



ADVANCING INTEGRATED HEALTHCARE

Screened for Developmental Delay, Now What? ECHO® Session Topic: “Team Based Approach to an Inclusive Office Environment for People with Neurodiversity”

Facilitator: Patricia Flanagan, MD

Faculty Presenter: Ariana DeAngelis, M. Ed.

Case Presenter: Elizabeth Butler MD

Date & Time: February 12, 2025

PLEASE NOTE: Project ECHO case consultations do not create or otherwise establish a provider-patient relationship between any clinician and any patient whose case is being presented in a project ECHO setting

Care Transformation Collaborative of RI



Agenda

Time	Topic	Presenter
12:00 – 12:05 PM	Welcome & Faculty Introduction	
12:05 – 12:25PM	<i>Didactic: Team Based Approach to an Inclusive Office Environment for People with Neurodiversity</i>	Ariana DeAngelis, M. Ed., Training Manager, The Autism Project
12:25 – 12:40PM	Case Presentation	Elizabeth Butler, MD, Ocean State Pediatrics
12:40 – 12:55PM	Q&A and Discussion	
12:55 – 1:00PM	Wrap up; Evaluation; Announcements	Susanne Campbell, CTC-RI



Welcome

Please note that the didactic portion of an ECHO session will be recorded for educational and quality improvement. The case presentation portion of an ECHO session will never be recorded.

Remember to never disclose protected health information (PHI), verbally or in writing, to preserve patient confidentiality.

We are participating in an open and welcoming learning environment. Thank you for generously sharing your knowledge and experience so that all can benefit from it!

Video Meeting Etiquette



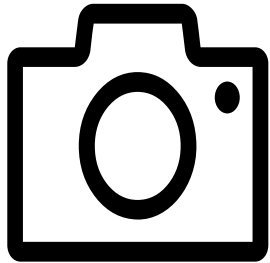
Mute your microphone when not talking.



Limit distractions as best as possible.



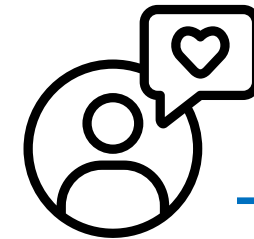
Use reactions & the raise hand feature.



Engage and turn your camera on if you are able.



Use the chat to ask introduce yourself, ask questions and share resources.



Engage - ask questions, offer feedback, provide support.

Faculty Introduction



Ariana DeAngelis is the Training Manager for The Autism Project© (TAP) in Johnston, Rhode Island. With an undergraduate degree in developmental psychology and a master's in special education (severe), Ariana worked as a teacher of autistic/neurodivergent students in Walpole and Malden, Massachusetts, and in Florence, Italy. While at The Autism Project©, Ariana has transitioned the training team to the virtual platform, and brought TAP trainings to self-advocates, professionals, and parents across the US, Europe, Africa, Asia, Central and South America. In collaboration with autistic adults, professionals and family members, Ariana continues to write and deliver trainings focused on supporting neurodivergent people across the lifespan.

Disclosures

- Session presenters have no financial relationships with a commercial entity producing healthcare-related products used on or by patients.

If CME credits are offered, all relevant financial relationships of those on the session planning committee have been disclosed and, if necessary, mitigated.

Learning Objectives

- Participants will understand the sensory, communication, executive functioning, and regulation challenges a patient faces while in a medical setting.
- Participants will develop a list of proactive strategies for addressing said challenges in their setting.
- Participants will develop a list of proactive strategies for preparing families and caretakers for an office visit.

