

# Understanding Autism Spectrum Disorder (ASD)

*Tools for Compassionate Nursing Care*

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# Disclosures

I have no conflicts of interest to disclose.

# Learning Objectives

- (1) Recognize how individual differences in communication, sensory processing, and behavior among patients with ASD may affect clinical interactions and care delivery.
- (2) Apply effective communication techniques and behavioral support measures when interacting with patients with ASD to reduce anxiety and behavioral escalation, and to promote treatment compliance.
- (3) Identify appropriate referral pathways to ensure continuity of care and long-term support.

# Mercyhealth: **Who we are**

# Four core service areas

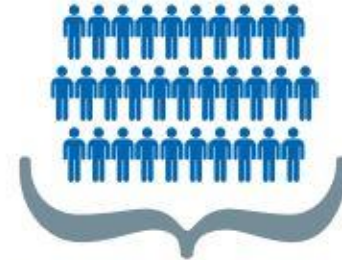


## Mercyhealth serves

2 states  
15 counties  
50 communities  
**2.4 million patients**

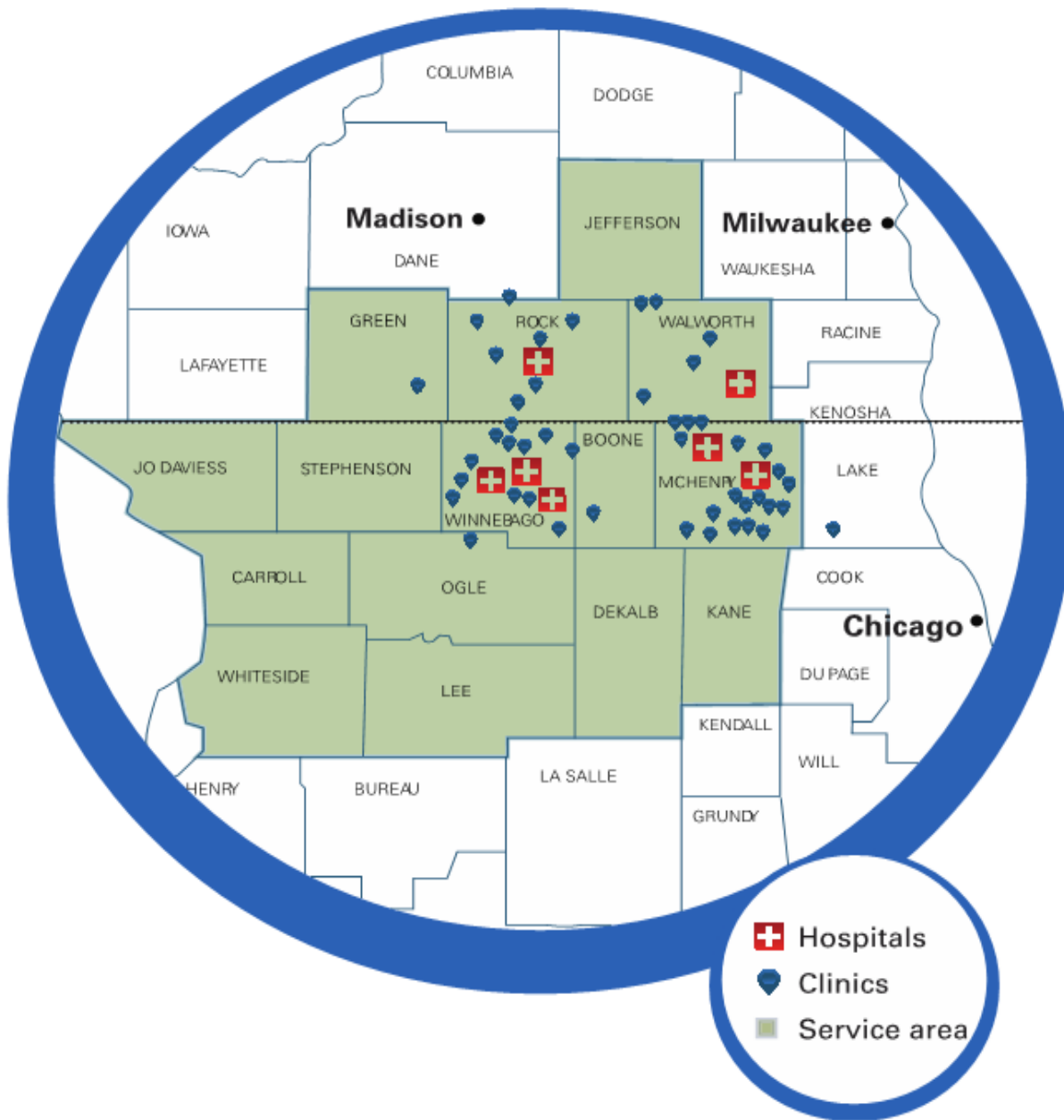


## 7,500 partner employees



## 900 W2 partner physicians





# Mercyhealth Mission:

Exceptional health care services,  
with a passion for making lives  
better



# A Brief History

1943

Leo Kanner identifies "infantile autism" as a separate condition from "childhood schizophrenia."

