The ABCs of ASD: Demystifying Diagnosis and Management

Denise Rizzolo, PhD, MPH, PA-C
Clinical Professor, Completion Program, Pace University
Thomas Meersman, DHSc, MMSc, PA-C
Program Director / Assistant Professor, North Central College MSPAS Program

Disclosures

- **Thomas Meersman** and **Denise Rizzolo** have no relevant relationships with ineligible companies to disclose within the past 24 months.

“autism” comes from the root “auto” meaning “self.” The term literally means a person removes or isolates oneself.

Myths about ASD

- Caused by “cold” refrigerator mothers
- Children with good eye contact do not have ASD
- Children who are “social” do not have ASD
- All people with ASD have extraordinary skills
- People with ASD just need love to get better
- People with ASD just need more discipline to get better

Prevalence

- About 1 in 44 children meet the characteristics of autism spectrum disorder (ASD) in the U.S. according to estimates from CDC's Autism and Developmental Disabilities Monitoring (ADDM) Network.

- These rates have tripled since 2000 (a 150% increase).

- Occurs in all racial, ethnic, and socioeconomic groups.

- ASD is approximately 4 times more common in males than females (some research can say up to five times).

Diagnosis

- **Three Social Communication Criteria (all):**
  - **Deficits in social-emotional reciprocity**
  - **Deficits in nonverbal communicative behaviors used for social interaction**
  - **Deficits in developing and maintaining relationships**
- **Two out four restricted or repetitive patterns**
  - **Stereotyped or repetitive behaviors**
  - **Excessive adherence to routines, ritualized patterns of verbal or nonverbal behavior, or excessive resistance to change**
  - **Highly restricted, fixated interests ; unusual preoccupations**
  - **Hyper-or hypo-reactivity to sensory input or unusual interest in sensory aspects of environment;**
- **Symptoms must be present in early childhood (but may not become fully manifest until social demands exceed limited capacities)**
- **Symptoms together limit and impair everyday functioning.**

Common Red Flags- How to Identify them

- Speech
- Eye contact
- Reciprocity/Joint Attention
- Pointing/Gestures
- Play
- Imitation
- Relationships

Speech Delay

- One of the most common complaints is a delay in speech
- Speech delay with no other associated symptoms can be a “late talker”
- Look for **Echolalia**
- Red Flags:
  - No babbling by 12 months
  - No words by 16 months
  - No two-word meaningful phrases (without imitating or repeating) by 24 months
  - Any loss of speech or babbling or social skills at any age **– regression is not typical and is a warning sign**

- Examine for receptive or expressive delays
  - Determine if they can understand what you are saying but have difficulty with actual speech – ask them to follow commands (e.g. “give this to Mom”)

Responding to his or her name

- When his or her name is called by a caregiver a healthy baby will typically respond by turning his or her body
  - Only about 20% of babies diagnosed with ASD will respond when his/her name is called.

Which of the following is an example of “joint attention”

A. A child playing next to another toddler on the floor

B. A child going to their room to grab a book

★ C. A child gesturing to another person to engage in the same activity

D. A child making a gesture towards an object

Joint Attention

- Joint attention emerges by 9 months and should be well established by 18 months
- Coordination of one's own attention between an object and another person to indicate a need to share interest.
- Frequently discussed as one of the hallmarks of autism

When does a child typically start to point ?

