





Care Coordination Session Topic: Autism

Facilitator: Pat Flanagan, MD

Faculty Presenter(s): Susan Jewel, Ariana DeAngelis, M.Ed.

Case Presenter(s): Keyondra Davis, Atlantic Pediatrics

Date & Time: November 29, 2023, 7:30-8:30AM

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







Time	Topic	Presenter
7:30 AM – 7:35 AM	Welcome & Faculty Introduction	Pat Flanagan, MD
7:35AM – 8:05AM	Didactic: Autism	Susan Jewel, Autism Project Ariana DeAngelis, M.Ed., Autism Project
8:05 AM – 8:25AM	Case Presentation & Discussion	Atlantic Pediatrics
8:25 AM – 8:30AM	Wrap up; Evaluation; Announcements	Susanne Campbell, CTC-RI







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



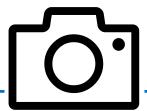
Mute your microphone when not talking.



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

- **Susan Jewel** is the manager of Family Support for The Autism Project © (TAP) in Johnston, Rhode Island. Susan and her team of CCHW's combine professional knowledge and lived experience to support parents, care givers, and self-advocates across the country. She connects them with resources, provides them with training, and offers materials and tools to support autistic people across settings.
- **Ariana DeAngelis** is the Training Manager for The Autism Project©. With an undergraduate degree in developmental psychology and a master's in special education, 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 and the world. In collaboration with self-advocates, 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

- Understand the distinction between a neurodevelopmental and behavioral diagnosis.
- Learn about coexisting medical and mental health conditions impacting autistic people.
- Learn about resources available to support persons with autism and their healthcare teams as they transition from pediatric to adult healthcare.

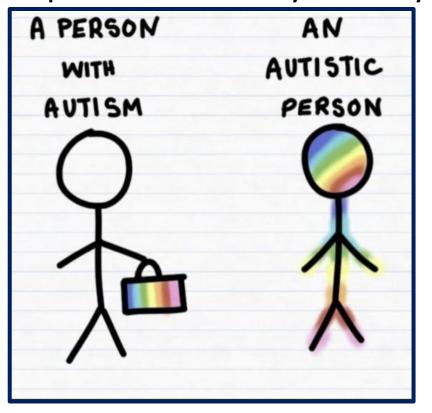






Language Choice

Your patient may choose person-first or identity-first language. Ask each patient how they identify.









"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 Psychological Association, 2020)







Historical View & Current Language

Autism Level 3 Autism Level 1 Autism Level 2

Asperger **Syndrome** PDD-NOS

Autistic

Disorder

(American Psychiatric Association, 2013)

2 Core Areas of Difference:

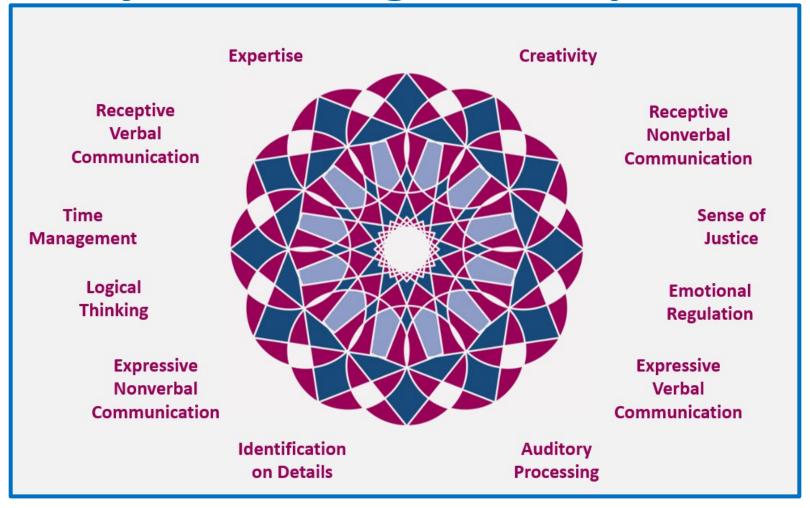
- 1. Social Communication (Verbal & Nonverbal) & Interaction
- 2. Behaviors, Interests, or Activities







A New Way of Looking at the Spectrum









At the UCLA CAN Clinic, the cost of a comprehensive autism evaluation for an adult is a minimum of \$5,000-\$6,000 USD. This clinic does take insurance, but many providers do not. These high costs limit access to an evaluation. As a result, autistic people may choose to self-diagnose, because they cannot access an official diagnosis.



