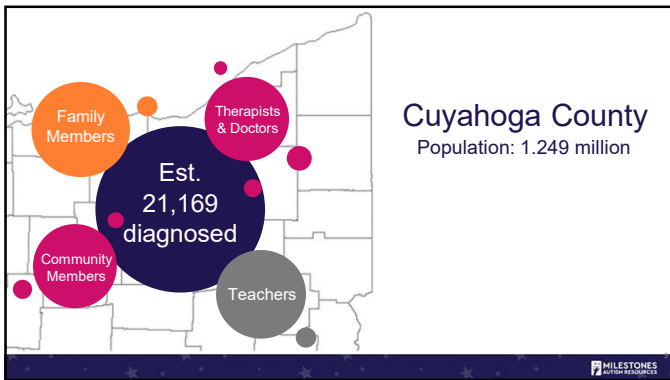




## About Milestones Autism Resources

**Mission Statement:**  
 Milestones Autism Resources improves the lives of individuals on the autism spectrum by educating, coaching and connecting the autism community with evidence-based information.

**Vision Statement:**  
 A community in which individuals on the autism spectrum reach their full potential as contributing members of society, recognized for their strengths and supported in their challenges.



## Expertise and experience in the room:

### How many of us here have a personal connection to autism?

## “Casual definition” of Autism

## What is Autism? (from the Autistic Self-Advocacy Network)

- “Autism is a developmental disability that affects how we experience the world around us. Autism is a normal part of life, and makes us who we are.”
- “There is no one way to be autistic. Some autistic people can speak, and some autistic people need to communicate in other ways.”
- “Some autistic people also have intellectual disabilities, and some autistic people don’t.”
- “Some autistic people need a lot of help in their day-to-day lives, and some autistic people only need a little help.”

## Autistic people might . . .

- Think differently – interested in patterns, details, and routine
- Process senses differently – extra sensitive to lights, sounds, movement; or under-sensitive and seek out big sensations
- Communicate differently – might prefer typing to spoken conversation, or might only be able to use pictures to communicate, or might repeated “scripted” words
- Socialize differently – hard to understand “unwritten” social rules, make eye contact, guess how other people feel



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## Autistic people might . . .

“Not every autistic person will relate to all of these things. There are lots of different ways to be autistic. That is okay!”




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## Current DSM Criteria for Autism




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## Current DSM Criteria for Autism

**All 3 of the following in Social Communication:**

- Difficulty with social emotional reciprocity
- Difficulty with nonverbal communication
- Difficulty developing and maintaining relationships with others

**At least 2 of the following in Restrictive and Repetitive Behavior, Interests, or Activities:**

- Repetitive speech, motor movements, use of objects or phrases
- Adherence to routines, resistance to change, distress at change of routine
- Restricted interest with intensity of focus
- Increased and/or decreased reactivity to sensory input, unusual interest in sensory environment

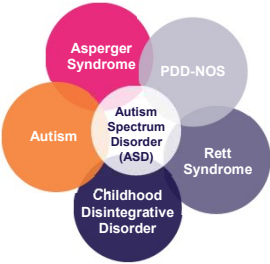


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## All About Autism

REFERRED TO AS:  
**Autism Spectrum Disorder (ASD)**  
*Autism, Asperger Syndrome, PDD-NOS, Rett Syndrome, Childhood Disintegrative Disorder*


SPECTRUM:  
**Affects each individual in varied intensity, dimensions, and presentations from day-to-day, moment-to-moment, context to context, and across the lifespan**



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## AUTISM IS A NON-LINEAR SPECTRUM

It does **not** look like this:




Autism is much more **complex** and **dynamic**. Every autistic individual is **unique**, and so are our traits and support needs. We all have varying degrees of autistic traits. Some may have serious sensory issues, while others have none, and so on. There is **endless variation**, and they change and evolve throughout our lives, even from day to day.

