# "Lost at Sea" in ASD?

Techniques for Improved Communication and Examination of Pediatric Patients with Autism Spectrum Disorders

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# Disclosure

• I have no financial relationships with commercial interests to disclose



#### **Pre-test Question 1**

- All of the following represent established approaches to facilitate the physical examination of a resistant/agitated patient with ASD <u>except</u>:
  - A. Use of distractive tools such as those found in a coping kit.
  - B. Using specific and detailed written and verbal instructions to outline the entire procedure at all once.
  - C. Modifying the physical environment to tailor the stimuli experience (i.e.- dimming lights, providing head phones, and chewy tubes).
  - D. Providing visual cues of the procedure/exam using visual models such as dolls or stuffed animals prior to performing the procedure.

#### **Pre-test Question 2**

- All of the following are methods of alternative communication that you may see commonly used by children with ASD to assist their communication and decrease anxiety/fear with health care providers during their exam <u>EXCEPT</u>:
  - A. Speech Generation Devices (SGD)
  - B. Picture Exchange (PE)
  - C. Functional Magnetic Resonance Imaging (fMRI) enabled speech device
  - D. Micro Switches

#### **Pre-test Question 3**

- Based on research performed on the physical examination of children with ASD, which of the following techniques is NOT a preferred technique for the routine behavioral management of fear/anxiety related to physical exam:
  - A. Intermittent graduated exposure to fearful stimuli
  - B. Tell-Show-Feel-Do (T-S-F-D)
  - C. Differential reinforcement of other behavior (DRO)
  - D. General sedation

# Roadmap

- Intro/Demographics/Terminology
- Sensory Concerns
- Communication Concerns
- Safety concerns (Anxiety/Fear)
- Mobility concerns
- Research

#### The Reality of Medical Care in Special Needs Populations

- Children with ASD and developmental disorders (DD)
  - Often require more frequent medical care
  - Experience more difficulties during the history and physical examination than neurotypical peers (Cuvo et al., 2010).

# The Fallout of Traditional Histories in ASD

- Health care providers often fail to obtain a detailed medical evaluation relying on:
  - Parents/caregivers
  - Incomplete preexisting medical records (Cuvo, Readan, Ackerlund, Huckfeldt, & Kelly, 2010).

#### Importance of Performing Proper Exams

- Negative health care experiences can adversely affect children with ASD/DDs perceptions of medical care for future visits
- Targeted behavioral support can facilitate the examination of this unique patient population, preventing child:
  - Stress
  - Adverse events
  - Future aversion to medical care (Drake, Johnson, Stoneck, Martinez, & Massey, 2012, p. 215)



# **Clinical Scenario**



6-year-old male patient, named Jack, presents to your outpatient clinic with chief complaint of "he feels warm" for the past 2 days per the parent. You observe as the patient is wheeled into his room by stroller/community access device that Jack is grunting, repeating the words "all done", watching a video on a tablet device, and constantly sucking on his finger. He appears agitated, makes poor eye contact with the nurse, and responds in a limited manner using "yes/no" answers to questions primarily with laminated cards his parent brought in for the examination. Your clinician coworker rolls their eyes, looks to you and says, "Well, I guess Jack is back again."

#### **Clinical Scenario**

- Your best course of action for Jack is:
  - A. Run and hide in the bathroom.
  - B. Take an early lunch.
  - C. Spend time catching up on charts and hope your colleagues see Jack instead.
  - D. Review his medical history and enter the room, discussing the history with the parent but never examining Jack due to "combativeness" and "non-compliance" during the clinical interaction.
  - E. None of the above.



## Definitions (Autism Speaks, 2018)

- Autism Spectrum Disorder (ASD)
- DSM-5 Criteria Symptoms
  - Persistent deficits in social communication/interaction
    - Deficits in:
      - Social/emotional reciprocity
      - Nonverbal communicative behaviors
      - Developing, maintaining, understanding relationships
  - Restricted, repetitive patterns of behavior, interest, activities
     <sup>(2+)</sup>
    - Stereotyped/repetitive movements/speech/use of objects
    - Insistence on sameness, routines, patterns
    - Restricted, fixated interests
    - Hyper/hyporeactivity to sensory inputs
  - Symptoms are not better explained by intellectual disability or developmental delay