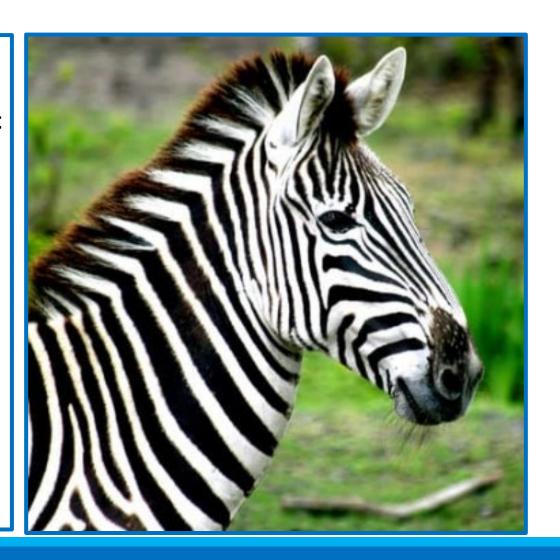






"Why do you need a label?" Because there is comfort in knowing that you are a normal zebra, not a strange horse. Because you can't find a community of other zebras, can't learn what makes a zebra thrive, what brings [you] a zebra joy, if you don't know you are a zebra and you are learning solely from horses. It is near impossible to be happy and mentally healthy if you're spending all your life thinking you're a failed horse, having others tell you you are failed horse, when all along you could be thriving and understood if everyone, including you, just knew you were a zebra.

(Retrieved from adhduk.co.uk)









According to the CDC, the current autism prevalence ratio is **1:36**. Within the autism community, the ratio of males to females is **4:1**. However, many autistic females and nonbinary people go undiagnosed. According to the National Autistic Society in the UK, here are some of the reasons why:

- "Autistic women and girls have characteristics that don't fit with the traditional profile in autism."
- "Autism assessments are less sensitive to autistic traits more commonly found in women and girls."
- "Women and girls are more likely to 'mask' or camouflage their differences."
- "Autistic traits in girls are under-reported by teachers."

https://www.autism.org.uk/advice-and-guidance/what-is-autism/autistic-women-and-girls







According to Van Der Miesen et al (2018), in the United States, **6.5%** of autistic adolescents and **11.4%** of autistics adults indicated that they wished to be a gender other than that which they were assigned at birth. This number contrasts the **3-5%** of the general population.

According to George and Stokes (2018), only **30%** of autistic adults identified as heterosexual (N=309).









Epilepsy: 10-30% of autistic people have epilepsy

Sleep Disorders: Sleep disorders impact roughly 80% of autistic people.

Gastrointestinal Disorders: GI Disorders impact 46%-85% of autistic people.

- Chronic Constipation
- Chronic Diarrhea
- Gastroesophageal Reflux
- Nausea
- Vomiting
- Chronic Bloating
- Abdominal Discomfort
- Ulcers
- Colitis
- Inflammatory Bowel Disease
- Food Intolerance

(Al-Beltagi, 2021)







Allergies: Autistic people are 1.6 times more likely to have eczema or skin allergies and 1.8 times more likely to have a food allergy.

Headaches: Autistic people are 2.2 times more likely to have severe headaches.

Ear Infections: Autistic people are 2.1 times more likely to have ear infections.

Immune Disorders: 25% of autistic people have immune deficiency or disfunction.



(Al-Beltagi, 2021)







ADHD: 50-70% of autistic people also have ADHD. (Hours et al, 2022)

Dyslexia: Researchers estimate that approximately **12**% of autistic people have dyslexia. (Brimo et al., 2021)

Dysgraphia: In a study of 1034 people with autism and ADHD, **59**% had dysgraphia and **92**% had a graphomotor challenge. (Mayes et al, 2019)

Tourette's: In a study of 679 autistic people, **18.4%** had symptoms of Tourette's syndrome (Kim et al, 2023).









The National Autistic Society in the UK reports that:

- 40-50% of autistic people have a clinical anxiety disorder.
- 5-7% of autistic people have **bipolar disorder** (compared to 1% of the general population).

In a study by Kirsch et al (2020), of 220 autistic individuals surveyed **54.1% had depression.**