Language Choice

Person-First vs Identity-First

*A Person
With Autism*



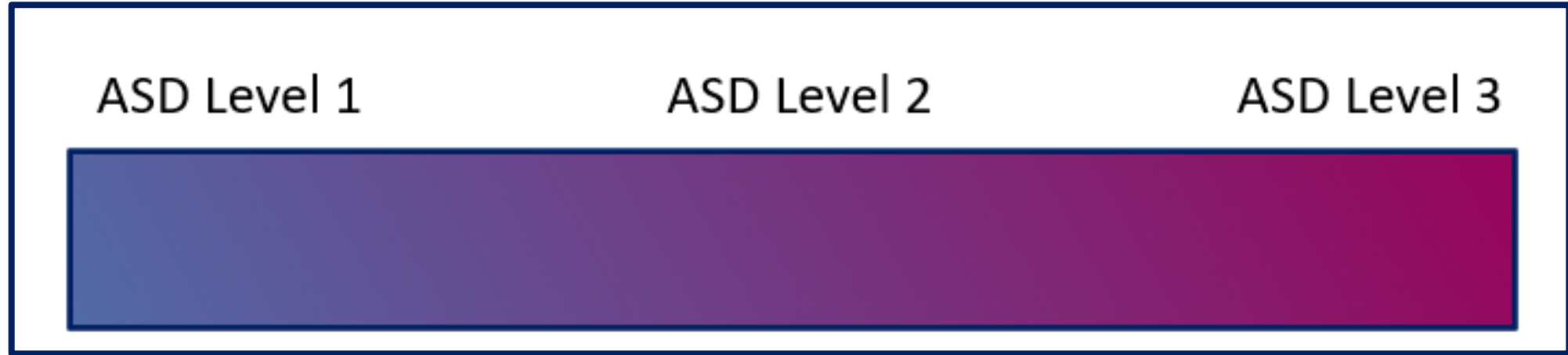
*An Autistic
Person*



*During the times I am read as **high functioning**, I am denied help and support for a lifelong condition I live with. When I am read as **low functioning**, I am denied agency over my life, and told I am not in a position to be trusted to make my own choices.*

-Laura Kate Dale, “Uncomfortable Labels”

“Autism spectrum disorder (ASD) refers to a **neurodevelopmental** disorder that is characterized by difficulties with social communication and social interaction and restricted and repetitive patterns in behaviors, interests, and activities. By definition, the symptoms are present early on in development and affect daily functioning.”