1944

Hans Asperger identifies "autistic psychopathy," and notes that the boys in his sample were "higher functioning."

1980

Autism is a standalone diagnosis in the DSM-III. It is divided into infantile autism, residual autism, childhood-onset pervasive developmental disorder, and atypical form

1994

Autism and Asperger's Disorder are listed as separate diagnoses in the DSM-IV.

2013

The DSM-5 combines all subcategories into one diagnosis, Autism Spectrum Disorder (ASD).

# Some Terminology

## **FIRST PERSON**

Person with  
Autism

## **IDENTITY FIRST**

Autistic Person

## **GENERALIZED**

Neurodivergent  
vs. neurotypical

## **DON'T ASSUME**

Asking questions  
is OK!



SOCIAL CHALLENGES

## What is Autism Spectrum Disorder (ASD)?

- Autism Spectrum Disorder is a neurodevelopmental disorder that is characterized by challenges with social skills, verbal and nonverbal communication, and repetitive behaviors.
- It can be diagnosed as early as 18 months, but some individuals are not diagnosed until much later in life
  - Signs and symptoms can be observed by parents before one year of age
    - Not responding to name, lack of a social smile, trouble with eye contact



COMMUNICATION  
DIFFERENCES



RESTRICTIVE/  
REPETITIVE BEHAVIOR

# Social Challenges



- Limited social engagement
  - Or engage others in less appropriate ways (example- getting attention)
  - May appear disinterested in social connection
- Difficulty following instructions
- Trouble navigating social norms
  - Personal space
  - Limited conversational reciprocity
- Trouble understanding nonverbal communication
  - Body language
  - Facial expressions
  - Tone of voice (example: sarcasm)
  - Limited eye contact

# Communication Differences



- Nonverbal (non-speaking)
- One-sided communication
- Differences in speaking
  - Monotone voice
  - Literality
  - Echolalia
  - Poor modulation of gesturing, eye contact, and speech

# Restrictive and Repetitive Behaviors

- Motor mannerisms
  - Hand flapping
  - Body rocking
  - Spinning
  - Tiptoe walking
- Echolalia
- Visual/sensory stimulation
  - Staring at lights
  - Lining objects up
  - Intense touching of objects
- Rigidity and insistence on sameness
  - Inflexible routines
  - Extreme food pickiness
- Intensely fixated interests
  - Intense focus on a niche topic
  - Attachment to unusual objects
- Self-injurious behavior
  - Head banging
  - Skin picking



# Addressing Misconceptions

## SOCIAL DIFFERENCES ≠ NO EMPATHY

- May struggle to identify social and emotional cues
- **Hyper**-responsivity can be seen as well



## INDIVIDUAL DIFFERENCES

- Understanding patterns of strengths and weaknesses
  - Case Example – Singing Taylor Swift Songs 😊

## NON-SPEAKING ≠ NO UNDERSTANDING

- Comprehension and conversation are not the same!