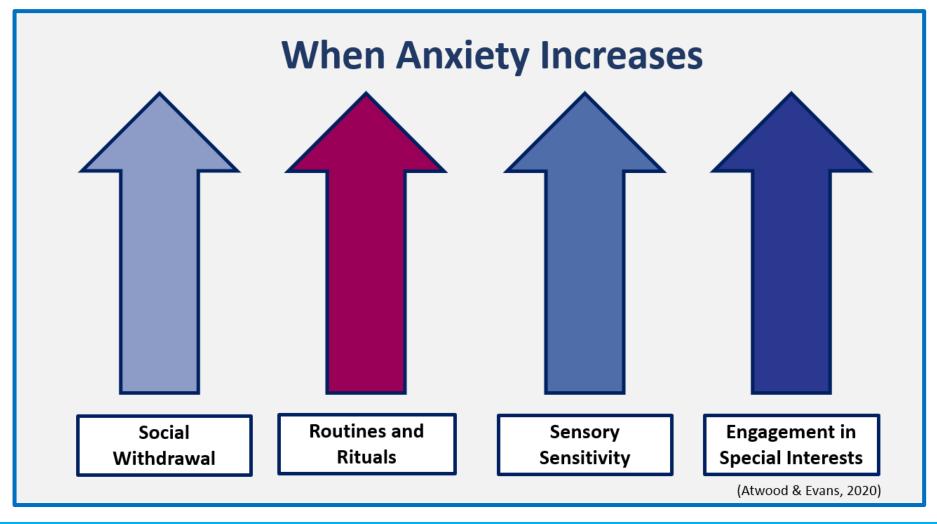
According to Martin et al, an estimated 17-37% of autistic people have Obsessive Compulsive Disorder.

Other diagnoses include phobias, schizophrenia, and substance use disorder.











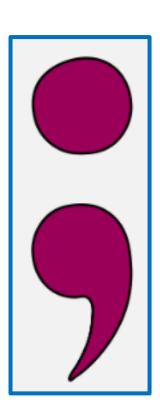




Dr. Sarah Cassidy of Nottingham University reports that:

- more than 60% of autistic people have considered suicide.
- more than 30% autistic adults have attempted suicide.
- nearly 80% of autistic adults have a diagnosed mental health condition.

https://www.autistica.org.uk/our-research/research-projects/understanding-suicide-inautism

















Narratives





Today, the Community Center is offering training on autism. The training begins at 1:00 PST. The community center is located at 6688 Beach Blvd. Buena Park, CA 90621. If you get lost, you can call (714) 562-3860.



When you arrive, you can park in the parking lot. You can park in any open space, except one that is labeled "Reserved" on the sign in front of the space. Parking is free and you do not need to get a parking pass.

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Educating the Community

Narratives





You can enter the Community Center through the front door.

When you enter the building, you can walk straight ahead to the ballroom. You can follow the trail of tan tiles to the ballroom door.

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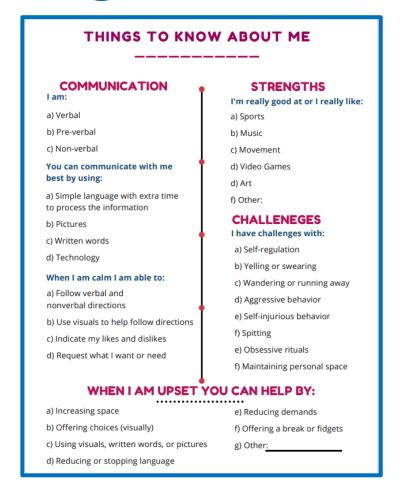








Gathering Information



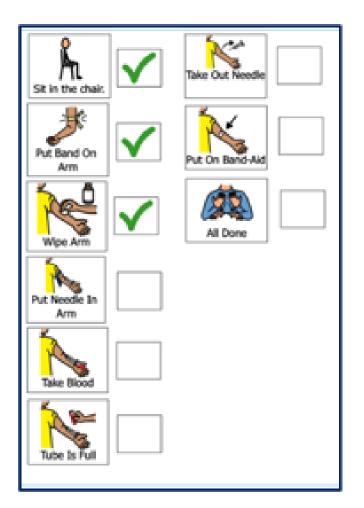








- If asking patients questions, provide adequate processing time (30 seconds or more) before repeating the question.
- If an autistic patient is coming in, provide the option to wait in the car and receive a text when they can be taken into the exam room.
- Make the visit as predictable as possible by providing a schedule or first/then board.









- Offer patients choices. If you are taking vitals, for example, offer the option to apply the blood pressure cuff on the right or left arm. Choice empowers patients and gives them some control over the situation.
- Avoid touching patients unexpectedly. Unexpected touch can be dysregulating.
- Patients may display inappropriate affect when distressed. They may laugh or smile when they are anxious or scared.
- If the person uses a calming tool or fidget, do not take it away unless absolutely necessary.







- Don't demand eye contact. Eye contact may be dysregulating for the person. If the
 patient is not making eye contact with you, it does not mean that they aren't
 listening to you.
- Don't use irony or sarcasm. Your patient may take you literally.
- Limit distracting or distressing sensory input.
- If possible, give the patients breaks as needed.
- If you know what the patient's interests are, consider speaking to them about it.
 This can help to calm the patient's anxiety and to engage them.









