



# Vaccine Education Initiative

**Immunize.org**  
**December 2022**

# Agenda

1. About the Autism Society
2. Understanding Autism
3. Vaccine Education Initiative
4. Practical Strategies
5. Q&A



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# Autism Society: Who We Are

The Autism Society is the largest and oldest, grassroots, Autism organization in the United States.

- **Mission:** To create connections, empowering everyone in the Autism community with the resources needed to live fully.
- **Vision:** Creating a world where everyone in the Autism community is connected to the support they need, when they need it.

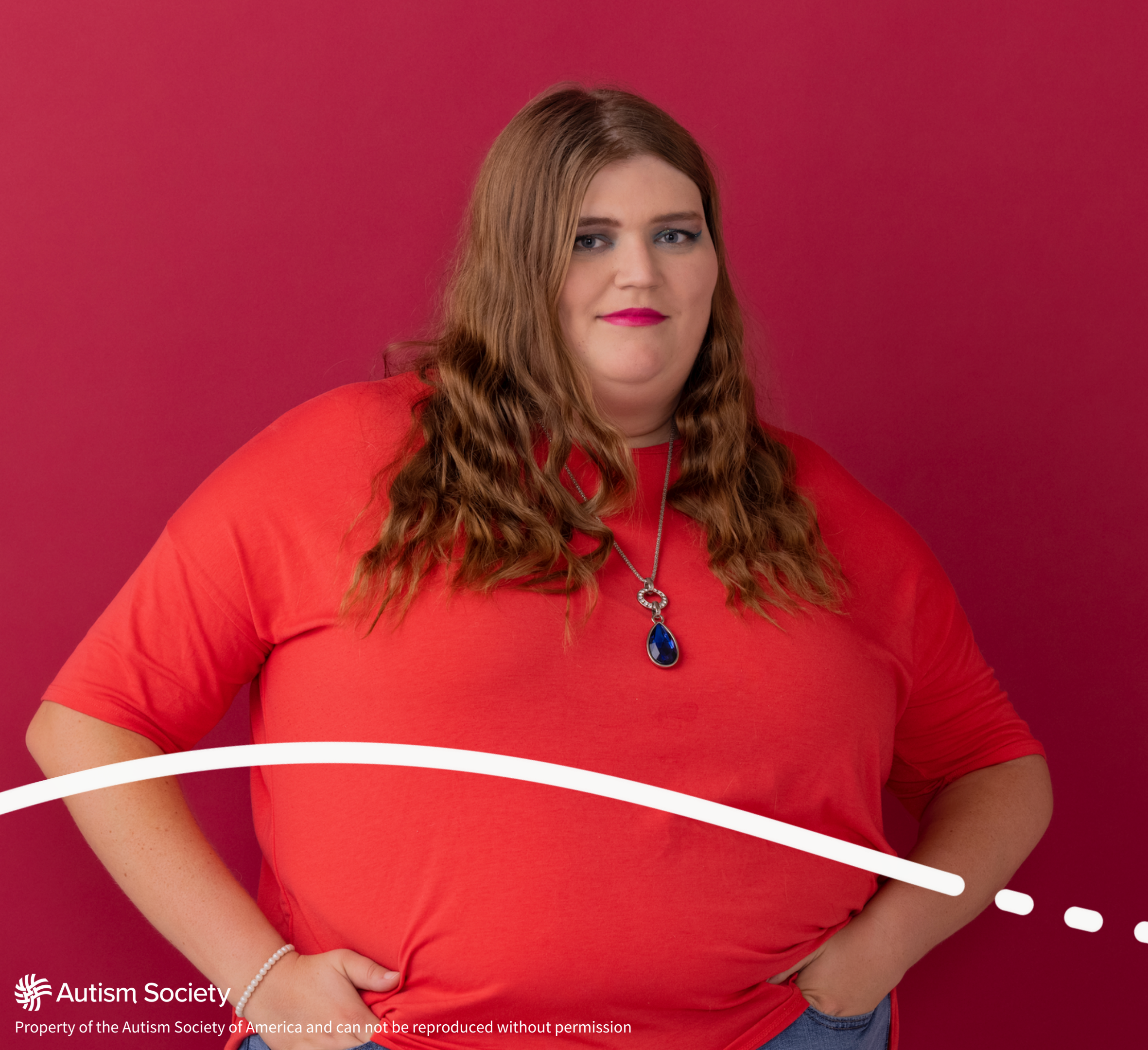


**Autism Society**  
The connection is you.

# Autism Facts & Statistics

- 1 in 44 children are diagnosed with Autism
- Around 1/3 of Autistic children are identified with an intellectual disability
- Nearly three-quarters of Autistic children are diagnosed with a co-occurring medical or mental health condition
- Anxiety disorders affect up to 40% of individuals with Autism
- **Vaccines do not cause Autism**





# Understanding Autism & Neurodiversity

<sup>TM</sup>  
The Connection Is You.