A. 6 months

★ B. 12 months

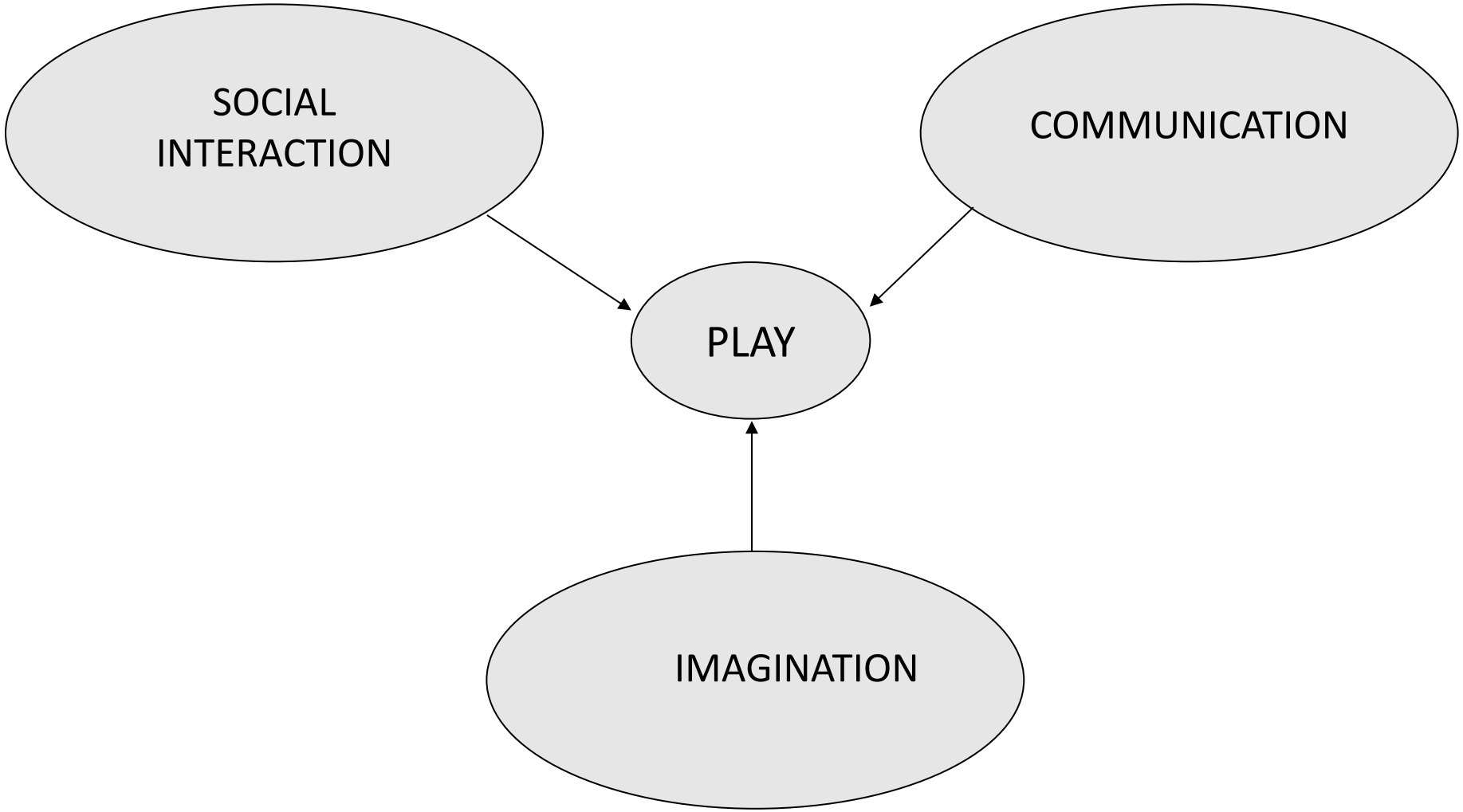
C. 2 years

D. 3 years

Pointing/Gestures

- Pointing -important gesture of the index finger used to request an object or to draw attention to an object to comment on it or share interest in it
  - typically develops by the age of 12 months
- Gestures - used to signal to someone else, such as a give, reach, wave, point, or head shake
  - nonverbal behaviors used to convey or exchange information or express emotions without the use of words

INGREDIENTS OF PLAY



STAGES IN PLAY

- Explorative Play - Sensory – Motor - 3months – 6 months
- Imitative Play – 9 months
- Independent Play - Functional and Parallel Play – 9 months – 2 years
- Symbolic Play – 12 – 36 months
- Pretend Play – 2 years – 2 years 6 months
- Peer Play - Reciprocal Play – 2 years 9months – 3 years
- Cooperative Play – 3 years 6 months – 4 years
- Group Play - rule based games – 5 years
- Organized Sport – 8 years

Play and Autism

- Symbolic play is deficient
  - Using a banana and pretending it's a car
- They have a lack of curiosity or to explore
- 'Theory of Mind' hypothesis was introduced, *Baron-Cohen, Leslie and Frith,1985* .It showed the link between the child's ability to pretend play and his potential ability to understand his own behaviour as well as other people's.

Relationships

- Social reciprocity – back and forth flow of conversation
- Difficulty in understanding the social world
- Difficulty in understanding the thoughts, feelings and intentions of others
- An unwillingness to allow others to share experiences - Lack of spontaneous seeking to share enjoyment, interests, or achievements with other people → Lack of social or emotional reciprocity
- Difficulty in understanding non - verbal cues – facial expression, tone of voice, etc.
- Failure to develop peer relationships appropriate to developmental level

Behaviors-What else to look for

- Insistence on sameness refers to a rigid adherence to a routine or activity carried out in a specific way, which then becomes a ritual or nonfunctional routine.
- Nonfunctional routines are specified, sequential, and apparently purposeless repeated actions or behaviors that a child engages in, such as always lining up toys in a certain order each time instead of playing with them
- Perseveration refers to repeating or "getting stuck" carrying out a behavior (e.g., putting in and taking out a puzzle piece) when it is no longer appropriate.

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.

