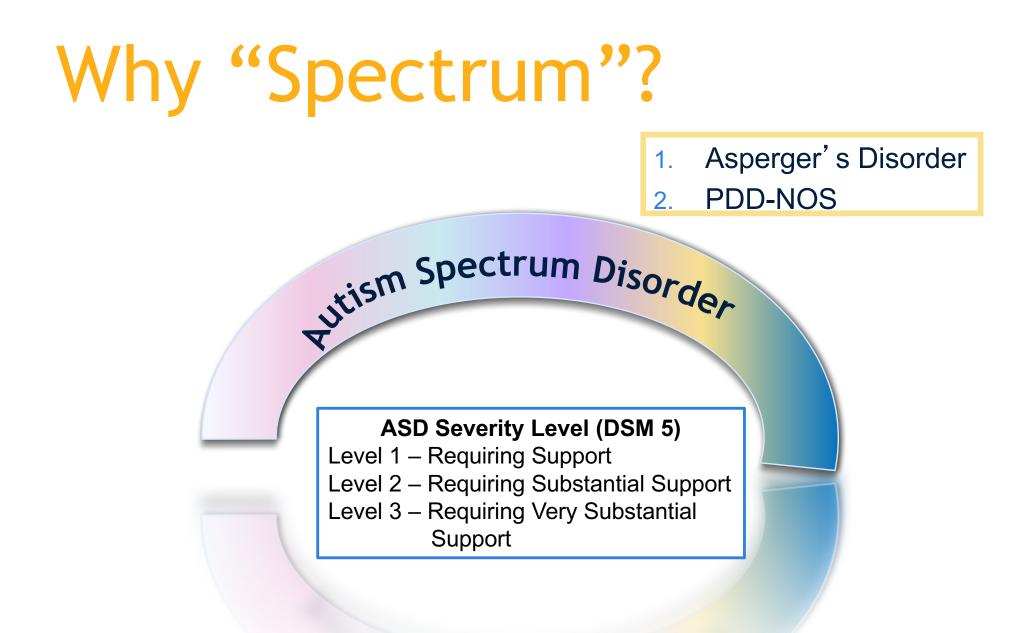
- 1. Deficits in social emotional reciprocity
  - Social approach
  - Back & forth in conversation
  - Sharing interest in other's interests
  - Initiating & responding communication
  - Understanding multiple perspectives
  - Non literal language
- 2. Deficits in nonverbal communication
  - Poor integration of verbal & nonverbal communication
  - Deficits in understanding and using gestures
- 3. Deficits in developing, maintaining & understanding relationships
  - Adjusting behavior to suit various social contexts
  - Understanding the implicit rules of relationships
  - Difficulty making friends

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# **Diagnosis Criteria:** Restricted, repetitive behavior, interests, and/or activities

- 1. Repetitive movements, use of objects, or speech
- 2. Insistence on sameness, inflexible adherence to routines, and/or ritualized patterns of verbal or nonverbal behavior
- 3. Highly restricted interest
- 4. Sensory Differences: Perception, Integration & Reaction
  - Over or under reactivity to sensation (e.g., touch, sound, smell)
  - Integrated use of sensory information in daily life
  - Unusual interest in sensory aspects of the environment



# Anxiety & ASD

- General population: >10% of children have anxiety
- ASD: 40-80% of children have anxiety
  - Higher functioning = higher rates of anxiety
  - Older = higher rates of anxiety

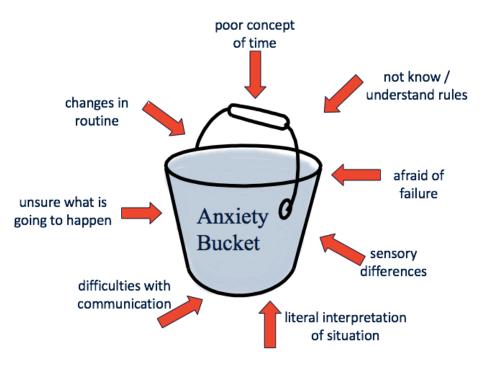
"The more anxious a person with ASD is, the less likely they are to able to cope with demands."

Kreiser (n.d.). Anxiety in Autism Spectrum Disorder; Mayes et al. (2011)



# Sources of Anxiety in ASD

- 1. the environment
- 2. interactions with others
- 3. concern for other
- 4. fearful anticipation of an event or outcome
- 5. disappointment



Trembat, D., Germano, C., Johanson, G., & Dissanayake, C. (2012). The experience of anxiety in young adults with autism spectrum disorders. *Focus on Autism and Other Developmental Disabilities*, 27(4), 213-224.

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# What might be hard for people with autism?