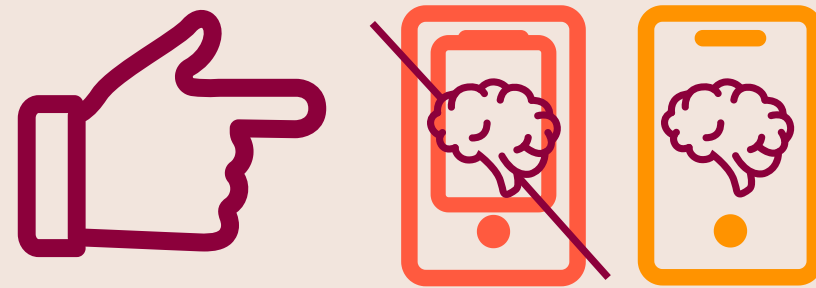
# Supporting Neurodiversity

Just as computers and phones have different operating systems, so do brains.



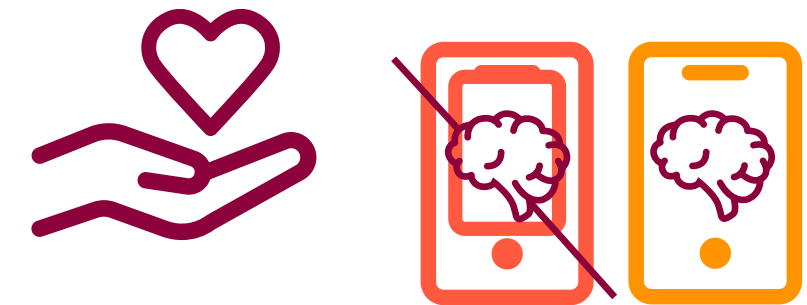
One isn't better than the other, **they are different.**

If you try to get an Autistic brain to be Neurotypical, it won't work properly.



Not because the brain is broken, but because you're trying to get it to be something it isn't.

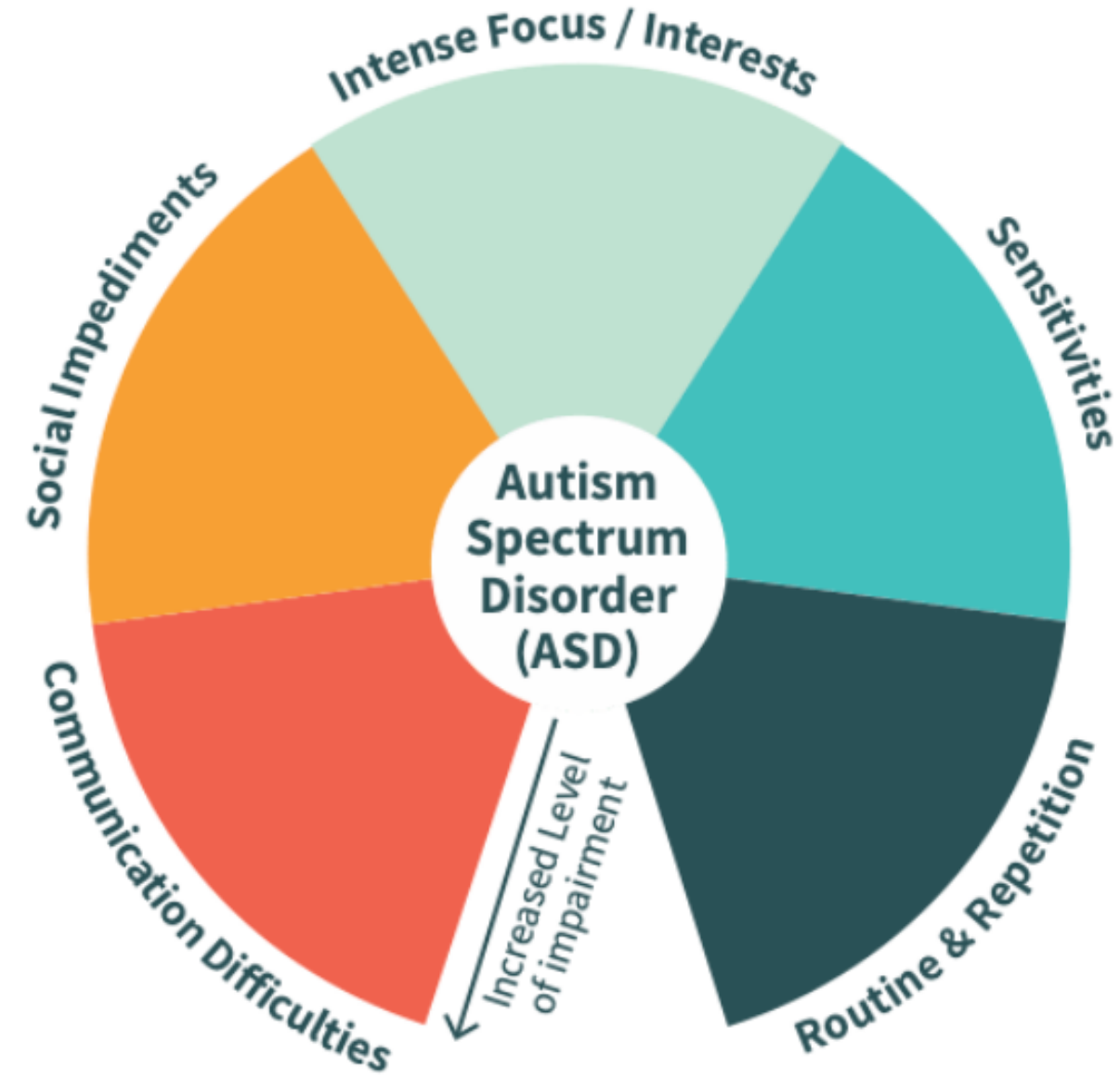
It isn't helpful to punish the Autistic brain for not being Neurotypical...



