

Making Special Accommodations for Special Needs Populations: Evidence-Based Tips and Tricks to Ease the Evaluation of Special Needs Patients

Dr. Thomas Meersman
DHSc, MMSc, PA-C
Assistant Professor of Physician Assistant Studies
Program Director
North Central College MSPAS program

AAPA We Are Family (Medicine) Conference

Austin, TX - 2/19/2022



Disclosure

I have no relevant relationships with ineligible companies to disclose within the past 24 months.

Objectives

- At the conclusion of this session, participants should be able to:
 - Categorize the unique sensory needs of children with autism spectrum disorder (ASD) and developmental disorders (DD).
 - Identify the responses that children with ASD/DD experience during physical exams, highlighting challenges related to anxiety and specific phobias.
 - Apply behavioral techniques to assist with the use of instruments/procedures that are often problematic in the examination of children with ASD/DD.
 - Describe the common components of coping kits and demonstrate the proper use of these elements during the examination of children with ASD/DD .
 - Discuss current research on the examination of children with ASD/DD, delineating components that may prove useful to clinicians and parents/caregivers.

Pre-test Question 1

- All of the following represent established approaches to facilitate the physical examination of a resistant/agitated patient with ASD except:
 - 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 EXCEPT:
 - 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 Reality of Medical Care in Special Needs Populations

77%

- % of primary health care providers- self-rated their ability to care for someone with ASD as (Wexler, Holmes, Shore, & Rollins, 2015):
 - Poor
 - Fail



The Fallout – History Taking and Physical Exams in ASD

(Cuvo, Readan, Ackerlund, Huckfeldt, &
Kelly, 2010).

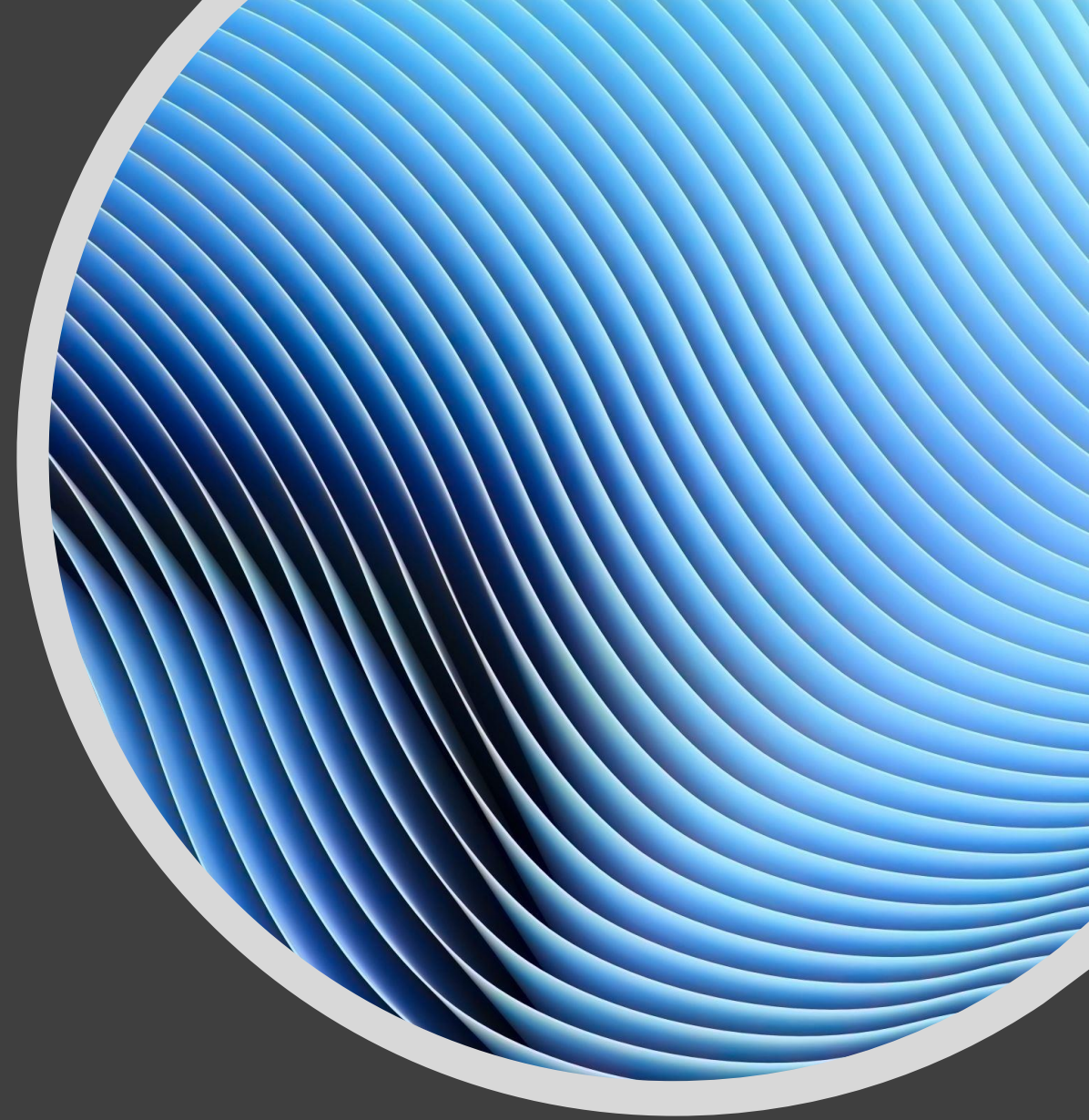
- Health care providers often fail to obtain a detailed medical **history** relying on:
 - Parents/caregivers
 - Incomplete preexisting medical records
- Essential health care **procedures** in this population:
 - Physical restraint
 - Sedation
 - Forgo procedures due to non-compliance