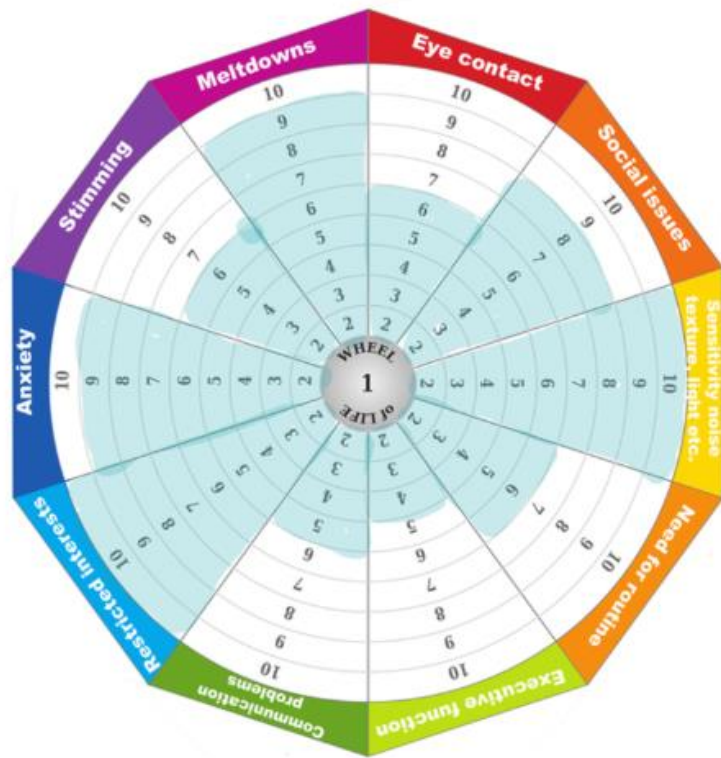


The Autism Spectrum is **NOT** linear

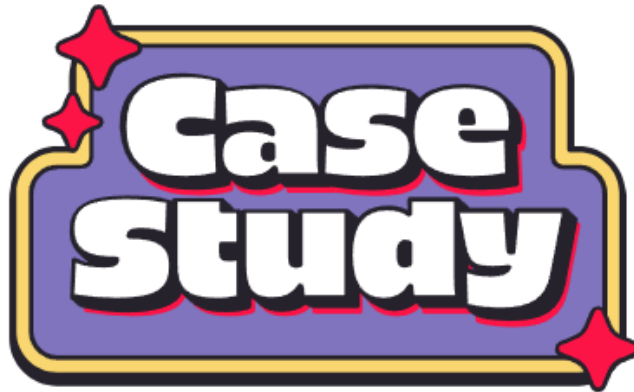



less autistic

very autistic



**You cannot assume you know what supports or accommodations a patient will need just because they have a diagnosis of ASD listed in their chart!**



# Case Study

A blood draw can be challenging for patients diagnosed with ASD. Imagine you are working with a 17-year-old who has a history of challenging blood draws. This patient has been labeled as “difficult” by previous staff. As you review his chart, you notice a diagnosis of ASD. What might you do differently?

# Case Study (Cont.)

## HELPFUL

1. Reduce unnecessary sensory input (including people!)
2. Identify a helpful communication strategy-  
MAY NOT BE SPEAKING!
3. Avoid figurative language
4. Presume competence!

## UNHELPFUL

1. Rushing- that may be YOUR stress
2. Talking too much – can create sensory overload and patient may struggle to follow
3. Nonverbal ≠ non-communicative.
4. Asking open-ended questions

# Social Stories



[Printable](#) Version – Social Story

# Healthcare “Resume”

- Patient creates a list of needs and accommodations that can lead to positive interactions with members of the healthcare team and can enhance their medical care
  - Resources like the [AASPIRE Autism Healthcare Accommodation Tool](#) can be useful

# Communication Suggestions

The next section asks about information that can help the patient's providers communicate with her better. It may be easier for providers to work with a shorter list of suggestions. We recommend you only pick the things that you think will make a big difference in the patient's healthcare.

If the patient needs something that is not listed, check the box that says it isn't listed and the report will ask the patient's healthcare provider to talk with her or a supporter about it. We chose not to allow write-in information because there is no way for the computer to check to make sure it is helpful to patients and providers.

It is okay to skip the question.

## What can healthcare providers do to help the patient understand them better?

- Use simple words and short sentences.
- Use very precise language, even if it means using longer sentences or advanced vocabulary.
- Be very concrete and specific.
- Show her diagrams, pictures, or models whenever possible.
- Use medical words.
- Avoid medical words.
- Ask the patient to repeat what you said in her own words.
- Write down important information or instructions.
- Give the patient very detailed information.
- Focus only on the most important information.
- Be patient with her if she needs to ask a lot of questions
- Give her extra time to process what you have said and check to make sure she is ready to move on.
- Do not try to talk to her while there are other noises (for example, beeping sounds, outside noises, people talking, babies crying).
- She doesn't need accommodations to help her understand providers.
- She needs accommodations to help her understand providers, but they are not listed here.
- Do not wish to say.

It is okay to skip the question.

## What can the healthcare provider's staff do before the visit to make it more successful?

- If possible, give the patient a way to make appointments without using the telephone.
- Schedule longer appointments if possible.
- Schedule appointments at a time when the provider is less likely to be late (for example, the first appointment).
- Let her or her supporters know what is likely to happen during an office visit (for example, what she can expect when checking in, during and after the visit, who will be seeing her, and how long things usually take).
- Notify her as soon as possible if there is an unexpected change (for example, she needs to see a different provider).
- Let her or her supporters fill out paperwork at home.
- Give her pictures, or let her supporter take pictures, of the office and/or staff.
- Give her detailed information about how to communicate with office staff between visits (for example, how to make appointments, contact her regular provider, or contact the clinic in an emergency).
- She doesn't need accommodations ahead of time.
- She needs accommodations ahead of time, but they are not listed here.
- Do not wish to say.