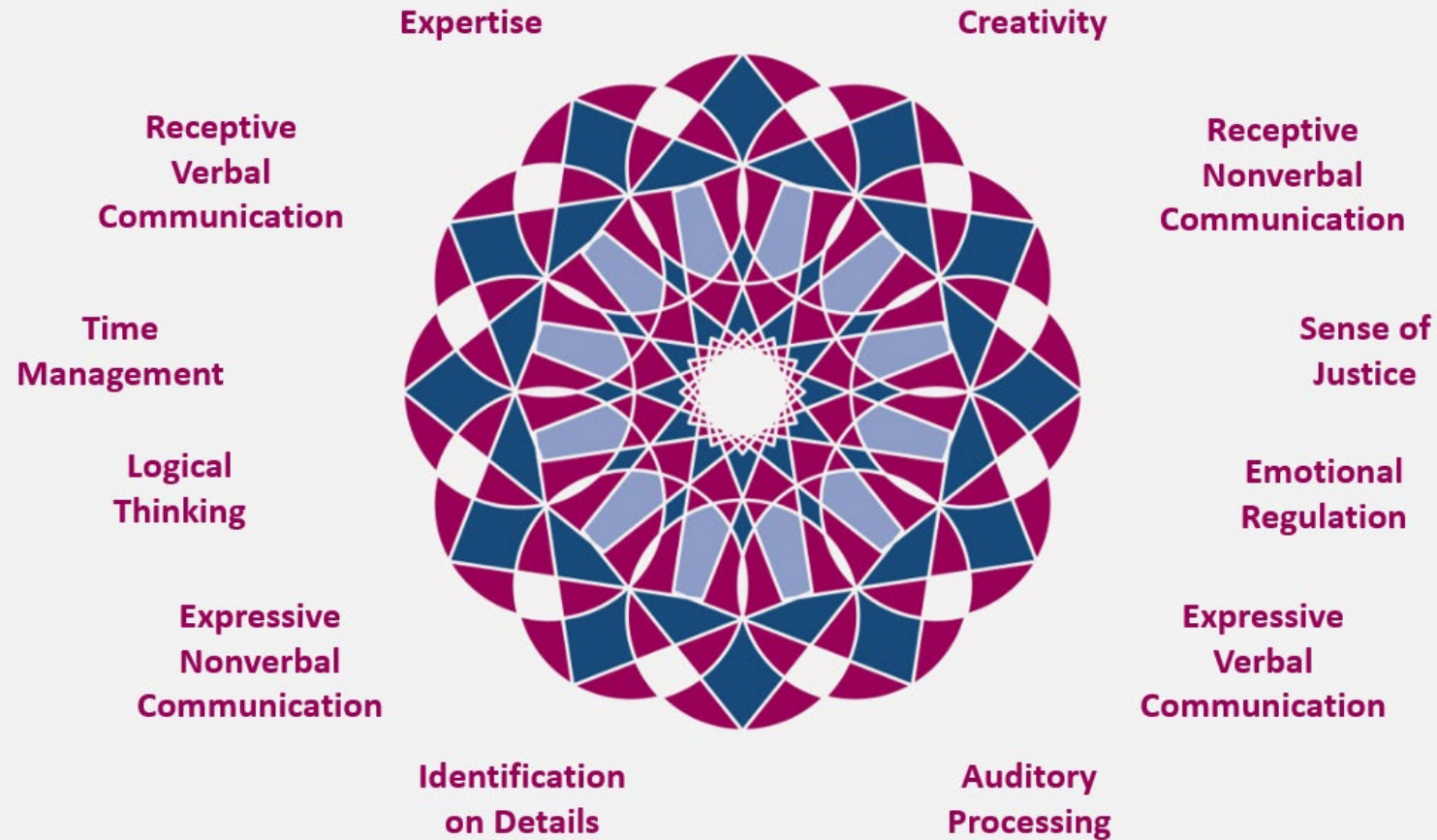


(American Psychiatric Association, 2013)

2 Core Areas of Challenge or Difference:

1. Social Communication (Verbal & Nonverbal) & Interaction
2. Fixed & Repetitive Behaviors, Interests, or Activities

A New Way of Looking At “The Spectrum”



© 2024 The Autism Project



The Patient's Experience



A Visit to the CNDC



A Visit to the CNDC



The External World:
What is the child's
experience?

- Visual
- Auditory
- Gustatory
- Tactile
- Olfactory

- Vestibular
- Proprioceptive
- Interoceptive

A Visit to the CNDC

The External World: What is the child's experience?

- Visual
- Auditory
- Gustatory
- Tactile
- Olfactory
- Vestibular
- Proprioceptive
- Interoceptive

(Bodison, 2022)