Instead, we can change our approach and make accommodations.

# What is Autism?

- Brain-based developmental disability
  - Range of complexity
  - Visible or Invisible
- Affects the way the brain processes and uses information, impacting:
  - Information Processing
  - Communication
  - Sensory Processing
  - Social Behavior
  - Emotional Regulation



# Language: Identity vs Person

## Identity First

Identity-first language puts a person's condition/disability before the person – for example, 'Autistic person'.

## Person-First

Person-first language puts the person before their condition/disability – for example, 'person with Autism.'





# Information Processing

1. Information comes in
2. Information gets processed
3. Information gets stored
4. Information is searched for  
in response to a stimulus

# Communication



- Expressive
  - Verbal, Partial Verbal, Non-verbal
  - Inconsistent Access
  - No access to verbal language



- Receptive
  - Access to verbal language, but trouble understanding or using social pragmatic language
  - Processing speed & style

# Communication

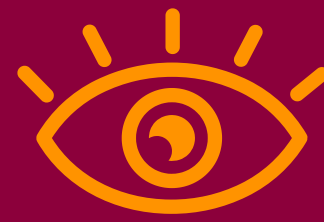
- 25%-30% non-speaking throughout the lifespan
- Additionally, 20% may present as nonverbal when highly stressed
- Occurs both with and without intellectual disability (ID)
- Communication Supports/other ways people communicate
  - Sign language
  - Icons/Pictures
  - Technology
  - Written directives



# Sensory Processing

Sensory and movement differences may have a significant impact on self-regulation and feelings of safety in one's body and in the community.

Individuals with Autism tend to filter incoming sensory messages differently. They may find some experiences extremely overwhelming and may not notice others.



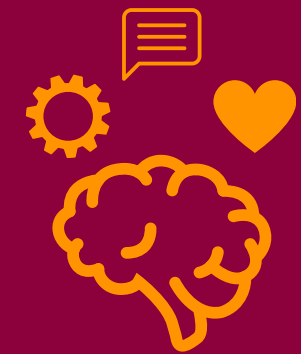
Sight



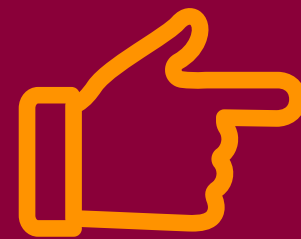
Sound



Balance



Interoception



Touch



Smell



Taste



Body-Awareness

# What is Stimming?

Repetitive body movements or repetitive movement of objects.

**Hyposensitive** – Behaviors arouse nervous system

**Hypersensitive** – Behaviors block an environment that is too stimulating and act as a calming mechanism/coping strategy