**Academic Autistic Spectrum Partnership in Research and Education**

[aaspire.org](http://aaspire.org) | [researchautism.org/healthcaretoolkit](http://researchautism.org/healthcaretoolkit)

**c/o Regional Research Institute, Portland State University**

1600 SW 4th Avenue, Suite 00, Portland, OR 97201

tel 503 723-4040, fax 503 725-4180; rri.pdx.edu

April 13, 2026

Re: Test B. Test

Test B. Test has used the Autism Healthcare Accommodations Tool (AHAT).

The attached report was custom generated from her responses to the AHAT survey. It includes recommendations for strategies and accommodations to facilitate care. Most of these suggestions can be implemented at no cost or low cost. We hope this information will make it easier for you and your staff to comply with Americans with Disabilities Act (ADA) requirements.

We recommend that you schedule an appointment to review the report with Test B. Test and, if appropriate, her supporters. Note: an extended visit or other longer time-slot may work best for this type of discussion.

Please also visit our website at [researchautism.org/healthcaretoolkit](http://researchautism.org/healthcaretoolkit) for more information and resources about providing healthcare to adults on the autism spectrum.

Test B. Test noted that she has difficulty scheduling appointments on her own. Please help her schedule an appointment. Her contact information is in the report. Test B. Test also noted that she has difficulty with transportation. If your office has the resources to do so, please help her arrange medical transportation.

The ideas for strategies and accommodations listed in the report are only meant as starting points to a more in-depth discussion. Patients and supporters have been informed that these are only ideas and that they are not necessarily possible or helpful.



## A. Information to Assist with Patient Communication

- **Receptive speech:** She often has a hard time understanding or processing what people say.
- **Expressive speech:** She can speak, but often has a hard time saying what she wants to say.
- **Reading:** She can read at a basic level
- **Writing:** She can write or type at a basic level
- **Telephone:** (123) 456-7890
- **Alternatives to speech:** Text-based alternatives to speech (text-based AAC, typing, written notes, iPhone app)

### Other important information about Test B. Test communication.

- She may have a hard time communicating, even if her speech sounds fluent.
- She can be involved in decisions about her care, even though she has difficulty speaking.
- She often takes language too literally.
- She may have difficulty understanding tone of voice, facial expressions, or body language.

### To help Test B. Test better understand what you are saying.

- Use simple words and short sentences.
- Use very precise language, even if it means using longer sentences or advanced vocabulary.
- Be very concrete and specific.
- Show her diagrams, pictures, or models whenever possible.
- Avoid medical words.
- Ask the patient to repeat what you said in her own words.
- Write down important information or instructions.
- Give the patient very detailed information.
- Give her extra time to process what you have said and check to make sure she is ready to move on.

# Summing It Up!

- Explain what you will do before you do it.
- If possible, show the patient the equipment beforehand. If safe, allow them to visually and/or physically inspect it.
- Provide a visual schedule.
- Allow caregiver/support person to stay in the room, as appropriate.

# Summing It Up!

- Set up a plan (First...Then...Finally)
- Be mindful that facial expressions and body language may not be understood.
- Continuously assess understanding.
- Don't expect eye contact.
- Can you work with/around self-stimulatory behavior (stimming)?
  - Remember, this behavior may help to alleviate a patient's anxiety!

**NOTE: This list is not exhaustive and does not work for every patient!**



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*What would happen if the autism gene was eliminated from the gene pool? You would have a bunch of people standing around in a cave, chatting and socializing and not getting anything done.*

DR. TEMPLE GRANDIN

# Autism Resources - Wisconsin

1. [The Autism Society of Wisconsin](#)
2. [Autism United of Wisconsin](#)
3. [Wisconsin Early Autism Project](#)
4. [Waisman Center at the University of Wisconsin-Madison](#)
5. [Mercyhealth Autism Program](#)

# Autism Resources – Illinois

1. The Autism Program of Illinois (TAP)
2. Illinois Center for Autism
3. Illinois Prioritization of Urgency of Need for Services (PUNS)
4. Special Recreation Association Network of Illinois (SRANI)

# Autism Resources – National

1. [Autism Speaks](#)
2. [Autism Hero Project](#)
3. [National Autism Association](#)

## Further Reading

1. *The Complete Guide to Autism & Healthcare: Advice for Medical Professionals and People on the Spectrum*-Anita Lesko\*
2. *Autism in Nursing and Healthcare*- Christopher Barber
3. *Autism and Being Monotropic: What Medical and Other Practitioners Need to Know*- Wenn B. Lawson\*
4. *Thinking in Pictures: My Life with Autism* – Temple Grandin\*

\* DENOTES BOOK AUTHORED BY INDIVIDUAL WITH LIVED EXPERIENCE



## Therapy



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# Questions and Discussion



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making lives better.®