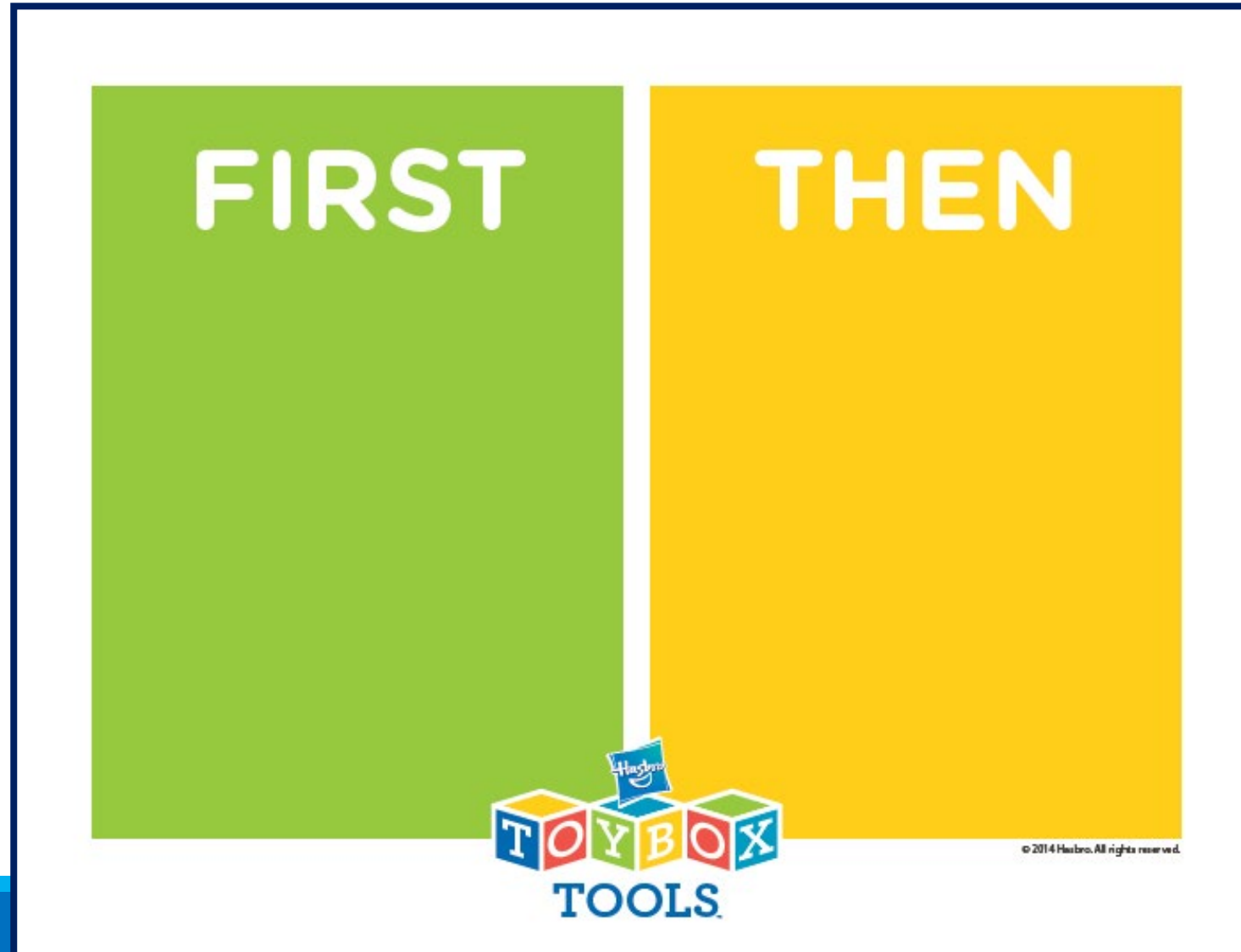
Providing Sensory Tools



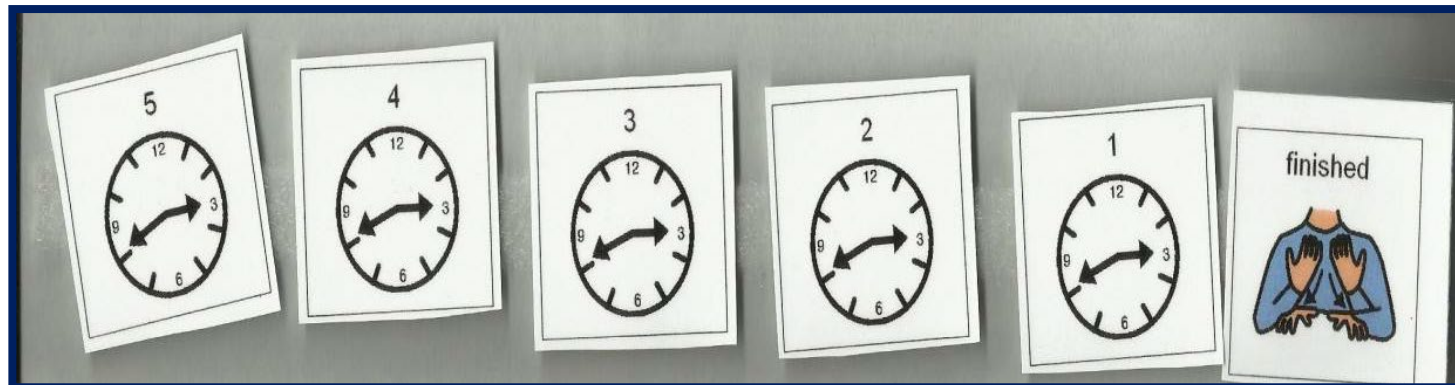


Types of Visuals













First-Then Boards



Countdown Timers



Routine Schedules

 Sit in the chair.		 Take Out Needle	<input type="checkbox"/>
 Put Band On Arm		 Put On Band-Aid	<input type="checkbox"/>
 Wipe Arm		 All Done	<input type="checkbox"/>
 Put Needle In Arm	<input type="checkbox"/>		
 Take Blood	<input type="checkbox"/>		
 Tube Is Full	<input type="checkbox"/>		

When I arrive at the CNDC, we will check in at the front desk. The nurse will ask my grownup to answer some questions and write down some information.