It looks more like this



@\_ninstagram\_

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**Neurological**  
disability that affects:

- Communication
- Social Interaction
- Sensory Processing
- Executive Functioning

**Developmental**  
characteristics begin prior to the age of 3

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**1 in 36 children in the United States**

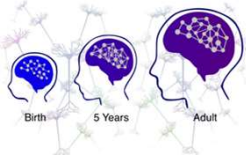
**Why the increased autism prevalence?**

- Better diagnosis / Change in diagnostic guidelines
- Efforts to have all children screened for autism
- Better identification in women/girls and children of color
- Decreasing waiting lists for diagnosis
- Heritability – autism run in families

(CDC, 2018) milestones.org

**What is Autism?**

- Neurodevelopmental Disability
- Surplus of synapses from lack of “synaptic pruning”
- Structural, biochemical or electrical differences in the brain



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**Diversity, Equity and Inclusion: Statistics**

- Fewer children of color get diagnosed and access services
- Latest data from the CDC show better diagnosis rate vs past but still not equitable

Barriers include:

- Stigma
- Low income
- Access to healthcare
- Language

**10% more likely AMONG WHITE vs BLACK CHILDREN**

**20% more likely AMONG WHITE vs HISPANIC CHILDREN**

**10% more likely AMONG BLACK vs HISPANIC CHILDREN**

Data & Image from CDC 2018 milestones.org

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- Research shows the average life expectancy for some autistic individuals is around 39 years
- Autistic individuals also succumb to health complications about 20 years earlier than non-autistic populations



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**All About Autism**

**Co-Occurring Disabilities**

- ADHD
- Anxiety Disorders
- OCD
- Sleep Disorders
- Eating Disorders
- Depression
- Fragile X Syndrome
- Gastrointestinal Issues/Bowel Diseases
- PTSD
- Seizures
- Tourette's Syndrome
- Ehlers-Danlos syndrome
- Intellectual Disability

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### Diverse groups use diverse language

- "Autistic person" (identity-first, what Milestones uses)
- "Person with autism" (person-first, what the Ohio Department of DD uses)
- "People who have disabilities"
- "Neurodivergent people"
- "Neurodiversity" or "Neurodiverse" referring to groups of people of all different types of neurology (but a single person isn't "diverse")

All of these are preferred by some people but not by others. All preferences are valid.

### Somewhere under the Double Rainbow

Total US Population

4.5% in total US population identify as LGBT

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### Somewhere under the Double Rainbow

ASD Population

1 in 5 of ASD population are LGBT+

Double Rainbow Non-LGBT+

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### Somewhere under the Double Rainbow

Teens & Adults with ASD

6.55 - 11.4% stated desire to be transgender

Desire to be Transgender Non-LGBT+

### Autistic people more likely to be LGBT+ than general population

15 - 35% LGBT+ identification among autistic people without an intellectual disability.

Transgender individuals are 6 times more likely to be autistic than cisgender population (Warrier, et al. 2020)

Total US Population

ASD Population

LGBT+ Non-LGBT+

Double Rainbow Non-LGBT+

### Trans and Gender Diverse Experiences for Autistic Individuals (Cooper, et al. 2022)

- Autistic people with diverse gender identities may have more difficulty articulating their experience to others
- Autistic people may experience tension between their gender dysphoria and autistic traits when transitioning
  - Ex: Sensory issues with clothing and makeup
  - Ex: Desire and need for routine and sameness
- Autistic people experience unique pressure related to social expectations around gender roles
- Autistic people have more difficulty getting access to medical care and services related to their gender diversity

**Awareness →**  
**Acceptance →**  
**Appreciation →**  
**Pride**



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**The Double Empathy Problem**

<https://www.spectrumnews.org/news/double-empathy-explained/>


**Autism in the Workplace – Best Practices**

- Eliminate "unwritten rules"
- Provide clear expectations
- Visual communication (in writing) is often clearer
- Flexibility of schedule and location are a great benefit
- Loud, busy, and social settings can be taxing
- Don't make assumptions – clarity is important.

