Autism and ADHD: How Does Neurodiversity Impact Clinical Care?

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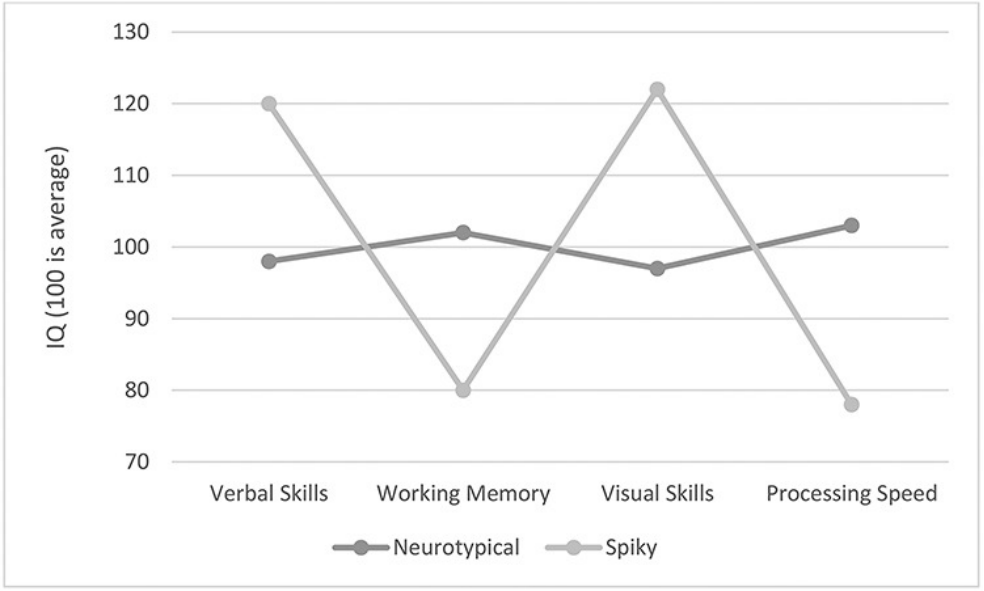
Objectives

- Recognize patients who have communication differences, learning disorders, autism, and ADHD.
- Learn strategies to help neurodiverse patients participate effectively in medical care and treatment planning.
- Review tools and strategies that may help you organize your practice to serve individuals with developmental differences.

Conceptualization of Neurodiversity



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Epidemiology of Neurodiversity

- Learning Disabilities
- 9% of US adults have some type of learning disability
- 1/16 public school students have an IEP for special education services
- ADHD 5-10% of world population greater in US than other countries M>F
- Autism 1/59 or 1-2% of US population M>F

Dyslexia

1. Dyslexia is the most common learning disability. Individuals with this medical condition have difficulty in the areas of language processing and struggle with reading
2. 10-15 percent of the US population is dyslexic. It is very common.
3. About 70 to 85% of children who are placed in special education for learning disabilities are dyslexic.[3]
4. People with dyslexia may be creative than average.
5. Dyslexia ranges from mild to severe. Around 40% of people with dyslexia also have ADHD.
6. People with dyslexia may have enhanced abilities to visually scan and to see incongruities/ to envision things in three dimensions.

Epidemiology of Neurodiversity

	Difficulty	Strength
ADHD 5-8% of US Population	**Time management** **Concentration, attention and self-regulation difficulties** **Insomnia, depression, injury prone** **Maintaining employment** **Difficulty with teamwork**	**Creative thinking** **Visual-spatial reasoning ability** **Hyper-focus, passion and courage**
Autism 1/59 1-2% of US Population	**Time management** **Concentration and coping with more than one task** **Social and communication difficulties** **Need for routine** **High level of trait anxiety**	**Memory ability, and specialized individual skills including reading, drawing, 3D visualization, music and computation** **Innovative thinking and detail observation**

Co-morbidity between the two conditions is high.
If Autism, approx. 70% ADD/ADHD
If ADD/ADHD approx. 10% have autism

Neurodiversity can be a strength for individuals and communities

Systems are rarely planned to accommodate difference

- Heath care environments are not usually created to acknowledge and support diversity.

Exam rooms all look the same

One waiting room available

Generally, one way to make or cancel an appt (phone)

One way to obtain medications

One way to receive patient instructions to take home (written).

How to identify patients with neurodiverse cognitive profiles

- ASK!
- -Do you have trouble with attention, focus, or memory? Are there ways we can help you to make your medical care more accessible?
- Have you ever been diagnosed with ADHD, autism or learning disabilities? Are you sensitive to noise, light, or textures in a way that makes it difficult to focus on what we talk about together?

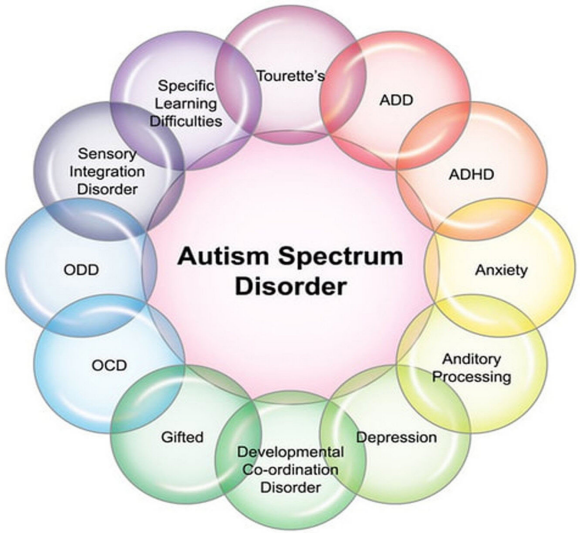
Is there anything I can modify now to make you more comfortable during this visit? I want to make sure we communicate in a way that is most helpful for you.