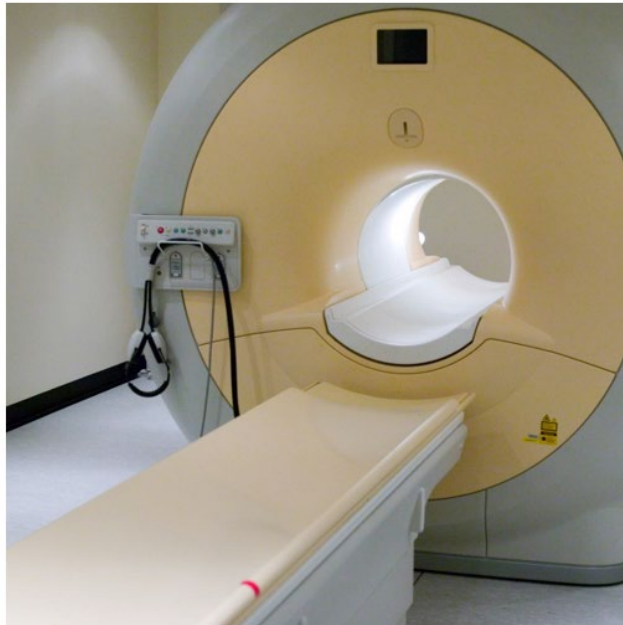


Next, I will go into the waiting room. I can bring my favorite things from home to play with while I wait for my name to be called.



When it is my turn, the nurse will call my name and we will go to another room.

An MRI is a special machine that takes pictures of the inside of my body. This does not hurt.



I will lay down on a table and the nurse may give me headphones to listen to music.