Roadmap

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

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

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

Movement Disorders

- Difficulty with proprioception
- Abnormal posture and movements of the face, head, trunk, and limbs
- Abnormal eye movements
- Repeated gestures and mannerisms
- Movement disorders can be detected very early – perhaps at birth
- Leads to posturing – extension of extremities

Roadmap

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Alternative Communication Options

Objects of Reference

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

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)

- 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)

Sign Language

- 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).

Roadmap

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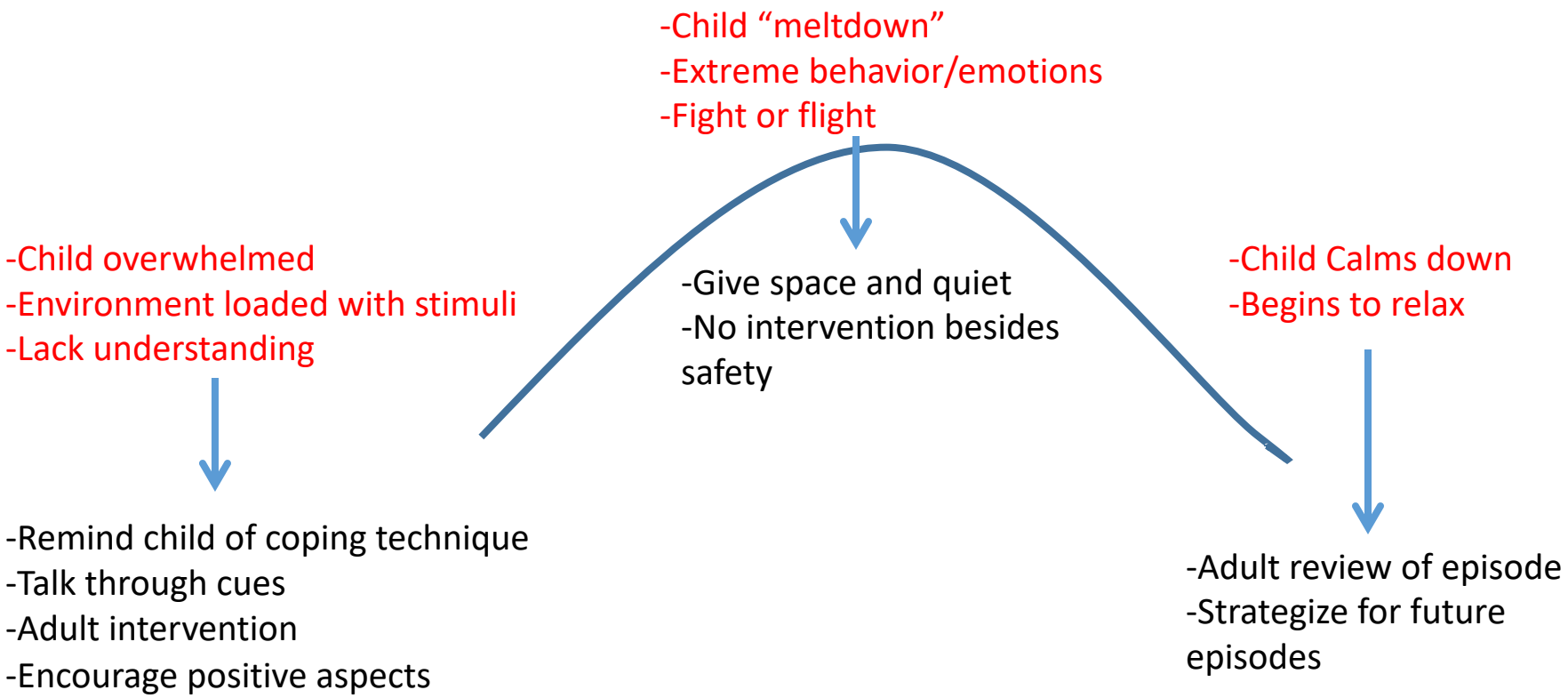
Anxiety
(Gillis, Natof, Lockshin, & Romanczyk, 2009).

- 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).

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

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

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)

- 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

Screening Tools M-CHAT

- M- CHAT http://mchatscreen.com/?page_id=154
  - validated for screening toddlers between 16 and 30 months of age to screen for ASD
  - can be administered and scored as part of a well-child
  - 23 questions parents fill out
- Risk categories based on scores
- Use Follow Up tool is 3-7
- Scores higher than 7 = referral

M-CHAT R/F (Follow up)

- The M-CHAT-R/F is designed to be used with the M-CHAT-R
- Designed to help reduce false positives
  - Users should be aware that even with the Follow-Up, screening tools continue to be challenging- there is no perfect tool to screen
- If a child is positive on the follow up it should be noted these children are at risk for other developmental disorders or delays, and therefore, referral is warranted for any child who screens positive.