#### Demographics – ASD

- Prevalence of ASD (Autism Speaks, 2018; Monz, Houghton, Law, & Loss, 2019)
  - 2018 CDC estimates:
    - 1 in 37 Boys
    - 1 in 151 Girls
      - Boys > 4 x more likely to have ASD than girls
  - Most diagnosed after age 4
    - Reliable diagnosis as early as 2-years-old





#### Important Terminology-Developmental Disorders(Harris, 2013)

- Please avoid:
  - Mental Retardation(MR)/"Retarded"
    - Adopted by medical societies in 1961
    - Replaced terms feeblemindedness, idiocy, and mental subnormality.
    - All are now considered pejoritive
  - APA revised preferred terminology in 2013 with DSM-5 and ICD-11.



• In US, federal statute has replaced MR with Intellectual Disability (ID).

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# Anatomy and Pathophysiology of

#### Autism (Lathe, 2006)

- MRI
  - Abnormal size of limbic structures
    - Fewer hippocampal dendrites, abnormal hippocampal volume
    - Higher neuronal density in amygdala, abnormal volume
- Histology
  - Prefrontal and temporal lobe cell columns increased in number, but smaller and fewer neurons per column
- fMRI
  - Examine blood flow and energy utilization
    - Reduced blood flow to temporal lobes
    - Asperger abnormal functional integration amygdala and parahippocampal gyrus
- Reduced neuronal metabolite in hippocampus/amygdala and cerebellum
  - Indicates diminished metabolic activity in these areas
  - Sign. Correlation between parent rated ASD severity and limbic neuronal density
- SPECT
  - Decreased blood flow to left temporal lobe
- PET
  - Decreased blood flow to temporal lobes

#### Pathophysiology of Autism - ASD Phenotype (Lathe, 2006)

- Memory
  - Hippocampal dependent memory affected in ASD
  - Repeat training can overcome hippocampal damage/lesions and also in ASD • Difficulty relearning "new rules"
- Anxiety/Stress
  - Associated with hippocampal function in ASD
- Desire for sameness
  - Decreased blood flow to right amygdala/hippocampus associated with obsessive desire for sameness
- Perception of facial emotions
  - Associated with limbic atrophy, facial recognition temporal lobe
  - Social interaction
    - Amygdala lesions associated with impaired evaluation of social stimuli
- Language
  - Limbic lesions associated with speech/language impairment
- Stereotypical/repetitive behavior
  - Associated with hippocampal lesions
- **Sensory Deficits** 
  - Temporal lobe/limbic lesions associated with auditory agnosia ("hearing blindness")

# Anatomy and Pathophysiology of

#### Autism (Lathe, 2006)

- Consensus:
  - Abnormalities in the medial temporal lobe, hippocampus, and amygdala
    - Cognitive, perceptual, social and language impairments of ASD
  - Cerebellar abnormalities
    - Impaired coordination/posture/locomotion

# Sensory Experience in ASD CGI Animated Shorts : "Listen" - by Alexander Bernard ... - YouTube - 2:41. Bernard, A., & Fernandez, M.(2016, June 7). Listen Senior Film.[Video File]. Retrieved from https://www.youtube.com/watch?v=ibylThIMErE DMV...

#### Sensory Experience of ASD

- Sensory processing difficulties are universally present in children with ASD (Lathe, 2006)
  - Hearing deficits in 8.6%
  - Varying visual impairments in 25%
- Sensory difficulties correlated with maladaptive behaviors (Nieto, López, & Gandía, 2017)
  - Key driver of parental stress
- Sensory disturbances may involve acoustic, visual, tactile, and pain stimuli (Lathe, 2006)
  - Heightened response
  - Reduced response

Hypersensitivity (over responsive)	Hyposensitivity (under responsive)	Impaired Sense	Accommodation in Clinic
	Poor response to visual cues	Vision	Pictures/items with high contrast
	Poor Balance/Coordinatio n	Proprioceptive/Vesti bular	Opportunities for rocking/swinging/w eighted vests or blankets
	Oral seeking	Tactile/oral	Chewable tubes
Spectrum of light		Visual	Room without fluorescent lamps
Loud Noises		Auditory/vestibular	Ear plugs/Headphones/ Close door
Sensitivity to touch		Tactile	Request permission prior to touching
Bright light		Visual	Dimmed lights/visor/sunglass es