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

- Developmental disabilities are defined as:
 - “a **diverse** group of severe **chronic conditions** that are due to mental and/or physical impairments that affect language, mobility, learning, self-help, and independent living... [that] may include autism spectrum disorder (ASD)” (Drake, Johnson, Stoneck, Martinez, & Massey, 2012, p. 215).
 - Often not a single condition but various causes show a set of symptoms (Rah, Hong, yoon, 2021)
 - High genetic causality
 - Difficulties in **multiple domains** (Rah, Hong, yoon, 2021; Zablotsky, Black, & Blumberg, 2017):

More Important Terminology- Developmental Disorders/ Special Needs Population

- **Developmental Delay** – failure to meet typical developmental milestones within typical time range.
- **Developmental Disability**- medical condition impairing development such as ASD, ADHD, intellectual disability
- **Intellectual Disability**- specific form of developmental disability, originating prior to age 18, limiting intellectual functioning.
 - May include a specific genetic disability, autism spectrum disorder, or global developmental delay (Kaiser & Roberts, 2013).



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 (2+)
 - 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
 - 2021 CDC estimates:
 - 1 in 44 US Children
 - 1 in 27 Boys
 - 1 in 116 Girls
 - Boys > 4 x more likely to have ASD than girls
 - Most diagnosed after age 4
 - Reliable diagnosis as early as 2-years-old

Autism Statistics and Facts. (2021). Retrieved from <https://www.autismspeaks.org/autism-statistics-asd>

Demographics

– ASD

(Facts and Figures. (2018).

Retrieved from
<https://www.autismspeaks.org/autism-facts-and-figures>)

- Challenges:
 - Nearly **half** all children **wander**/bolt from safety
 - High rates of **self injurious** behavior
 - Head banging, arm biting, skin scratching most common
 - Intellectual Disability and ASD
 - 31% also have ID
 - 25% borderline Intelligence Quotient
 - 44% average-above average IQ
 - Medical expenditures average **4.1-6.2** times higher
 - Passage of autism insurance legislation, including mandates requiring some level of coverage, in all 50 states and Washington, D.C. (Bernard, 2019).
 - Treatment for autism a medical necessity, including ABA in some states.
 - Increased access to medical care/treatment