Diagnostic Tests

- There is no biological way of confirming a diagnosis of ASD should be based on:
  - the observation of the behavioral features using the DSM-V-TR® framework.
- The Autism Diagnostic Observation Schedule (ADOS)
  - current gold standard for observing features of ASD and should be used in making a diagnosis, along with information from parents

Types of Therapy for Individuals with ASD – An overview...

What is ABA Therapy?
(Demchak et al., 2020)

- ABA = Applied Behavioral Analysis
- ABA Strategies Include:
  - Prompting Methods
  - Complex behaviors broken into small steps
    - Modeling
    - Gestures
    - Verbal/Visual/Physical prompts
  - Reinforcing desired activity through
    - Social Praise
    - Activity Reinforcers
      - Earning a favorite activity
      - Points, stickers, tokens, etc.

What is ABA Therapy?
(Demchak et al., 2020)

- Decrease Problem Behaviors through:
  - Differential Reinforcement of Other Behaviors (DRO)
    - Raising a hand instead of talking out
  - Response Consequences
    - Loss of tokens
  - Systematic Extinction to decrease behavior
    - Not allowing access to tablet for child who tantrums

- Summary:
  - ABA is a scientific approach to studying human behavior with applications to those with ASD, developmental disability, and typically developing.

What is Pivotal Response Training?

(Autism Speaks, 2021; Cadogan & McCrimmon, 2015)

- PRT= aka – Pivotal Response Therapy
- Core theory – moderating "pivotal" areas can spill-over into multiple other domains
- Behavioral tx for autism
  - Play-based
  - Pivotal areas include
    - Motivation
    - Response to multiple cues
    - Self-initiation
    - Self-management

What is Pivotal Response Training?

(Autism Speaks, 2021; Cadogan & McCrimmon, 2015)

Similar to ABA:

- Based on ABA principles
- Increasing positive behaviors
- Positive reinforcers
  - Toys
  - Social Praise

Differs from ABA:

- Less time demand
- Naturalistic environment
- Promotes family involvement
- Self-monitoring of own behaviors

What is DIR Therapy?

(Praphatthanakunwong et al., 2018)

- D=Developmental
- I= Individual Differences
- R=Relationship-Based model
- AKA – DIR/Floortime
- Goals of DIR:
  - Holistic development of individual
  - Relationships building

What is DIR Therapy?

(Praphatthanakunwong et al., 2018)

- Promotion of Relationships through:
- Floortime
  - Children and caregivers play or do activities together
- Home based practice
- Individual Therapy Sessions
  - Communications
  - Emotions
  - Needs
  - Logic
- Parental training in Floortime techniques reinforces development of social/emotional skills in children with ASD

Roadmap

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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

Participant

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

One of the biggest fears of parents is that immunizations cause autism or neurodevelopmental disorders

Keys to Understanding the Myths

- Be familiar with the physiology and public health concepts associated with immunizations.
- Be informed regarding the *evidence-based* benefits and risks associated with vaccines.
- Be prepared to dialogue with caregivers about their concerns regarding vaccine safety.
- Be patient with those with an anti-vaccine mindset.

Public Health Implications

- Herd or community immunity
- Protection for vulnerable individuals by providing immunity to those around them.
  - Reduced incidence of disease means less likely to be transmitted to those vulnerable.
- Only successful when there is high vaccination compliance.

MMR AND THE WAKEFIELD PAPER

- Wakefield,a British gastroenterologist, mentioned a possible link between the MMR vaccine and increased ASD risk.
  - Report evaluated physiologic changes in the gut and noted a coincidental increase in prevalence of ASD in this population
  - Lacked specifics- no identification of peptide, no consistent timeframe
  - Small sample size- 12 children- and not a RCT but rather a case series.
- Additional research explored and subsequently refuted a link between the MMR vaccine and ASD.
- Sequelae: 10 of Wakefield's 13 co-authors retracted their support for the MMR-autism hypothesis. Retraction by the *Lancet* in 2010. Wakefield lost his medical license in 2010.

MMR- Evidence

Danish Study

- Used National Registry to evaluate over 500,000 children
- No differences in relative risk of autism between those who did or did not receive the MMR vaccine

Canadian Study

- Looked at pervasive developmental disorder and MMR vaccine
- Evaluated almost 28,000 children in 55 schools throughout Quebec
- Found autism rates increased with decreased MMR vaccination rates

Reminders from the Experts (M. Bellatuono, personal communication, November 28, 2018)

01

Use clear, simple language

02

Give child time to process information

03

Repeat instructions

04

Redirect by using visual tools

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?
Tips?
Criticism?

- E-mail:
- rizzolde@gmail.com
- tmmeersman@noctrl.edu