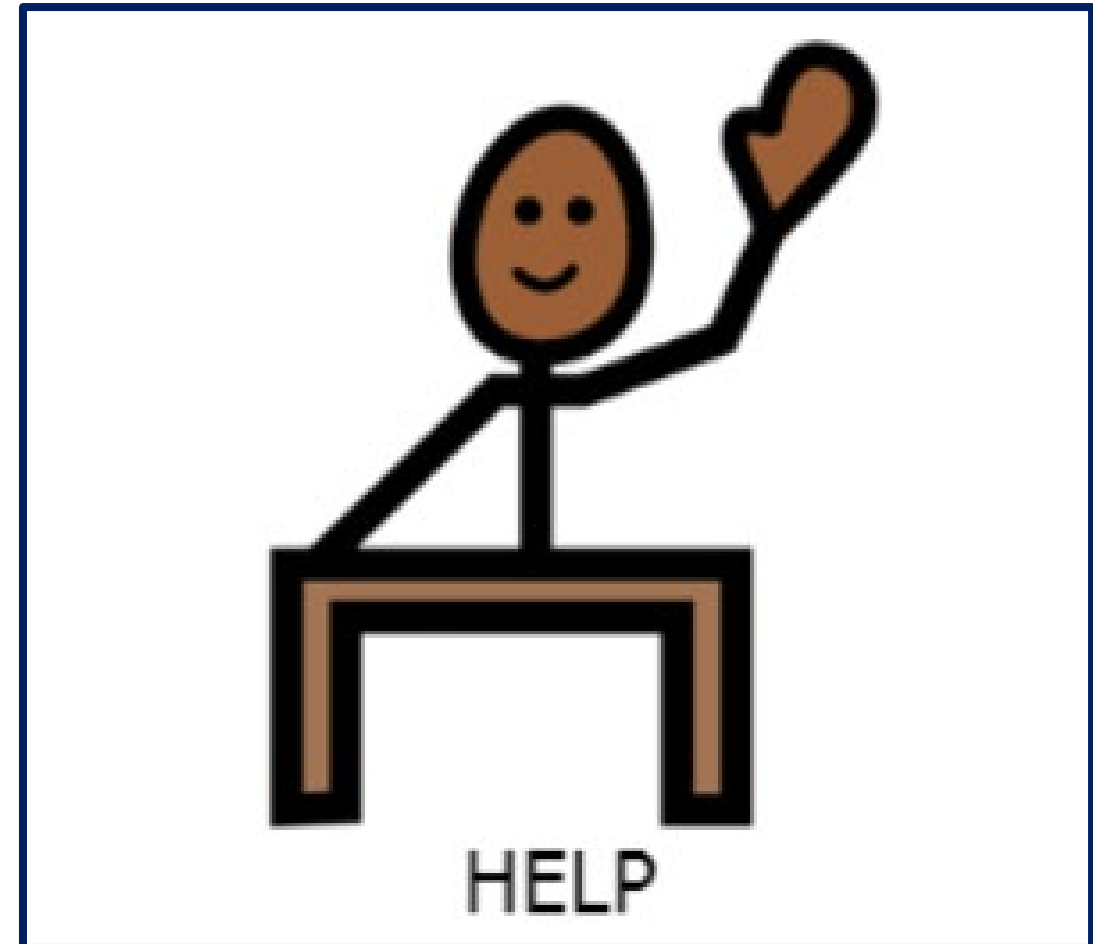


Video Preview



ADVANCING INTEGRATED HEALTHCARE





THINGS TO KNOW ABOUT ME

COMMUNICATION

I am:

- a) Verbal
- b) Pre-verbal
- c) Non-verbal

You can communicate with me best by using:

- a) Simple language with extra time to process the information
- b) Pictures
- c) Written words
- d) Technology

When I am calm I am able to:

- a) Follow verbal and nonverbal directions
- b) Use visuals to help follow directions
- c) Indicate my likes and dislikes
- d) Request what I want or need

STRENGTHS

I'm really good at or I really like:

- a) Sports
- b) Music
- c) Movement
- d) Video Games
- e) Art
- f) Other:

CHALLENGES

I have challenges with:

- a) Self-regulation
- b) Yelling or swearing
- c) Wandering or running away
- d) Aggressive behavior
- e) Self-injurious behavior
- f) Spitting
- e) Obsessive rituals
- f) Maintaining personal space

WHEN I AM UPSET YOU CAN HELP BY:

- a) Increasing space
- b) Offering choices (visually)
- c) Using visuals, written words, or pictures
- d) Reducing or stopping language
- e) Reducing demands
- f) Offering a break or fidgets
- g) Other: _____