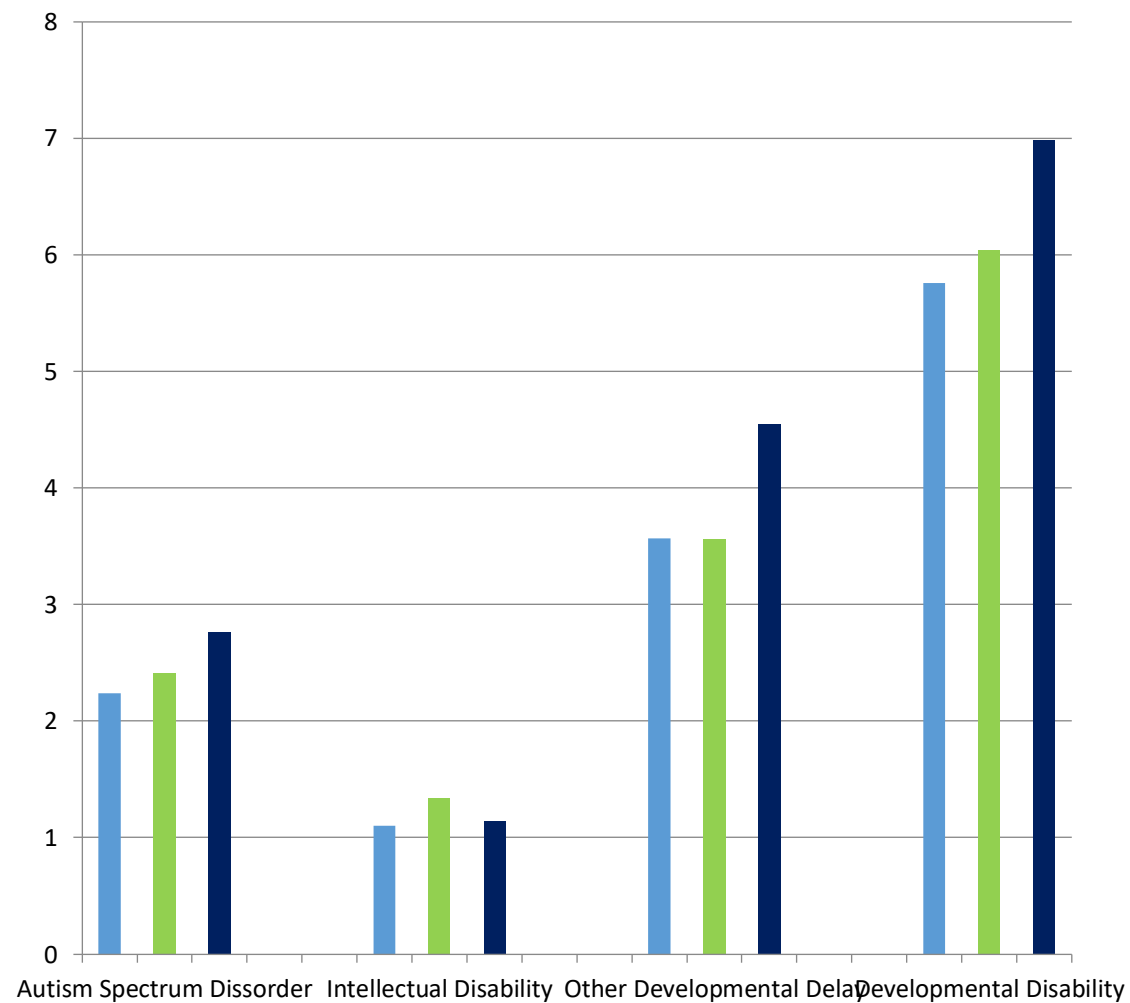
Demographics of DDs

Prevalence of DDs in United States (Zablotsky, Black, & Blumberg, 2017)

- Developmental Disability 2014-2016 in CDC Sample
 - Children aged 3-17 – Increase from 5.79% to 6.99%
 - No relative significant increase in ASD or Intellectual Disability(ID)
 - DD- Boys (8.15%) > Girls (4.29%)
 - ASD – Boys (3.63%) > Girls (1.25%)

- Adapted from Zablotsky et al., 2017

Prevalence of Developmental Disability in Children aged 3-17 2014-2016



Prevalence of Developmental Disorder Worldwide (Rah, Hong, and Yoon, 2020)

- United Kingdom - 4.8% school age children in state-funded schools (Emerson, 2012)
- Taiwan – Developmental Delay – Up from 0.16 to 3.25% over 12 year period children aged 0-6-years-old

Incidence in all Causes of DDs (% increase)			
<u>ASD</u>	<u>Developmental Delay</u>	<u>Language Disorders</u>	<u>Boys vs Girls (Gap)</u>
13.7%	817.6%	30.7%	31.4% (Up from 19.1%)

- Increases in DDs believed to be independent of changes in diagnostic criteria, research methods, or diagnostic awareness (Rah, Hong, and Yoon, 2020).

Important Terminology- Developmental Disorders(Harris, 2013)

- Please avoid:
 - Mental Retardation(MR)/“Retarded”
 - Adopted by medical societies in 1961
 - Replaced terms feeble-mindedness, idiocy, and mental subnormality.
 - All are now considered pejorative
- 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

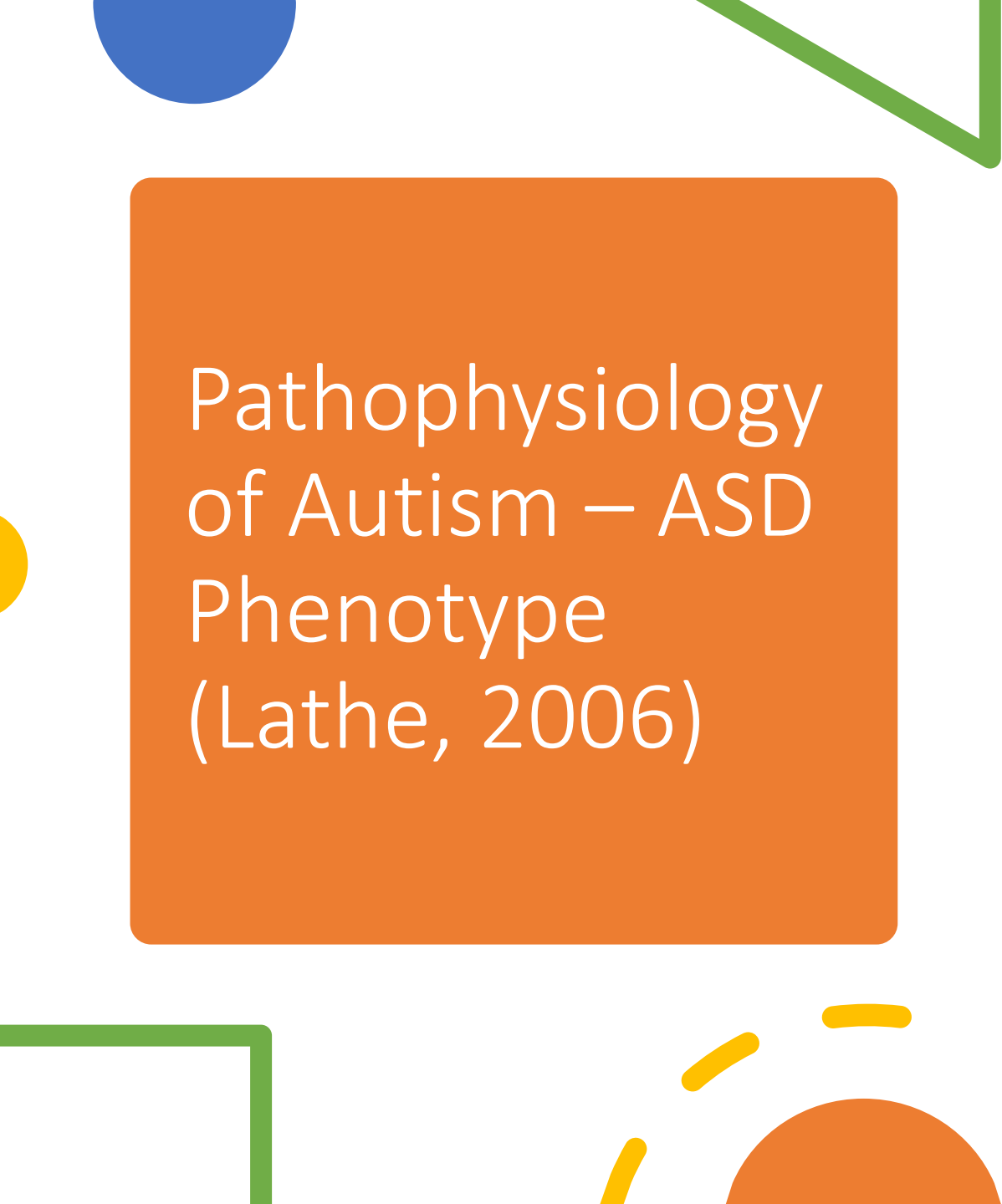
- Decreased blood flow to left temporal lobe