Contact information

Didactic:

Susan Jewel, CCHW

sjewel@lifespan.org

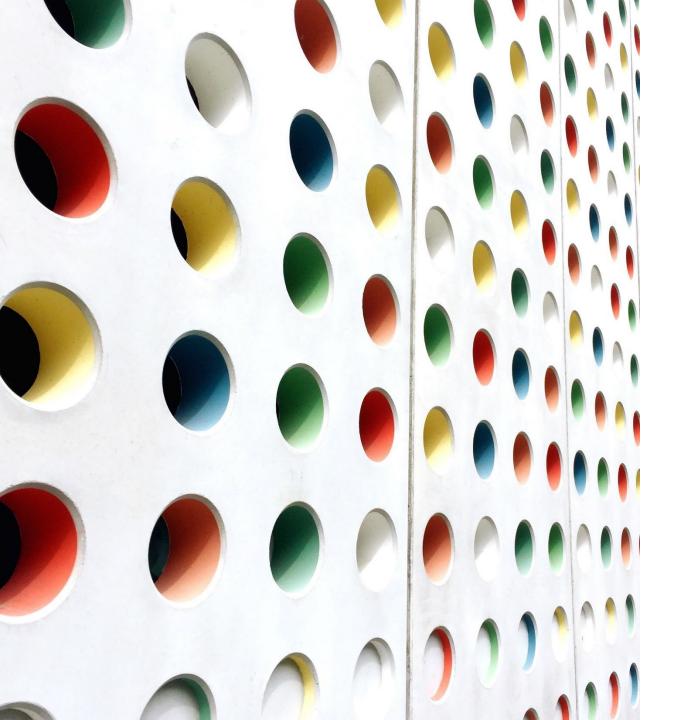
401-785-2666 ex. 3

Case Presentation:

Ariana DeAngelis, M. Ed.

adeangelis1@lifespan.org

401-785-2666 ex. 4



Care Coordination: Developmental Transitions from Infant-Adolescent

BY: ATLANTIC PEDIATRICS
OFFICE STAFF

STOP RECORDING

Case Study

- ❖Pt is a 4yr old male
- ❖ Enrolled in ABA Daycare
- **❖** Latino
- ❖UHC/RiteCare Health Ins.
- Lives with Mom, Dad and new infant brother (mom works days rotating with dad does nights)
- ❖Dx with Autism (May 2021)
- *Has eating disorder, expressive language delay, sensory modulation disorder

Why this case demonstrates successful strategies of improving care coordination.

- Family struggling to understand the cause of pt's autism
- *Mother struggling to get assistance for needs like; initial diagnosis, therapy and etc.
- Assisting pt by helping to create a care plan that eliminates some of the worries for the parents.
- Setting goals and milestones to show the progress of pt development through following care plan
- Provider also assisted by becoming certified in CARS (childhood autism rating scale)

Goals

- ❖Speech Improvement
- ❖ Behavior Improvement
- ❖ Learn independence with ADL's
- Obtaining additional knowledge and tools to pass on to the family
- Help the pt be able to transition through change such as;
 - > Daycare-Kindergarten , etc.
 - > New sibling
 - > Practice accommodations

OT Goals

- *Demonstrate independent carry over of education @ home
 - Ongoing approach for 10 wks
- *Tolerate 10min oral motor warm up to increase lip/cheek strength
 - Moderately improved, ongoing for 4 weeks
- Demonstrate improved activity tolerance such as sitting in a chair for 10min
 - Moderately improved, 3-5 opportunities, 10 weeks
- Sensory-based food hierarchy approach (touch 1 new food weekly without gag or refusal)
 - > Achieved/Ongoing, for 6 weeks

- ❖Improve self feeding skills
 - Moderately improved, 3-5 opportunities, 8 weeks
- Transition through preferred and non-preferred tasks without incident or meltdown
 - ➤ Moderately improved, 3-5 opportunities, 10 weeks
- Planned therapy interventions weekly
 - > 1x a week for 10 weeks

Additional information pertaining to the case

- ❖ Parents express difficulty with behaviors, speech and eating difficulties
- ❖ Provider looking to assist family with outlets and directed tasks that will help increase attention and sensory difficulties
- ❖ Provider and Family are working towards seeing improvements in pts daily living as well as future transitions while the pt continues to grow.
- Looking to reduce challenges with effective communication and follow ups to discuss and make any changes necessary with pt needs

Questions/Group advice?









- Please provide us your feedback!
- Evaluation/Credit Request Form : https://www.surveymonkey.com/r/CCECHOCME2023



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.







This is our final Care Coordination ECHO Session

All recordings can be found:

https://ctc-ri.org/news-events/pcmh-news-and-articles/cme-coursework







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