- What are your preferred pronouns/what is your gender identity? People with diverse gender identity have higher rates of autism (est. 20%).

Neurodiverse cognitive profiles may be present even when no history is given

- People who have education that far exceeds their employment or social situation with no clear explanation may have neurodiverse cognitive profiles or autism.
- History of many job losses/changes could suggest untreated or undertreated ADHD or other cognitive differences.
- Not completing high school could suggest unrecognized learning disorders and/or cognitive differences.

Considerations to Support people with Neurodiverse cognitive profiles in healthcare settings



Sensory Supports

Communication Supports

Family/Social Supports

Sensory Preferences

- Sensations are different for everyone. Something you find benign could be painful for someone else.
- Common sensory challenges neurodiverse people face in medical care:
  - The waiting room (unfamiliar sounds/smells/crowded)
  - The exam table paper (the sound it makes, the way it feels)
  - The lights (too bright, make a noise)
  - The blood pressure cuff (painful/anxiety provoking/sound of velcro)
  - The gown/paper tops (scratchy/smelly/unfamiliar)
  - Sounds in the hallway or outside the room are anxiety provoking

Communication strategies

- People with lower working memory may benefit from shorter, less complex instructions with written reminders of what was said.
- People with slower processing speed will benefit from time to respond, if given time many can fully participate in care but will need time to process.
- People with lower ability overall may benefit from concrete examples of what will happen, if they do or do not choose medical options, and may benefit from having a support person with them in person or by phone in visits.

Receptive vs Expressive Language

-Autistic people have varying levels of expressive language. Receptive language often is much greater than expressive speech.

-Patients who are entirely non-verbal may understand most or all of what you say during a visit even if they never speak.

-Even people with college level reading comprehension and speech may be unable to effectively communicate in a health care visit or use a telephone, especially if receptive and expressive language are divergent, or when anxiety is high.

Communication preferences

- People with ADHD may benefit from written instructions on the AVS but because papers are often lost/misplaced, consider offering that your patient could record a voice note, text the information to themselves, or write it in a notes app.
- People with reading disabilities may also benefit from recorded after care instructions. Phones make this quite straightforward.
- Individuals with autism may prefer written aftercare instructions and may prefer to communicate during the visit by writing rather than talking to you. This can be done with paper and pencil, text to voice apps, or in virtual visits- the chat function works well.
- Many neurodiverse people do not like/will not talk on the phone. Consider how this may impact scheduling appts/reminders. Offer texting/mychart/mychart proxies.

Family/social supports

- Balance autonomy/privacy and appropriate support
- Ask the patient if it would help to have anyone else share information or help with follow up
- if caregivers are not present at the visit, the patient can call them from the visit using his/her/their own phone
- If appropriate, help the pateint to put release on file so supportive family/friends can call the office/help with scheduling and follow up.

Tools to help improve patient care

- For autism specifically: www.autismandhealth.org
- Collaboration between a few academic centers and autism self advocacy groups. Goal to improve medical care for individuals with autism. Tools can help anyone have a more tailored medical experience.
- There is an option there for patients to use a survey tool that creates a personalized letter to be shared with care providers that makes suggestions about how to best help them receive and participate in care effectively.

Example of recommendation letter

Autism Healthcare Accommodations Report

Name: John Doe **Date of Birth: 1981-6-6**

The purpose of this report is to help you, your staff, and John Doe have more successful visits. Due to the heterogeneous nature of autism spectrum disorders (ASD), the information and recommendations in this report have been **custom generated** to be specific to John Doe.

I Information to Assist with Patient Communication

Receptive speech: He can usually understand spoken language well.

Expressive speech: His ability to speak changes depending on the situation.

Alternatives to speech: He uses text-based alternatives to speech (text-based AAC, typing, written notes, iPhone app).

Reading: He can read at a college level.

Writing: He can write or type at a college level.

Telephone: He cannot use the telephone.

Other important information about John Doe's communication.

- He may have difficulty communicating, even if his speech sounds fluent.
- He often takes langauge too literally.
- He can write or type better than he can speak.

To help John Doe better understand what you are saying.

- Use very precise language, even if it means using longer sentences or advanced vocabulary.
- Write down important information or instructions.
- Try not to talk to him while there are other noises.

Office of Developmental Primary Care

- http://ODPC.ucsf.edu

Well developed program in the department of family and community medicine at UCSF to improve healthcare outcomes for people with disabilities.

Good library of forms that may be useful to help patients prepare for upcoming visits/families to organize care needs.

THE CAST MODEL OF CARE

Primary care clinic opened in 2014 specifically to care for autistic people

Ohio State Wexler School of Medicine

--MDs double boarded in IM and Pediatrics, housed in a general medical office, serves as a teaching site for medical students/residents.

--Pre-visit assessment: staff call prior to the visit to ask about sensory/communication preferences/learn about past healthcare experiences

--Pts may wait in their car/bypass the waiting room/ staff walk them directly to exam rooms when it is their turn

--lights in exam rooms may be dimmed, can be brighter if needed by providers

CAST model continued

- Longer visit times 60 min new/30 min f/u
- Team includes FT RN, FT SW, Psychiatry 0.2
- Providers work to monitor medications (often antipsychotics) including managing risk for obesity collaboratively

Shared training videos for patients and providers available online at:

https://wexnermedical.osu.edu/primary-care/adult-autism-center

Available Procedure Videos:

Blood pressure, EKG, injection, blood draws

Each procedure has both a staff training video and a patient experience video

References

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