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/lymbic lesions associated with auditory agnosia (“hearing blindness”)



Pathophysiology of Autism – ASD Phenotype (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 of 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 Experience of ASD

- Sensory disturbances may involve acoustic, visual, tactile, and pain stimuli (Lathe, 2006)
 - Heightened response
 - Reduced response
 - Less clear anatomical/physiological linkage than non-sensory ASD deficits

Hypersensitivity (over responsive)	Hyposensitivity (under responsive)	Impaired Sense	Accommodation in Clinic
	Poor response to visual cues	Vision	Pictures/items with high contrast
	Poor Balance/Coordination	Proprioceptive/Vestibular	Opportunities for rocking/swinging/weighted 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/sunglasses

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 sensory stimuli that can trigger of sensory disturbances 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



Language and Developmental Disability

- **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)

- Key consideration
 - *Lack of expressive language does not signify a lack of receptive language*.



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Language and ASD


- “Inadequate” use of language key feature of ASD (Lim, 2011).
 - Early speech delay/regression
 - 1/3rd to 1/2 of individuals with ASD are unable to communicate at a level to express daily needs.
 - Non-verbal
 - 25-30% of children with ASD fail to acquire speech without direct intervention (Mulhern, Lydon, Healy, Mollaghan, Ramey, & Leoni, 2017).



Language and ASD

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





Language and Developmental Disability

Significant speech deficits found in 62% of severely intellectually disabled (Mulhern et al., 2017).

Significant decline in speech acquisition in individuals with DDs after age 5-years-old.

Language and Developmental Disability

- Similar to ASD challenges with speech acquisition affect quality of life
 - Decreased independence
 - Decreased social adaptive functioning
 - Struggles integrating with peers and more withdrawn
 - Development of speech one of most significant predictive factors of positive outcomes for:
 - Behavioral symptom severity
 - Improved socialization





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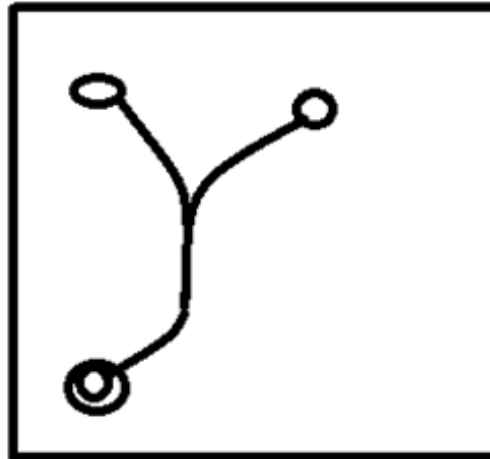


