Broadening the 'Spectrum' of Our

Care: Key Evidence Based Pearls to Ease the Examination of Patients with Autism Spectrum and Developmental Disorders

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Disclosure

• I have no financial relationships with commercial interests to disclose

Other Important Disclosures

- Not only a PA myself, but I am also married to a PA
- Clinical and Academic PA
- Father of three boys: Age 2, 5, 7



Pre-test Question 1

- All of the following represent established approaches to facilitate the physical examination of a resistant/agitated patient with ASD/DD <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/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
 - 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/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

Roadmap

- Intro/Demographics/Terminology
- Sensory Concerns
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The Fallout of Traditional Histories in ASD/DD population

- 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)

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).



- Nationwide survey of primary care health care professional (Wexler, Holmes, Shore, & Rollins, 2015).
- Self-rated ability to care for patients with ASD
- 77% felt their ability to care for someone with ASD as:
 - Poor
 - Fair

• Essential health care procedures in this population, often rely on: (Cuvo et al., 2009)

Physical restraint

- Sedation
- Forgo procedures due to non-compliance

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 "noncompliance" 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 et al., 2012, p. 215).
 - Difficulties in multiple domains (Zablotsky, Black, & Blumberg, 2017):
 - Learning
 - Behavior
 - Self-care

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 (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

Demographics – ASD (Autism Speaks, 2018; Monz et al., 2019)

- Challenges:
 - Nearly half all children wander/bolt from safety
 - High rates of self injurious behavior
 - Head banging, arm biting, skin scratching most common
 - Highly Concomitant intellectual disability (ID)
 - 31% also have ID
 - 25% borderline ID
 - 44% average-above average intelligence
 - Medical expenditures average 4.1-6.2 times higher in ASD
 - Passage of autism insurance legislation in 48 states
 - Increased access to medical care/treatment

Demographics of DDs

- Prevalence of DDs in United States (Zablotsky et al., 2017)
 - Developmental Disability 2014-2016 in CDC Sample
 - Children aged 3-17 Increase from 5.79% to 6.99%
 - DD- Boys (8.15%) > Girls (4.29%)
 - ASD Boys (3.63%) > Girls (1.25%)



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).



More Important Terminology Developmental Disorders (Atkinson, 2013; Kaiser &

- Roberts, 2013).
 - <u>Developmental Delay</u> failure to meet typical developmental milestones within typical time range.
 - 50% delay developmental age vs. chronological age
 - (5) cognitive, social/emotional, physical, communicative, adaptive
 - <u>Developmental Disability</u>- chronic medical condition impairing development such as ASD, ADHD, intellectual disability
 - <u>Intellectual Disability (ID)/intellectual disability disorders</u> (IDD)- specific form of chronic 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).
 - <u>Pervasive Developmental Delay</u>- NOS

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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 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

Sensory Considerations in DDs

(Developmental Delay, 2014; Brownlee, 2010; Benameur, 2018)

- Sensory integration
 - Impaired interpretation of sensory information
 - The "typical" experience
 - Non-painful stimuli Sensory adaptation
 - Painful stimuli- sensitization
 - DD- Impaired transmission/interpretation of stimuli to the brain
 - Can involve visual, auditory, gustatory, tactile, vestibular, and proprioceptive senses

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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

Newman, 2008)

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Language and DD

- High rates of concomitant speech deficits and DD (Meersman & Mathieson, 2019)
- 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



• "Inadequate" use of language key feature of ASD.

- Early speech delay/regression
- 1/3rd 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
Developmental Level and 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



Developmental Level and 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





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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

Speech Generation Devices (SGDs)

PICTURES REMOVED ON HANDOUT DUE TO COPYRIGHT

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Speech Generation Devices (SGDs) Pictures removed on handout due to copyright

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Sign Language (Vandereet et al., 2013)

- Impairments in fine and gross motor functioning may limit the use of sign language in children with ID
 - ***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

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Phobias in ASD/DD

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

Distraction Tools (Breslin & Liu, 2015; Drake et al., 2012)

- Examples:
 - Coping kits
 - Social stories/Written schedules
 - Sensory input activities
 - Other visual communication techniques
- Limit auditory and verbal instructions to short verbal commands

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)

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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

Mobility/Examination

• DD (Palisano et al., 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 Wheeled mobility in almost all settings. Self mobility severely limited even with assisted technology. Physical assistance from 1-2 others for transfers.

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

- Applied Behavioral Analysis (ABA)
- 6 subjects, aged 3-6 y.o., ASD, PDD-NOS
- Medical Office setting
- Developed tailored procedures based on the reasons for non-compliance.
- 10 component, 10-minutes physical exam performed by PA (pretest)

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

- Participants watched 9-min DVD modelling successful exam
 - Dinosaur puppet narrated steps of exam praising good behavior
 - Close ups of medical equipment
 - Target responses modelled

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 to seconds









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/DD
- Improved willingness to cooperate through an observed change in child behavior in 79% of cases (19/24).

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

- Population
 - Mean age of 8.4 years
 - Majority non-verbal (10/18)
 - ASD school setting
- 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

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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




Post-Test Question 1

- All of the following represent established approaches to facilitate the physical examination of a resistant/agitated patient with ASD/DD <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).
 - 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/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
 - 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

Summary –

- These are simple techniques
- Effective resources are inexpensive
- Donate your time (a.k.a.- hit the breaks) (M. Bellatuono, Personal Communication, November, 28, 2018)
- 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???

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