An Introduction to Autism

Thursday, October 19 | 2:00 p.m. ET

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Agenda

• Identify Autism Spectrum Disorder
• Possible Manifestations/Features
• Communication Challenges
• Interventions/Services
• Communication Tips
• Resources
Objectives

• Improve interactions with individuals on the autism spectrum

• Identify services sought through employee benefits
Poll Question

How much do you feel you know about Autism Spectrum Disorder?

- Almost everything
- A little
- Nothing
What is Autism Spectrum Disorder?
Autism Spectrum Disorder

Autism
Asperger’s Syndrome
PDD-NOS
CDD

Inconsistency
Splitting diagnoses was difficult
Definition

A complex neurodevelopmental disability that impairs a person’s abilities to process input, communicate, and interact

- “Neurodevelopmental disability” = based in the brain and the way the brain works
- Appears to be based on combination of genes and environment
- Can be co-occurring with other conditions; critical to seek professional diagnosis
Manifestations/Overarching Features
Autism Spectrum?
Autism Spectrum?
Autism Spectrum?
Autism Spectrum
Neurodiversity

“The idea that people experience and interact with the world around them in many different ways; there is no one ‘right’ way of thinking, learning, and behaving, and differences are not viewed as deficits”

- ASD, ADHD, ABI, NVLD, OCD

- 7 Principles of Universal Design
Demographics

• No association with race, ethnicity, or socioeconomic status

• 4x more common in males

• Prevalence
  i. 2007 (*2000): 1 in 150
  ii. 2009 (*2006): 1 in 110
  iii. 2012 (*2008): 1 in 88
  iv. 2016 (*2014): 1 in 68
  v. 2023 (*2020): 1 in 36
Differences in the Brain

• Neural connections built at/after birth
  https://www.youtube.com/watch?v=VNNsN9IJKws

• Pruning

• Experiences not translated into skills

• Stress response system

• Example:  https://www.youtube.com/watch?v=aPknwW8mPAM&t=6s
Three Core Concepts in Early Development

Experiences Build Brain Architecture

NATIONAL SCIENTIFIC COUNCIL ON THE DEVELOPING CHILD
Center on the Developing Child

https://www.youtube.com/watch?v=VNNsN9Ukws&t=75s&ab_channel=CenterontheDevelopingChildatHarvardUniversity
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Accommodation Examples

<table>
<thead>
<tr>
<th>Sensory</th>
</tr>
</thead>
<tbody>
<tr>
<td>- fire drill notice</td>
</tr>
<tr>
<td>- alternative lighting</td>
</tr>
<tr>
<td>- noise cancelling headset</td>
</tr>
<tr>
<td>- desk pedaling unit</td>
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| Personal digital assistant|

| Task separation |

| Job coaching |
Duration

- Children may:
  - Have delayed development from birth,
  - Develop typically until sudden loss of skills [age 2-3], or
  - Seem on track until enough language/social skills would be present but instead atypical communication/preoccupations can be observed
- Does not end with childhood

Lifetime Social Cost

Social costs associated with autism for 1990-2019 are estimated at $7 trillion dollars. If the rate of increase in prevalence continues, costs to society could reach nearly $15 trillion by 2029. These estimates only reflect what society pays, not the additional expenses families incur out of their own pockets.

Learn More About Cost

https://tacanow.org/about-autism/
Experiences

Non-speaking: 40%  
Elopement: 49%  
Anxiety: 40%  
Seizures: 38%  
Sleep disorders: 53%  
Above-avg. IQ: *40%  
Gastrointestinal problems: 4x more  
Unmet medical needs: 4x more  
Co-occurring medical conditions: 95% (avg. of 4.9 each)
Intersection of Laws

**ADA-Americans with Disabilities Act**
- Extension of Section 504 in terms of civil rights and protection against discrimination
- No safeguards regarding special education
- Covers most establishments including privately owned and state funded
- No direct FAPE requirement
- No evaluation and placement

**Civil Rights Law**
- Protects all individuals with disabilities
- No protections if expelled from school for behavior that does not arise from a disability
- All related to special education in some way

**Section 504**
- First federal civil rights law to protect rights of individuals with disabilities
- Children must have a physical or mental impairment to qualify for accommodations
  - Provides student with a written education plan
  - No federal funding
  - Procedural safeguards: grievance procedures but general notice requirements
  - Has fewer rights than the student who receives special ed. services under IDEA
  - Evaluation and placement: no consent required for placement, reevaluation only if major changes occurring and only periodic evaluations

**IDEA 2004-Individuals with Disabilities Educational Act**
- Federal Special Education Law
- Federal funding is available to help with the education of students with disabilities
- Disability must affect academic performance
- Only 13 disabilities are covered by IDEA
- Requires an IEP
- Children have right to FAPE even when expelled from school
- Procedural safeguards: no grievance procedures and detailed notice requirements
- Evaluation and placement: decisions regarding this made by a multidisciplinary team, annual evaluation, and reevaluation every 3 years, and requires consent before placement
Dependence

Adults with ASD:

- 49% live with parent/relative
- 27% live in group homes
- 8% live in institutions
- 5% living situations are unknown
- 10% live independently

https://tacanow.org/about-autism/
Middle-aged adults with ASD: 2.6x more likely to have a diagnosis of Alzheimer’s/other dementias

Risk

age 72 is the average life expectancy of an individual without autism

age 36 is the average life expectancy of an individual with autism

40x more likely to die from preventable injuries

https://tacanow.org/about-autism/
• No cure
• Continuing stress on caregivers

"People who are 'high functioning' or 'don't look or act autistic' are still having a hard time. A lot of us do this thing called 'masking,' where we basically act as if we are neurotypical based on the stuff we learn from others. It is very exhausting to keep up that fake persona." —u/jakobebeef98
“Autists are the ultimate square pegs, and the problem with pounding a square peg into a round hole is not that the hammering is hard work. It’s that you’re destroying the peg.”

~ Paul Collins
Accessing Services

Health/Nursing Care
Speech and Language Therapy
Behavioral Health
Mental Health
Occupational Therapy
Physical Therapy
Additional Therapies (Developmental, Equine, Music, etc.)
Special Education
Mentoring
Accessing Services

Education Advocacy
Financial Assistance
Employment Preparation
Service Animals
Adaptive Toys/Bikes/Learning Tools
Durable Medical Equipment/Adaptive Clothes
Consumable Medical Supplies
Respite Care
Legal/Financial Planning

*Check with local advocacy groups about emergency/police ID programs and unique offerings
Services

ACNet sites

Tele-mentoring available

15 countries
Reduce sensory input - but make fidgets available.

Be direct and use literal language.

Tell them it is okay to stim.

Allow for the use of coping skills like counting, deep breathing, or recitations.

Don’t wait for/require eye contact.

Offer breaks.

Meet their preference/ability for means of communicating.

Check for understanding.

Don’t judge. Be patient and mindful of their right to maintain dignity. Remind others not to stare, whisper, or tolerate bullying. But later explain what you know instead of keeping the topic in the shadows.
Engage, listen, and model inclusivity

Focus on strengths

Consider whether forms and processes can change
“always done this way” → why?

Interviews:
- Small talk
- Eye contact
- Concepts vs Concrete

Event Neuroinclusivity:
- info about venue, etc.
- closed captioning
- quiet areas for breaks and lunch
- standing space for people who need to move
Takeaways: Autism is…

- Not Visible
- Everywhere
- Variable
- Not “Curable”
- Manageable With Resources
- NOT Misbehavior
Together
Together
Submit questions to our presenters using the Chat.
Thank You

Please complete your event evaluation

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