Alternative Communication Options

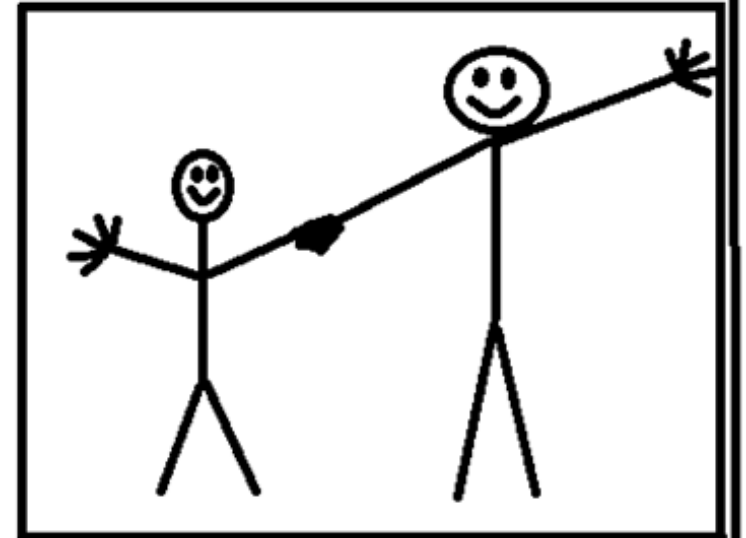
Objects of Reference

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

First



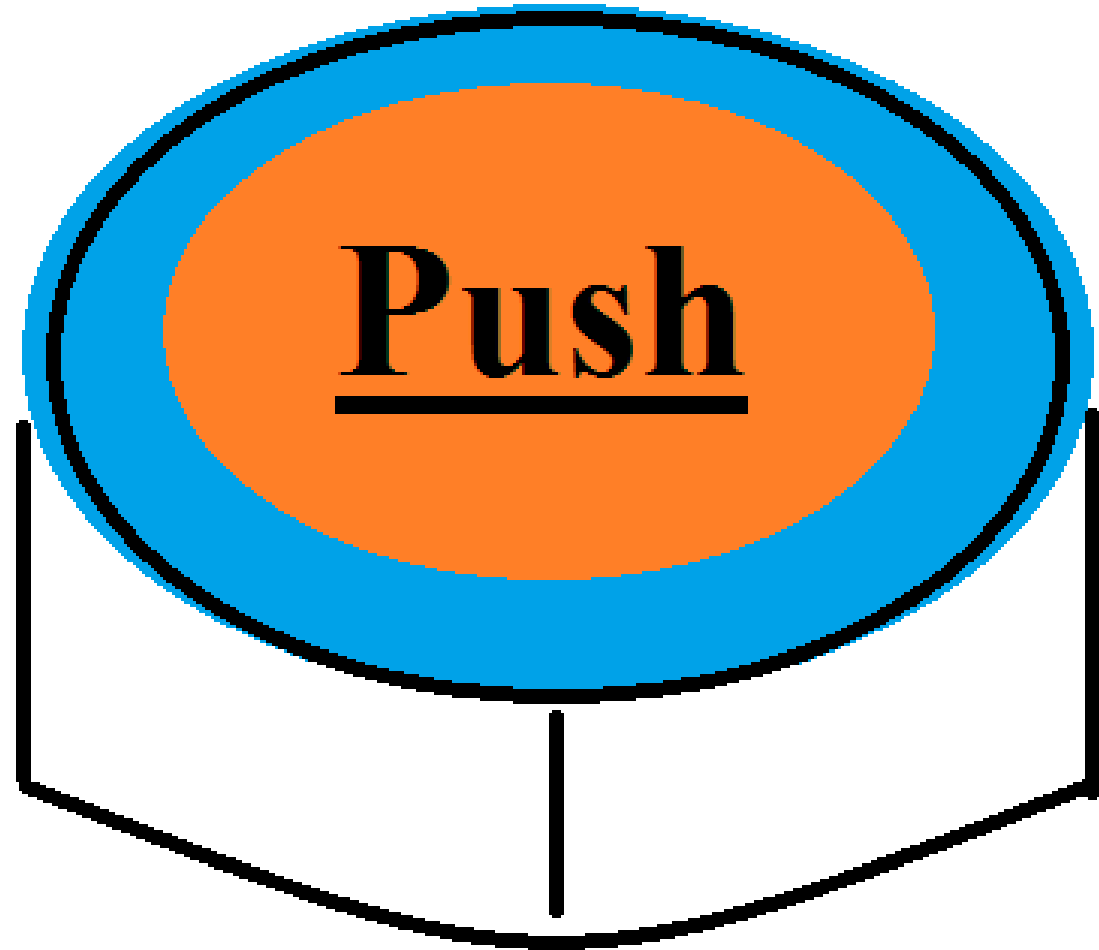
Then



Micro Switches

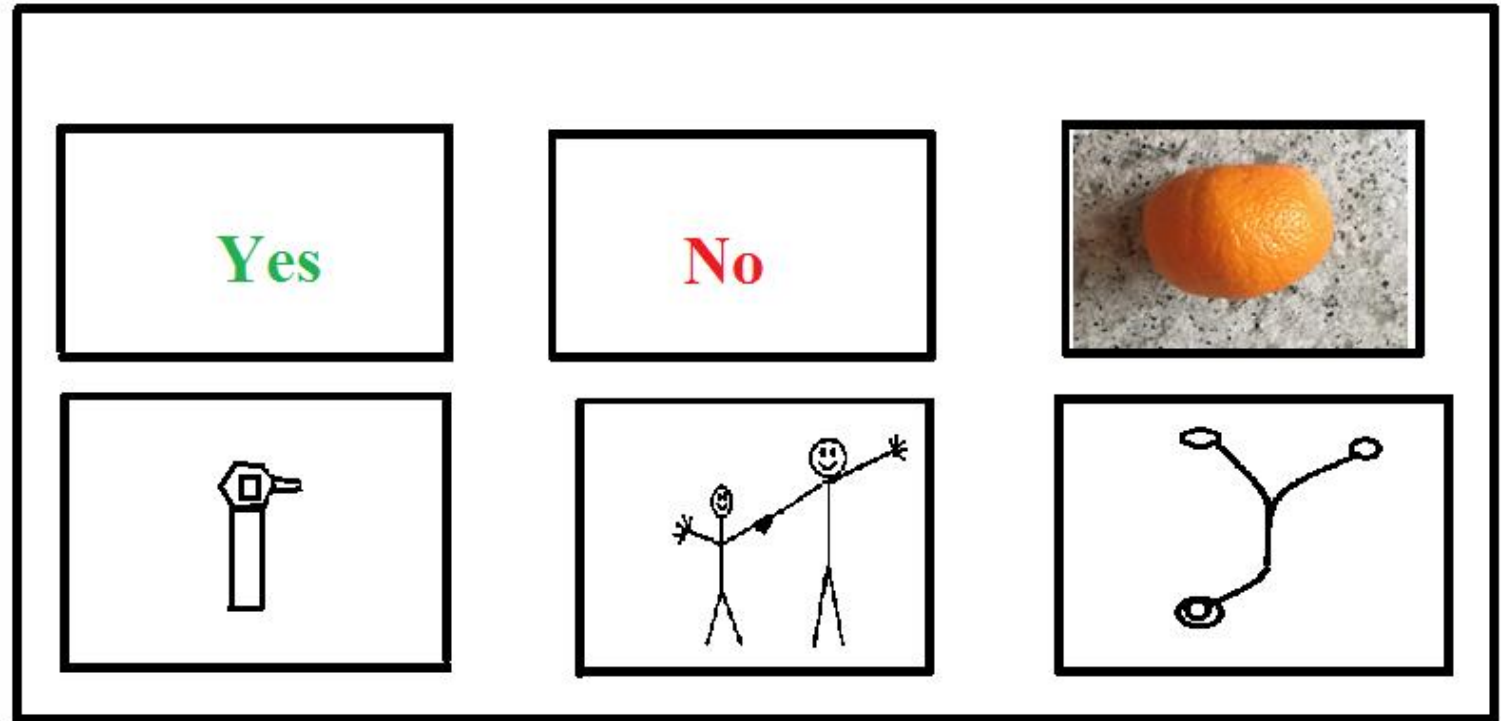
(Cable, 2015; Lancioni, O'Reilly, & Basili, 2001)

- Applying tactile pressure to an electronic switch
 - Wobble
 - Pressure
 - Pull
 - Pedal type inputs (Lancioni, O'Reilly, & Basili, 2001)



Picture Exchange (PE)
Ganz et al., 2014
Lancioni et al., 2001



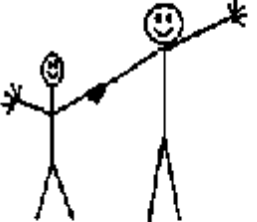
- PE techniques comparable effectiveness speech generation devices in children with comorbid ID (Ganz et al., 2014)



Speech Generation/ Generating 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
 - Increased rate, complexity, and length of speech in children with impaired speech (Luckins & Clarke, 2021).
 - Gains sustained and generalized, including verbal speech
 - Increased probability of listener response (Broadhead et al., 2020)

Speech Generation Devices (SGDs)

No stethoscope goodbye		
Yes	No	More
		



Sign Language (Vandereet et al., 2013)

- Impairments in fine and gross motor functioning may limit the use of sign language in children with ID (Vandereet et al., 2013)
 - ***Sign language may be an adjunct for communication, provided:
 - Baseline cognition is relatively high
 - Fine motor skills are advanced enough to allow hand manipulation to form signs consistently
 - Compared to other AAC forms of communication, manual sign language is poorly understood/responded to by individuals unfamiliar with the manual signs (Broadhead et al., 2020).