Hypersensitivity (over responsive)	Hyposensitivity (under responsive)	Impaired Sense	Accommodation in Clinic	
Withdrawing from soft touch		Nociceptive/Tactile	Avoid rough stimuli	
Avoidance of textures		Tactile	Avoid painful/rough stimuli	
Smell		Gustatory	Avoid perfumes, colognes, or scented items	
	Seek out strong tastes/odors	Gustatory	Flavored chewable tubes	
	Unresponsive to loud noises	Vestibular/Auditory	Noisy toys, play loud music, running commentary	
(Brownlee, 2010; Fun and Function, 2018; Developmental Delay, 2014; Newman, 2008)				

#### **Big Picture Check**

- Which of the following statements are TRUE regarding triggers of sensory stimuli for children with ASD?
  - A. Hypersensitivity to stimuli is the most common general sensory trigger.
  - B. Hyposensitivity to stimuli is the most common general sensory trigger.
  - C. Sensory triggers are similar in this population to those of neurotypical peers.
  - D. BOTH hyposensitivity and hypersensitivity are common general sensory triggers

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#### Language and ASD

- Basic Terms
  - Speech (Mulhern et al., 2017) ability to articulate needs or thoughts
  - Vocalizations (Mulhern et al., 2017) act/process of producing voice sounds
  - Receptive language (Lim, 2011)
    - What the individual understands
  - Expressive language (Lim, 2011)
    - What is spoken/expressed by the individual



## Language and ASD (Lim, 2011; Mulhern, 2017)

- "Inadequate" use of language key feature of ASD.
  - Early speech delay/regression
  - 1/3<sup>rd</sup> to ½ of individuals with ASD are unable to communicate at a level to express daily needs.
    - 25-30% of children with ASD fail to acquire speech without direct intervention
    - Possible linkage with comorbid intellectual disabilities
    - Challenges/inability to decode auditory speech

# Language and ASD

(Lim, 2011; Mulhern, 2017)

- Verbal ASD children display aberrant speech:
  - Unusual word choice
  - Echololia
  - Unresponsiveness to questions
  - Lack of drive to communicate
  - Absent reciprocal "Give and take" of communication
  - Inability to understand body language, tone of voice, subtle language queues

#### **Corresponding Characteristics in**

#### ASD (Hudson, 2006)

#### • Level 1

- Responds to name
- Aware of others
- Indicates needs through gestures
- Prefers soothing touch
- Enjoys rhythm/repetition
- Orients to facial expression

#### • Level 2

- Acquires language
- Engages in discovery/inquisition
- Imitation/play
- Prefers structure/limits
- Requests help/communicates needs
- Gains control of body/motor skills

#### **Corresponding Characteristics in**

ASD (Hudson, 2006)

- Level 3
  - Develops imagination
  - Mimics adults
  - Able to provide detail
  - Understands rules/orders
  - Greater awareness of body
  - Increase language

#### • Level 4

- Seeks details
- Tells others rules
- Maintains routines
- Makes plans, more structured
- Gains reasoning skills

#### **Corresponding Characteristics in**

ASD (Hudson, 2006)

- Level 5
  - Establishes goals
  - Aware of peer opinions
  - More advanced problem solving
  - Weighs options/outcomes
  - Abstract thinking
  - Understands sequence of events
  - Makes personal choices

#### **Corresponding Characteristics in**

#### ASD (Hudson, 2006)

- Developmental checklists
  - Used to determine developmental level
  - Tailor make Participation and Information Plans. Ex.-
    - Medical interaction MRI
    - Developmental level Level Two
    - Information processing characteristics
      - visual learner
      - overstimulated by people
      - needs processing time
    - Developmental level considerations -
      - Simple, visual steps
      - Use repetition
      - Comforted by close contact, holding preferred object
#### Language Considerations

- Challenges with speech acquisition affect quality of life
  - Decreased independence
  - Decreased social adaptive functioning
    - Struggles integrating with peers
    - Comorbid behavioral difficulties and language deficit common

#### Roadmap

- Intro/Demographics/Terminology
- Sensory Concerns
- Communication Concerns Continued...
- Safety concerns (Anxiety/Fear)
- Mobility concerns
- Research

## **Objects of Reference**

• Visual representation of the tasks asked of the individual (Goldbart et al., 2014).