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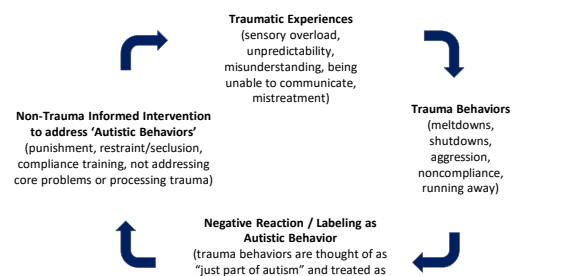
**Autism & Trauma**

- 3.5% of the general population meet criteria for PTSD
- Nearly 60% of autistic individuals meet criteria for a PTSD diagnosis at some point in their lives



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**Autistic Trauma Cycle**



**Traumatic Experiences**  
 (sensory overload, unpredictability, misunderstanding, being unable to communicate, mistreatment)

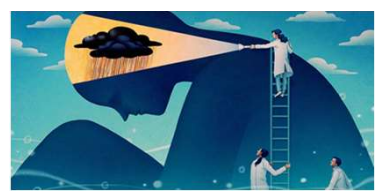
**Trauma Behaviors**  
 (meltdowns, shutdowns, aggression, noncompliance, running away)

**Negative Reaction / Labeling as Autistic Behavior**  
 (trauma behaviors are thought of as "just part of autism" and treated as "behavior problems")

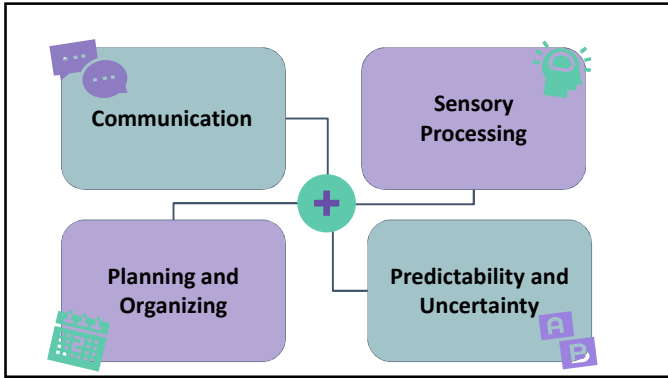
**Non-Trauma Informed Intervention to address 'Autistic Behaviors'**  
 (punishment, restraint/seclusion, compliance training, not addressing core problems or processing trauma)

**Risk Factors for Suicide and Self-Injury in Autistic Populations**

- Co-occurring psychiatric conditions
  - Depression and anxiety
- Lack of social supports
- Unmet support needs
- Camouflaging/Masking
- Late diagnosis
- Female
- Autistic Burnout



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"I prefer and find it easier to communicate in text... But with every doctor I speak to, they wave away the note-card and look at me to ask the same question I have just answered and interpret my confusion as my being non-compliant with the medicine. I wish health care providers would read the notes I make for them. I wish they would be patient as I pause a lot and stutter when I am overloaded."

"They asked him, on a scale of one to ten, where is your pain. First time he said, 'How do you weigh your pain? ... I don't weigh my pain.'"

"How do you feel? Too vague. 'Can you describe your symptoms?' I can somewhat answer this, but not fully. It's a starting point, not endpoint. Specific questions related to symptoms are good: 'Does your side hurt?' 'Are you keeping food down?'"