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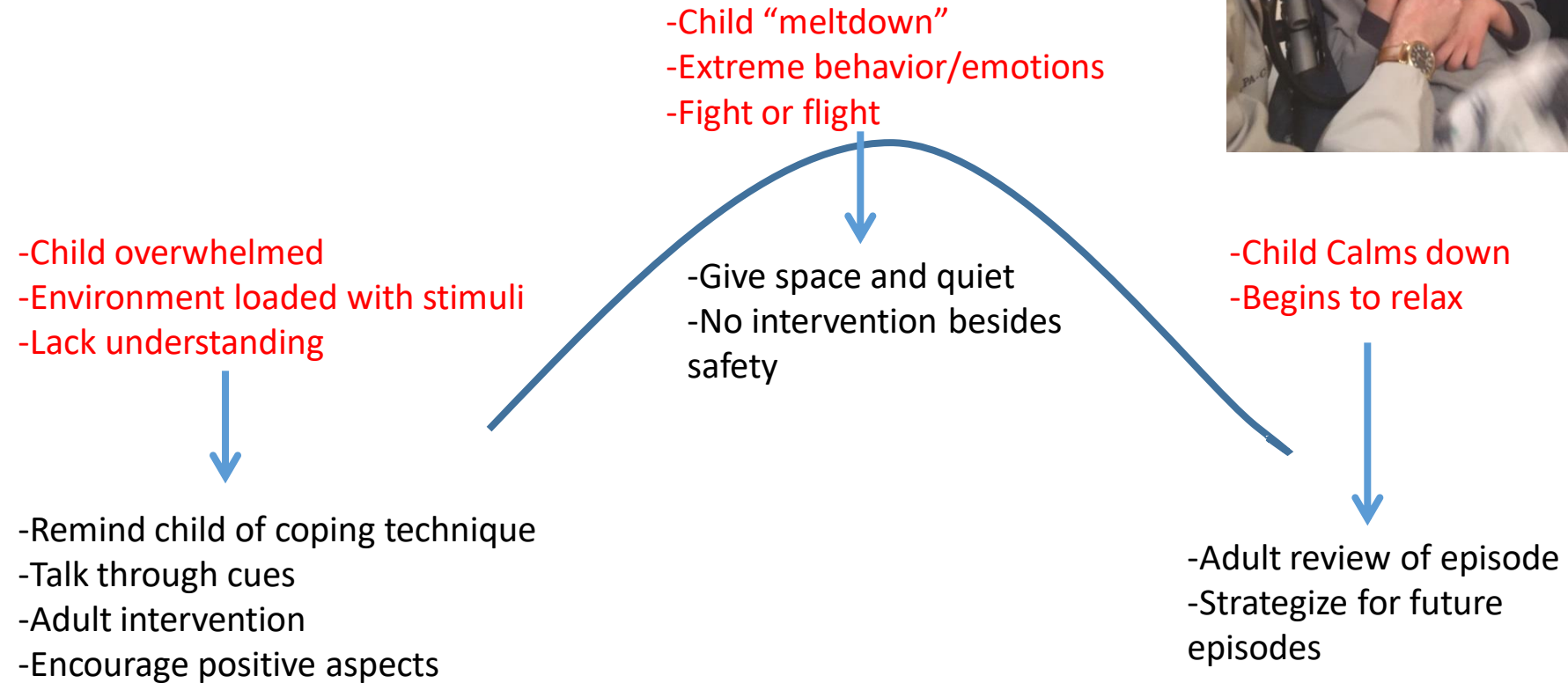
Anxiety (Gillis, Natof, Lockshin, & Romanczyk, 2009).

- Anxiety and fear associated with medical evaluation is increased in the pediatric ASD population.
 - Specific phobias affect
 - 44% of children with ASD
 - 5% of typically developing children (Gillis et al., 2009)
- Minimizing anxiety to medical instruments and procedures higher yield in ASD population (Gillis et al., 2009).



Mountain of Emotion

(Hudson, 2006)





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

Coping Kits- Improved willingness to cooperate through an observed change in child behavior in 79% of cases (19/24). (Drake et al., 2012)

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 concerns**
- Research



Mobility/Examination

(Breslin & Liu, 2015).

Attire

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

Equipment

-Substitute for different color/texture if distracting or child is tactile sensitive

Rely on support personnel

Mobility/Examination

- DD (Palisano, Shimmell, Stewart, Lawless, Rosenbaum, & Russell, 2009)
 - Gross Motor Function Classification System
 - Level I – Walks without limitations at school, outdoors, etc
 - Level II- Walks in most settings. Environment/setting may use wheelchair based on preference
 - Level III- Walks with handheld device (cane/crutches/walker)
Wheelchair outdoors, environment.
 - Level IV- Wheeled mobility in most settings. Self mobility using powered mobility options. Adaptive seating, assisted transfer.
 - Level V – Self mobility severely limited even with assisted technology. Physical assistance from 1-2 others for transfers.



So how do we ensure we are meeting children's needs and assessing their level of functioning?

ASD Needs Assessment

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



Initial Assessment (Hudson, 2006)

- Child's 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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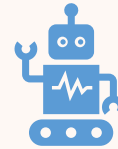
Training Compliance with PE (Cuvo et al., 2010)



**Applied Behavioral Analysis
(ABA)**



**Developed tailored procedures
based on the reasons for non-
compliance**



**10 component, 10-minute
physical exam performed by PA**



**Participants watched 9-min
DVD modelling successful
exam**

Dinosaur puppet narrated steps of exam
praising good behavior
Close ups of medical equipment

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

- Each exam/training session
 - Contact desensitization – gradual exposure to non-preferred stimuli
 - Shaping – address skill deficits
 - Differential reinforcement of other behavior (DRO) – use of preferred reinforcers
 - Escape extinction – aversive stimuli present for at least 10 seconds