2/8/2021







#### Speech Generation Devices (SGDs)

(Hagan and Thompson, 2013)

- Advanced means of communication that uses touched symbols to trigger recorded messages.
- Mimic verbal speech
  - Speakers
  - Increase communication competence in children with ID
  - Studies also showing effectiveness in children with multiple disabilities and ASD

2/8/2021

#### Speech Generation Devices (SGDs)

Yes	No	More
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#### **Big Picture Check**

- All of the following are methods of alternative communication that you may see commonly used by children with ASD/DD to assist their communication and decrease anxiety/fear with health care providers during their exam <u>EXCEPT</u>:
  - A. Speech Generation Devices (SGD)
  - B. Picture Exchange (PE)
  - C. Micro Switches
  - D. Functional Magnetic Resonance Imaging (fMRI) enabled speech device.

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#### Phobias in ASD

• Communication tools and distractive items may decrease anxiety/stress and assist the clinician with performing an exam (Drake et al., 2012).



#### **Distractive Items/Techniques**

- Otoscope light onto a child's hand, moving forward and back to display the lights scope (Narula-Isaac, 2005)
  - Repetition of this routine beneficial in ASD
- Chewable toy (Drake et al., 2012)
- Light-up spinning fan toy (Drake et al., 2012)
- Bubble wand (Weltman, 2007).
- Tablet/Smartphone

#### Other Distractive Items in Coping Kit

- Sand
- Ear plugs / ear phones
- Visors/ hats
- Fidget toys
- Weighted vest / weighted blanket
- Soothing music
- Lava Tubes (bubbles/floating objects)

#### **Big Picture Check**

- Question: Besides communication, what are the other two main areas of focus for your physical examination of the ASD/DD child in this lecture?
  - A. Sedation
  - B. Restraints
  - C. Safety Concerns (anxiety/phobias)
  - D. Mobility Concerns

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### **Mobility/Examination**

• ASD (Breslin & Liu, 2015).

(Recommendations adapted from article assessing motor skills in school)

- Attire
  - Logos on clinician clothing may be distracting/point of perseveration
  - Child clothing preferences may be related to tactile input
    - Shirt tags
    - Loud clothing
- Equipment
  - Substitute for different color/texture if distracting or child is tactile sensitive
- Rely on support personnel

#### **ASD Needs Assessment**

- Noncompliance during exam (Cuvo et al., 2010):
  - Low passive compliance with exam requirements
  - Receptive language deficits
  - Challenges in learned behavior/mimicking
    - Visual discrimination
    - Opening mouth
    - Taking deep breath
- So how do we ensure we are meeting children's needs and assessing their level of functioning?

#### **ASD Needs Assessment**

- Ideal:
  - Quick
  - Easy
  - Parent/caretaker facilitated
  - Administered at the point of entry/triage for medical care
  - Non-invasive
  - Inexpensive
  - Take into consideration communication, anxiety and mobility for each child

#### Initial Assessment (Hudson, 2006)

- Childs Name:
- Medical Diagnosis:
- Reason for medical visit:
- Excels in these skills:
- Activities in which the child enjoys:
- Activities the child avoids:
- Motivators:
- Stress triggers:
- Adaptations already in place:
- Communication system in place:
- Known Sensory issues:
- Special Diet/food allergies:
- Optional add ons:
  - Mobility Needs:
  - S.W.O.T

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# **Coping Kit Study**

(Drake et al., 2012)

- Coping kits were used by clinical staff to:
  - Reduce anxiety
  - Distract
  - Provide additional communication to children with ASD
- Improved willingness to cooperate through an observed change in child behavior in 79% of cases (19/24).

# Training Compliance with PE (Cuvo et al., 2010)

- Applied Behavioral Analysis (ABA)
- Health care procedures analyzed as a behavioral sequence of steps
  - Steps scored
  - Compliance analysis
- Reason for non-compliance identified with functional behavioral analysis techniques
- Developed tailored procedures based on the reasons for non-compliance

# Training Compliance with PE (Cuvo et

al., 2010)

- Medical Office setting
- ASD and Pervasive Developmental Disorder NOS patients
- 10 component, 10-minutes physical exam performed by PA (pretest)
- 6 subjects
  - Aged 3-6 years-old
  - Male and female
- Inclusion Criteria
  - ASD/PDD-NOS
  - Failure to pass all 10 components of exam
  - History of exam non-compliance
  - Joint attention
  - Reactive to response consequences
  - Follow a visual schedule
  - Follow simple instructions