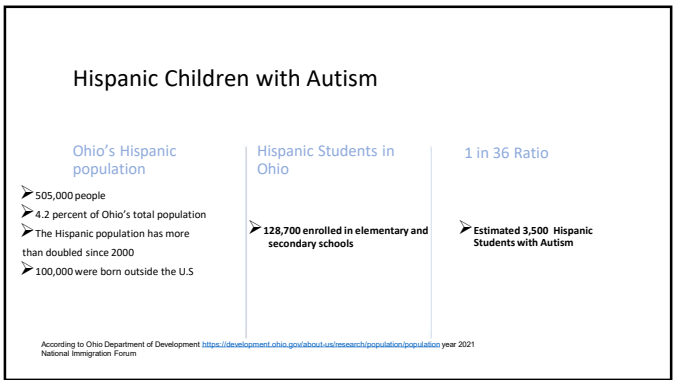
AASPIRE Healthcare Toolkit

"...I have just traveled to the office on a very loud bus or train. The lights in the office are very bright and that is exacerbated by the white walls. Sometimes the waiting rooms are crowded and I cannot filter out the background of people talking or shuffling magazines. I feel disoriented by being led down long hallways to different rooms.... I am not able to bring up my concerns because it is all I can manage to figure out what the doctor is saying so I can respond to his questions. "

"I don't know my own body. ...So when I feel all these different sensations, everywhere, I don't know which is the real problem and which is just sensation."

"The problem is it is difficult for me to isolate specific sources of pain and identify duration and intensity. It's sort of like the equivalent to white noise."

AASPIRE Healthcare Toolkit



## Evidence-Based Strategies & Solutions

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Important to compare the person's current presentation to their **own** baseline




## Evidence-based Strategies: Social Stories

Social Stories help autistic people reliably access information about social situations. Social stories are used to convey information and can aid in predictability and executive functioning.

**The Social Story Goal**



In accordance with Social Humility and the Social Story Definition, the Goal of a Social Story is to accurately and respectfully describe one of life's many topics while ensuring that the intended message remains intact from Author to Audience.




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## Evidence-based Strategies: Schedules

- Provide expectations for both staff and patient
- Use visuals best suited to individual's processing (photos, clip art, writing, etc.)
  - Helps with executive functioning
- Can use *First/Then* schedule for short-term predictability
- Allows for independence in knowing what will happen
- Can be used repeatedly for common occurrences
  - Dry erase board or paper

**Today's Schedule**




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**First/Then**


lunchtime → TV

orange juice

**Macro schedule for going to the doctor**



**Micro schedule for getting a shot**



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Name: Patient Example  
Date: December 19th, 2012


Name	Used For	Instructions	Morning	Afternoon	Evening	Night
Aspirin 81 mg	Heart	Take 1 pill by mouth once a day	●			
Lisinopril 10 mg	Blood Pressure	Take a half pill (5 mg) by mouth once a day	●			
Furosemide (Lasix) 80 mg	Water Pill	Take 1.5 pills by mouth once a day	●	●		
Potassium Chloride (K-Dur) 10 Meq	Vitamins and Supplements	Take 2 pills by mouth twice a day.	●	●		●
Warfarin 5 mg	Blood Thinner	Take 1 pill by mouth once a day at night				●
Famotidine 20 mg (Pepcid)	Reflux	Take 1 pill by mouth once a day	●			

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## Evidence-based Strategies: Schedules

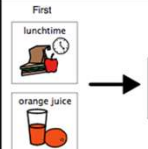
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**Today's Schedule**




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First







→







Then




**Macro schedule for going to the doctor**
















**Micro schedule for getting a shot**



Name: Patient Example  
Date: December 15th, 2012



Name	Used For	Instructions	 Morning	 Afternoon	 Evening	 Night
Aspirin 81 mg	 Heart	Take 1 pill by mouth once a day	●			
Lisinopril 10 mg	 Blood Pressure	Take a half pill (5 mg) by mouth once a day	●			
Furosemide (Lasix) 80 mg	Water Pill	Take 1.5 pills by mouth once a day	●●			
Potassium Chloride (K-Dur) 10 Meq	 Vitamins and Supplements	Take 2 pills by mouth twice a day.	●●			●●
Warfarin 5 mg	 Blood Thinner	Take 1 pill by mouth once a day at night				●
Famotidine 20 mg (Pepcid)	 Reflux	Take 1 pill by mouth once a day	●			