#### **University Life**

- Group projects
- Navigating university events
  - Expectations
  - Sensory preferences
- Residence life
- Interacting with faculty and peers
- Asking questions

#### Social Life

- Making & keeping meaningful friendships
- Participating in recreational activities
- Dating or being in a committed relationship

#### **Daily Living Skills**

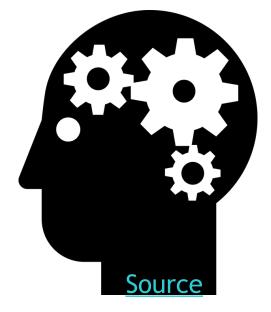
- Changes in routine
- Clothing
- Eating
- Going to a bank or other services
- Going to restaurants & other activities
- Sleeping

#### Recreation

- Less varied recreation
- Less social recreation
- Similar interest in a variety of recreational activities

# What autism is NOT!

- Intellectual disability
- $\sim 1/2$  of people with ASD have normal or above normal IQ
- ≠ "Genius"
- Parts of their brain function differently
  - Strengths
  - Challenges





## What autism is NOT! Loners



## ALONE but NOT by CHOICE

- Fewer friends than people with other disabilities (Bastiaansen et al., 2004; Solish et al., 2010)
- 88% have NO 'out-of-school' interactions with friends (Wagner et al., 2002)
- Few adults report having peer relationship (Orsmond et al., 2004; Saldana et al., 2009)
- Caregivers and support personnel sometimes identified as friends (Kuo et al., 2011)

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- Experience more loneliness (Bauminger et al., 2003; Huang & Wheeler, 2006)
- Experience persistent social isolation (Friedman et. Al., 2013)
- Desire friendship and meaningful relationships (Friedman et. Al., 2013)
- Barriers to Social Relationships: Social & communication skills, and the lack of knowledge of others

# So, what is it like to have autism???



Link to video of twin sisters who have autism describing what autism is to them: <u>http://youtu.be/qbf-81Ll3wk</u>

# What are people with autism great at?

- Attention to details
- Being Direct "you will know where you stand"
- Expert in topics of interest
- Focusing on visual details (more than the whole)
- Memory
- Thinking "outside of the box"
- Thrive on routine
  - Consistent
  - Dependable
  - Loyal



## 10+ things you can do to help

- 1. Make the implicit, explicit
  - Non verbal language
  - Non literal language
  - Social rules
- 2. Be mindful of what you say/do; they are not "socially blind"
- 3. Consider initiating communication
- 4. Allow extra time for responses -- verbally & writing
- 5. Remember, they may think or act "differently"; they are not weird or rude
- 6. Remember, we are all different in some ways

- 7. Be patient; they may have had multiple negative interactions or experiences
- 8. Be aware that typical environment may be difficult to manage: noise, touch, smell or visually busy environments
- 9. Be accepting of unusual sensory or social behaviors (e.g., smelling your hair or touching your shirt)
- 10. Accommodation is for ALL, don't single anyone out 11....



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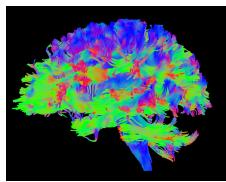
# Jefferson OT: ASD Lab

http://www.jefferson.edu/university/health-professions/departments/occupational-therapy/research/autism.html

- 1. EuREKA Project: Enhancing recreation with children with ASD
- 2. GOALS<sup>2</sup> Program: Supporting academic learning & living needs of college students with ASD
- 3. EASI: Evaluation of Ayres Sensory Integration: Developing tools to assess senses
- 4. Sensory Integration Intervention Efficacy: Enhancing function through sensory integration occupational therapy intervention
- 5. Sensory Integration Intervention Mechanism: Degree and type of changes in Neural Connectivity following sensory integration occupational therapy intervention
- 6. SAFE: Creating Sensory Aware and Friendly Environments







#### And many more: Jefferson Autism Research Program

http://www.jefferson.edu/university/research/programmatic-research/programmatic-research-domains/jeffersonautism-research-program.html



### **EuREKA Project**

- Helping children with autism reach their own goals about recreation
- Parent/family driven
- Use Coaching in Context Approach





### **GOALS<sup>2</sup> Program**

- Helping young adults with autism and other disabilities achieve their own goals in higher education (learning & living)
- Client driven
- Use Coaching in Context and other approaches



### **Coaching in Context**

FOCUS on Person's STRENGTHS & ENVIRONMENT / TASK MODIFICATIONS

#### **Goal-Setting Visit**

- 1. Family-selected goals (e.g., COPM)
- 2. Make goal measureable (e.g., GAS)
- 3. Identify bridges & barriers