### TEACCH (Orellana, Martínez-Sanchis, & Silvestre, 2014)

- Treatment and Education of Autistic and related Communication Handicapped Children Model Study
  - Study aim reduce use of unnecessary general anesthesia and high dose sedation during dental procedures using TEACCH
  - Participants with Aspergers, ASD, and PVD-NOS
  - N= 72
    - Children (n=38) 4-9 years, Adults (n=34)- 19-41
  - 10-component dental exam
  - Pre-test
  - Five training sessions
  - Post-Test

#### TEACCH (Orellana et al., 2014)

- Successive training approaches
  - Interact with exam equipment/instruments and with dentist
  - Tell-Show-Feel-Do (T-S-F-D) For example...
    - Tell what's going to happen, Show what they will do, Feel instrument, Do the exam technique.
  - Visual pedagogy 20 step-by-step photos
  - A-V modeling live modeling videotaped and played back
  - Behavioral trials step through 10 component exam
  - Auto modeling photos of subjects modeling behavior used later in practice sessions

#### TEACCH (Orellana et al., 2014)

#### Results

- Higher cognitive functioning pts showed larger improvements in exam completion and behavior.
- Pre-test 73% of children and 67% adults showed reluctant behavior
- Post-test- 81.6% of children and 100% of adults showed positive behavior

#### TEACCH (Orellana et al., 2014)

- Conclusions of this study
  - Value of teaching
  - Point of view of "culture of autism"
    - Take into account sensory profile of ASD
  - Effective protocol for ASD exams
  - Guideline can be extended to other health care practices
# Exposure-based interventions in children with ASD (Gillis et al., 2009)

- Population
  - Mean age of 8.4 years
  - Majority non-verbal (10/18)
  - All students of specialized ASD school
- Results:
  - Repeated exposure to a clinical setting to fearful stimuli during a routine exam <u>decreased</u> fear-related behaviors
    - 83% of participants (15/18)
    - 3 remaining participants still fearful
    - Still showed progress after 38, 42, and 62 visits
    - Did not complete protocols, but still made progress

# Exposure-based interventions in children with ASD (Gillis et al., 2009)

- Take home:
  - This type study may be difficult to implement clinically
  - May still be facilitated in:
    - Applied behavioral analysis (ABA)
    - Specialized ASD school
    - Intensive behavioral health setting

# More Tricks of the Trade (M. Bellatuono,

personal communication, November 28, 2018)

- Use clear, simple language
- Give child time to process information
- Repeat instructions
- Redirect by using visual tools

## **Post-Test Question 1**

- All of the following represent established approaches to facilitate the physical examination of a resistant/agitated patient with ASD <u>except</u>:
  - A. Use of distractive tools such as those found in a coping kit.
  - B. Using specific and detailed verbal and written instructions to outline the entire procedure all at once.
  - C. Modifying the physical environment to tailor the stimuli experience (i.e.- dimming lights, providing head phones, and chewy tubes).
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## **Post-test Question 3**

- Based on research performed on the physical examination of children with ASD/DD, which of the following techniques is NOT a preferred technique for the routine behavioral management of fear/anxiety related to physical exam:
  - A. Intermittent graduated exposure to fearful stimuli
  - B. Tell-Show-Feel-Do (T-S-F-D)
  - C. Differential reinforcement of other behavior (DRO)

• D. General sedation

## **Clinical Scenario Revisited**

- Jack, 6-year old
- Needs assessment completed
  - Sensory
    - Oral hyposensitivity/seeking
    - Light hypersensitivity
  - Communication
    - Non-verbal, uses visual communication
  - Mobility
    - Stroller/Community Access Device
  - Anxiety
    - Hates ENT exams



# Putting it all together

- Accommodations made
  - Lights
  - Chewy tube
  - Examine in stroller
  - Specialized Techniques used
    - Custom First-Then Board
    - T-S-F-D
    - Repetition
    - Video after completion



## **Take Home Points**

- These are simple techniques
- Effective resources are inexpensive
- Donate your time (a.k.a.- hit the breaks)
- Identify and address sensory needs/ triggers-crucial to smooth outcomes. DON'T REINVENT THE WHEEL, ASK PARENTS!
- One child unnecessarily sedated/restrained/traumatized is one too many
- Small efforts make big differences in special needs
- Bail out your colleagues grab these charts- help these kiddos!



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