THINGS TO KNOW ABOUT ME



Likes & Special Interests



TRIGGERS



SENSORY CHALLENGES



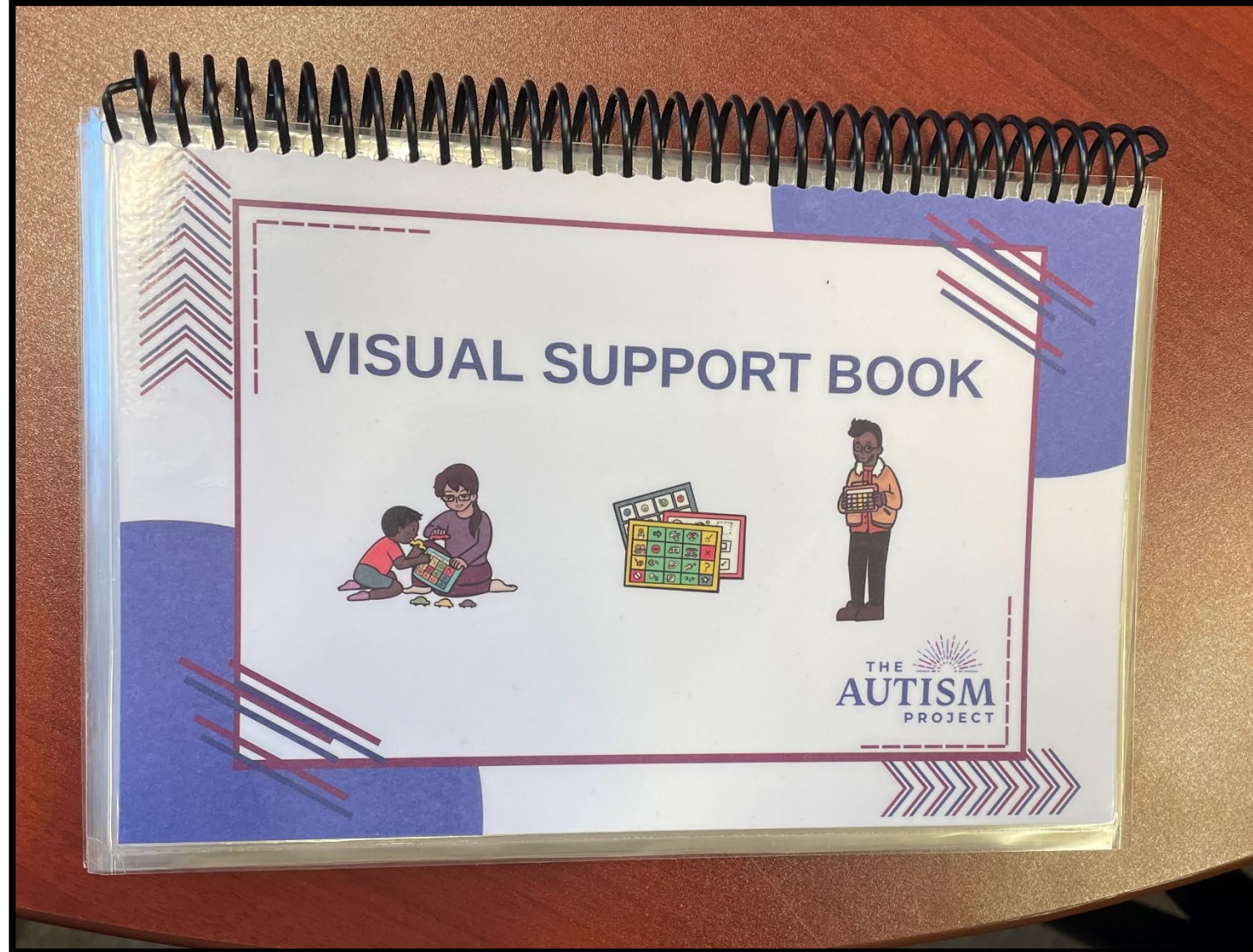
HELPFUL TOOLS

For more information contact:



1516 Atwood Ave
Johnston, RI 02919

401-785-2666
www.TheAutismProject.org



- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Washington, DC
- American Psychological Association. 2020. *Autism And Autism Spectrum Disorders*. [online] Available at: <https://www.apa.org/topics/autism> [Accessed 1 December 2020].
- Bodison, S., (June-July 2022). [Lecture notes on sensory processing and integration}. Mrs. T.H. Chan Division of Occupational Sciences, University of Southern California.
- Laura Kate Dale. (2019). *Uncomfortable labels : my life as a gay autistic trans woman*. Jessica Kingsley Publishers.
- Mr. Potato Head Countdown Timer: <https://toyboxtools.hasbro.com/en-us>
- Autism Sensory Video: https://www.youtube.com/watch?v=DgDR_gYk_a8
- Doctors Office Preview: <https://www.youtube.com/watch?v=1be8NSAt-XA>
- Hasbro Client Tip Sheet: <https://public.3.basecamp.com/p/tcbRrbyVES8ddwKapMo2mAXJ>
- Successful Telehealth Visit (English): <https://public.3.basecamp.com/p/dqjrkkqieNJWJLHMy1FNDJz3>
- Successful Telehealth Visit (Spanish): <https://public.3.basecamp.com/p/9bgtJkBQG1o1oMjvdpoWL7sT>



Questions?