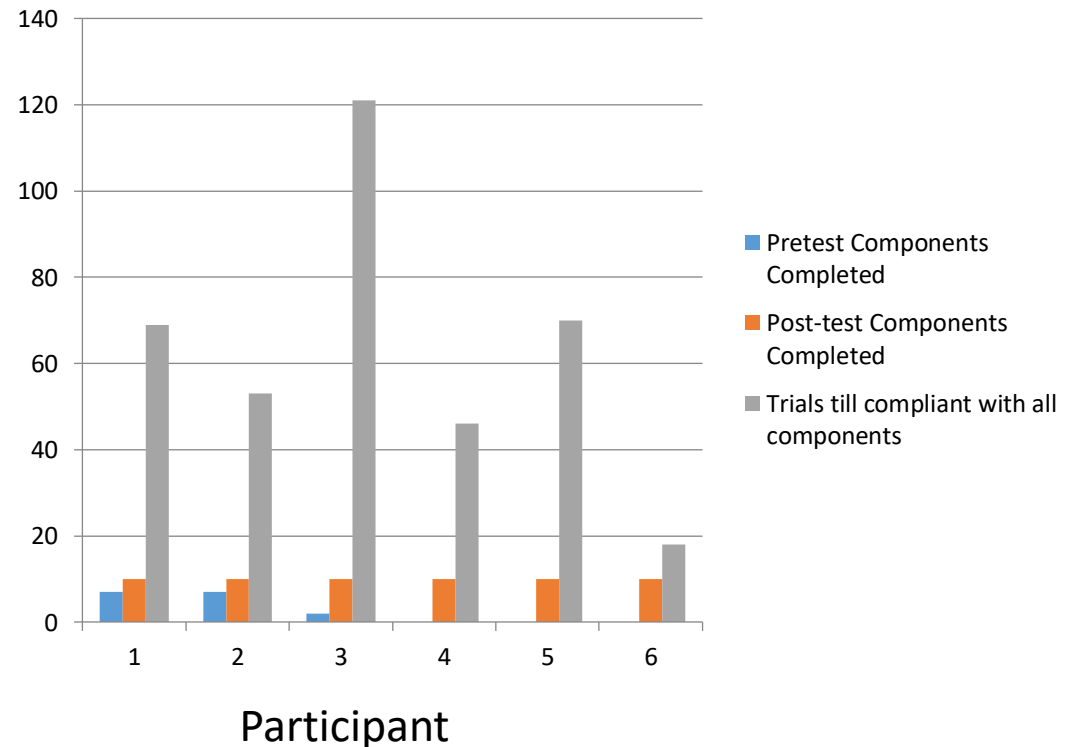


Training Compliance with PE (Cuvo et al., 2010)

- Results
- **All participants** eventually completed all 10 exam components
- Most problematic

exam components:

- Lung
- Mouth/throat
- Nose
- Ear



TEACCH (Orellana et al., 2014)

- Training approach
 - 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
 - Results –
 - Pre-test – 73% of children and 67% adults showed reluctant behavior
 - Post-test- 81.6% of children and 100% of adults showed positive behavior

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 decreased 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

More Tricks of the Trade (M. Bellatuno, personal communication, November 28, 2018)

1

Use clear,
simple
language

2

Give child time
to process
information

3

Repeat
instructions

4

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 except:
 - 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).
 - D. Providing visual cues of the procedure/exam using visual models such as dolls or stuffed animals prior to performing the procedure.

Post-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 EXCEPT:
 - A. Speech Generation Devices (SGD)
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 - C. Functional Magnetic Resonance Imaging (fMRI) enabled speech device
 - D. Micro Switches

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

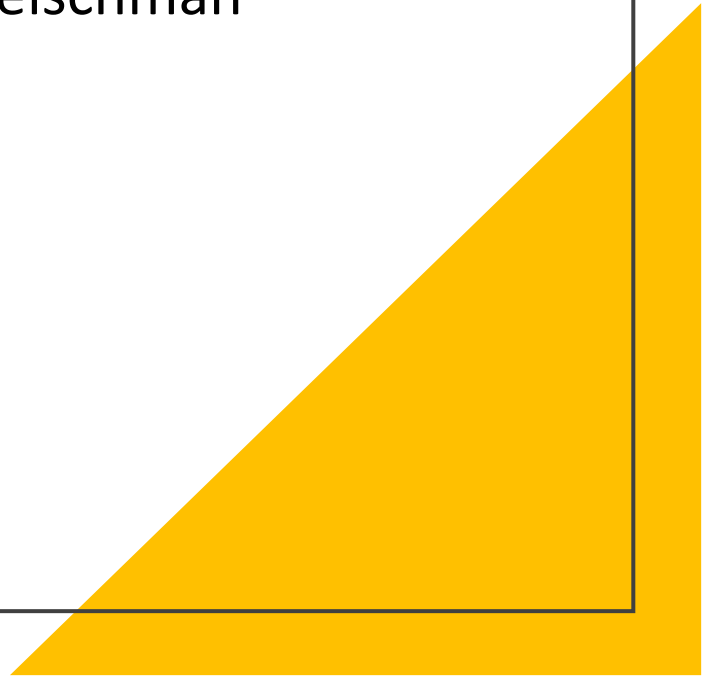
- Accommodations made
 - Lights
 - Chewy tube
 - Examine in stroller
- Specialized Techniques used
 - Custom First-Then Board
 - T-S-F-D
 - Repetition
 - Video after completion

Summary

- 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!

One last
thought...

“I don’t want to be autistic. But I
am, so don’t be mad. Be
understanding.” – Carly Fleischman



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Questions???
Comments?
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- E-mail:
tmmeersman@noctrl.edu