#### Intervention Visits

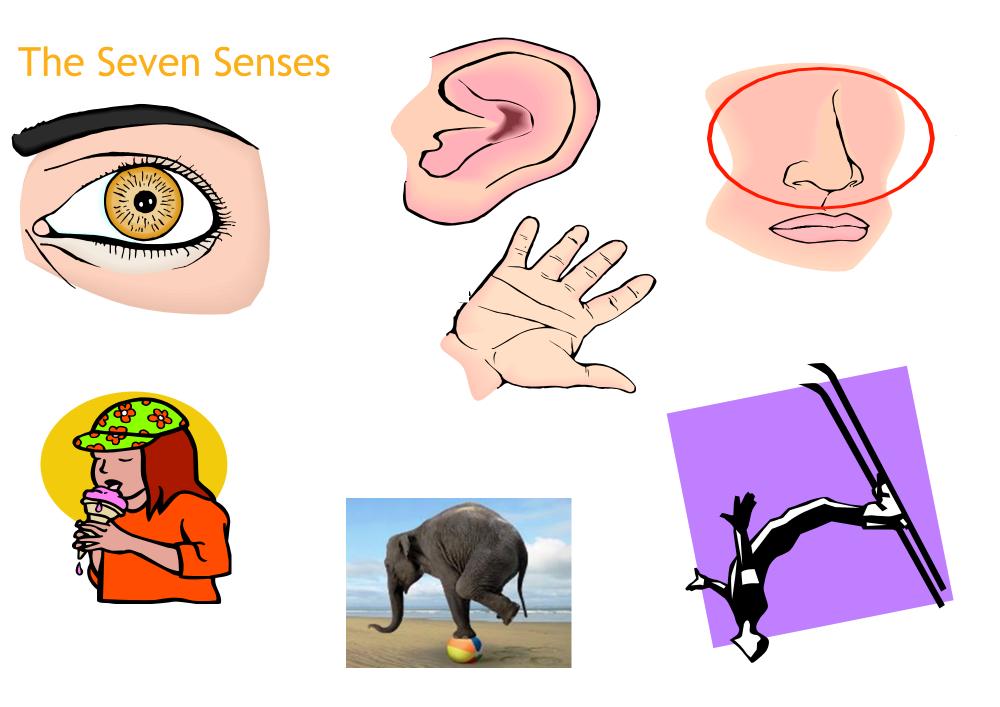
- 1. Debrief
  - ightarrow Goals attainment rating
  - $\rightarrow$  Action plan review
  - $\rightarrow$  Identify bridges & barriers
- 2. Brainstorm
- 3. Plan
  - $\rightarrow$  Family/client select strategies
  - → Interventionist provides resources or training when family/client identifies the need

### <u>Dr. Roseann Schaaf's Projects</u>: Focus on Sensory Features of Autism Spectrum Disorders

Link to Dr. Schaaf's talk:

https://www.youtube.com/watch?v=loS7fNszzSE&feature=youtube

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### Differences in Perception, Integration, Reactivity









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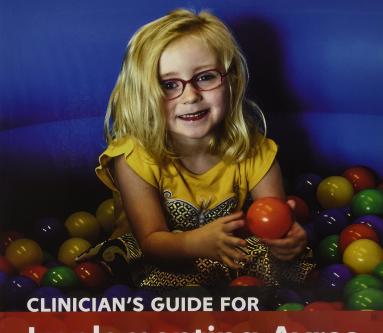
### Evaluation: Developing New Psychometrically Sound Assessments to Understand Autism Sensory Symptoms

#### Evaluation in Ayres Sensory Integration (EASY)





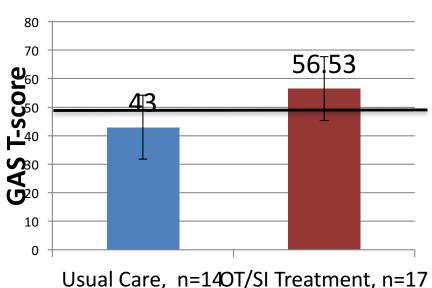
#### Sensory Integration Intervention to Improves Function



### Implementing Ayres Sensory Integration®

Promoting Participation for Children With Autism

Roseann C. Schaaf, PhD, OTR/L, FAOTA, and Zoe Mailloux, OTD, OTR/L, FAOTA

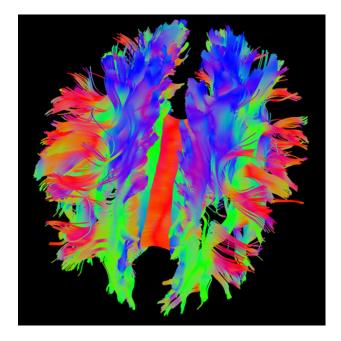


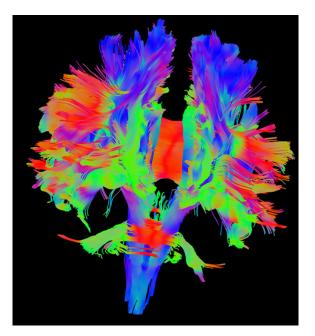
#### 1. Ayres' SI vs OT

#### 2. Ayres' SI vs Behavioral Intervention

#### Both studies received NIH funding

# Change in Brain Connectivity Following Intervention?







### Training the Next Generation of Occupational Therapy Clinicians and Researchers





### Together We Can Make a Difference!



### Questions, Suggestions & other Thoughts



How to participate?