Screened for Developmental Delay, Now What? ECHO® ECHO Case Presentation

Presenter(s): Elizabeth Butler, MD

Date: Feb 12, 2025

Contact Info: 401-886-7881

PLEASE NOTE: Project ECHO case consultations do not create or otherwise establish a provider-patient relationship between any clinician and any patient whose case is being presented in a project ECHO setting

Care Transformation Collaborative of RI

Reasons for Selecting this Case

Do Not Include PHI

Why did you select this case?	To highlight some challenges pediatrician might have when diagnosing and managing child with developmental delay.
Goal for this case presentation?	To share strategies I have used when discussing developmental delay with families.
What questions do you have for the group?	How can we a pediatricians improve this process? How to handle familial hesitation to seek services / assistance / diagnosis/

Information about the Case

Do Not Include PHI

What is the family identifying as the concern?	Initial concerns included difficulties with feeding, reflux, diarrhea, allergy to cow's milk protein. As child grew there was persistent concern with feeding and insufficient weight gain. Family also noted sleep difficulties and slow acquisition of words.
What is the provider/clinician see as the concern?	Failure to thrive, receptive language delay, behavior concerns, prolonged bottle feeding, overconsumption of milk, delayed socialization, limited / picky diet, overconsumption of screentime, toe-walking, constipation.

Patient and Family Information (as relevant) Do Not Include PHI

Age (0-5)	Currently age 3 years.
Gender	Female.
Race/Ethnicity (if relevant)	First generation immigrant (Asian), relevant due to prolonged travel to country of of origin during this time
Insurance	Private commercial insurance
Family composition	Mother, father
Current living situation	Mother, father, no outside childcare/daycare

Patient and Family Information (as relevant) - continued

Health related social needs	Socialization with same-aged peers, dental care, limits on screentime, parental support system, liaison for parent to access services.
Parent and Family Health Wellbeing	Challenging, parents sometimes disagree on clinical plan and have competing priorities.
Observation of parent and child interaction	Parents easily frustrated, typically console child with screentime. Child buries face in parent chest and does not make eye contact with examiner. Parent tends to yell or talk loudly when child does not cooperate. Child does not follow simple commands and cries for most of all visits.
Developmental Screening Results and Trends	M-Chat: Refer. SWYC (6mo): Not at risk SWYC (18 mo, 15 mo, 12 mo, 9mo): Refer.
Safety Concerns	No.
Nutrition and Feeding	Limited repertoire, overconsumption of milk, prolonged bottle use, overconsumption of sugary beverages, parent feeds child, child does not eat independently, child views screen during all mealtimes.
Behavior Concerns	Yes

What goals does the family/caregiver have?

Do Not Include PHI

To improve eating and gain weight, to establish a consistent sleep schedule, to improve communication skills, to work on behavior management (tantrums, meltdowns) and to work on social skills.

Family Identified strengths/successes/challenges:

Strengths & Successes

In close contact with pediatrician, therapeutic alliance with pediatrician

Eager to ask questions and learn about possible diagnosis and next steps

Challenges

Completing referrals, completing intakes, accessing care, family / parent involvement.

Lack of completion of plan, slow to initiate plan

Do Not Include PHI

Practice Identified successes/challenges:

- Child's
 - diet improved
 - sleep improved
- ? established care / plan for services

- Family/Caregiver:
- Therapeutic alliance with pediatrician
- different strategies for behavior management
- setting manageable expectations surrounding diet , sleep, behavior
- discussion regarding screentime

?Difficulty with completion of plan

? follow-through

? lost to care - ? moving

Facilitator Summary & Clarifying Questions



Recommendations from the group

Questions? And Contact information

- Didactic: Ariana DeAngelis, M.Ed. ADeAngelis1@brownhealth.org
- Case Presentation: Elizabeth Butler, MD elliebut@gmail.com

Announcements & Reminders



Next Session Date:	March 12, 2025 @ 12pm
Topic:	<i>Setting the Stage for Developmental Observation</i>
Presenter:	Cynthia Loncar, PhD

Evaluation & CME

- Please provide us your feedback!
- Evaluation/Credit Request Form :
<https://www.surveymonkey.com/r/CareCoordinatioECHOEval>
- Please request CME credits or a certificate of participation when filling out the evaluation at the end of the meeting.



Application for CME credit has been filed with the American Academy of Family Physicians. Determination of credit is pending.