## Some examples:

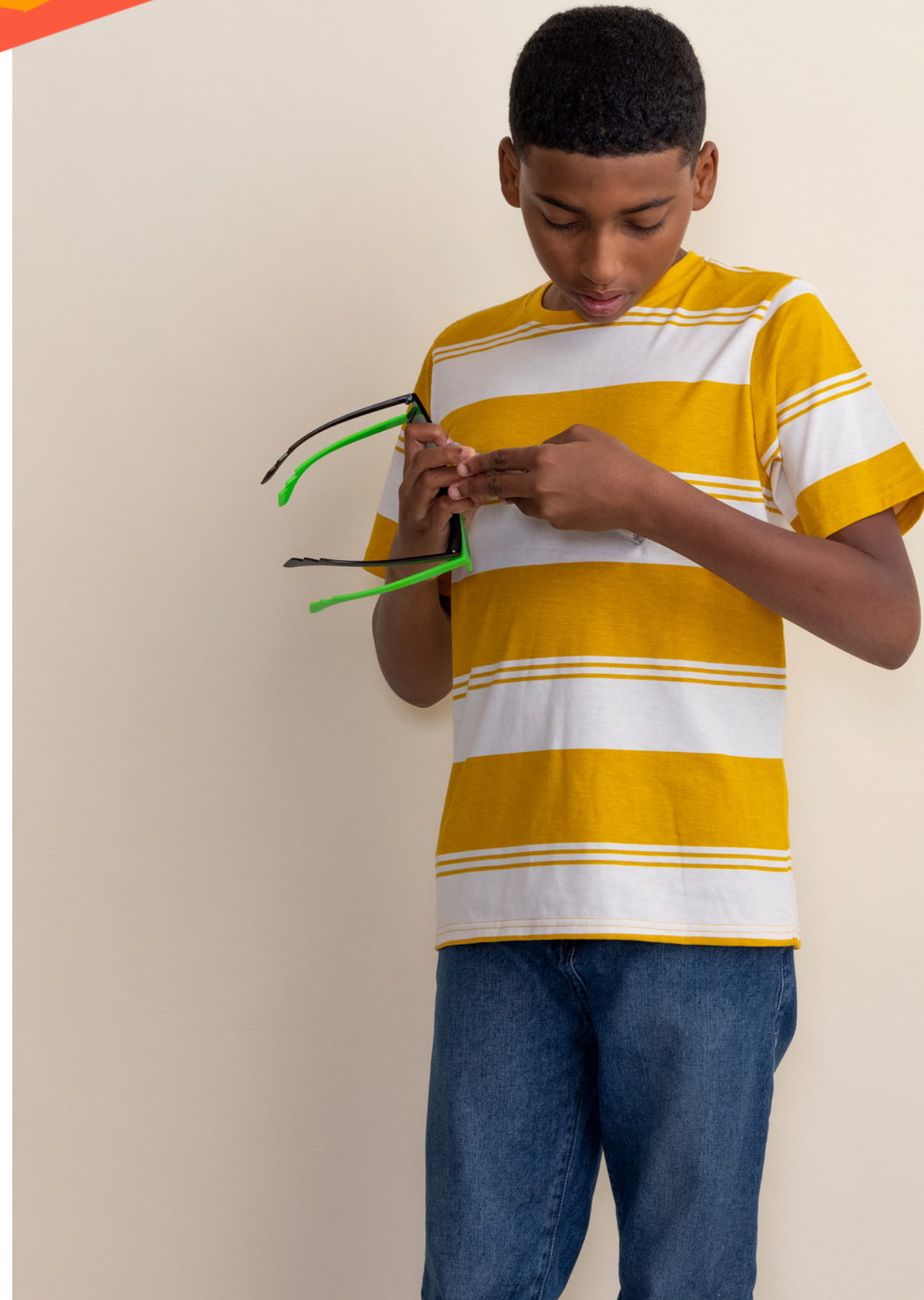
- Fidgeting
- Pacing
- Rocking, Spinning, Jumping
- Other repetitive behaviors



# Sensory Overload & Anxiety

Too much information can cause stress, anxiety, and possibly physical pain. This can result in withdrawal, distressed behavior, or sensory meltdowns.

"If I get sensory overload then I just shut down; you get what's known as fragmentation...it's weird, like being tuned into 40 TV channels."





## **INCLUSION**

**is the foundation for  
the core issues  
affecting the global  
Autism community.**

# Health Equity



# Accessible Healthcare in the Autism Community

- Social determinants of health
- Screening & diagnosis
- Co-occurring medical conditions
- Trust barriers
- Misinformation
- Lack of healthcare training





# Vaccine Education Initiative



Leveraging the power of **connection** to

- Provide **Education**.
- Inspire **Confidence**.
- Create **Accessibility**.

# Autism Society of America's Guide to Accessible Vaccine Clinics

## Sensory Considerations

- Turn lights low, reduce fluorescent lighting when possible.
- Variety of seating options when available (chairs, cushions, bean bags, etc.)
- Play calming video/music with low volume on available TVs/screens in shared spaces.
- Make a variety of sensory fidgets available at check in to use throughout the appointment (ideas below).
- Noise canceling headphones available at check in
- Reduce crowding to eliminate social and visual overwhelm.
- Offer weighted lap pads
- Patience and a smile will go the extra mile.

### Click Bullet Points for Resources!

- Music/Video**
  - Soothing Jellyfish Aquarium
  - Relaxing Music with Nature Sounds - Waterfall
  - Coral Reef Aquarium
- Sensory**
  - Sensory Fidget Tubes
  - Squishy Stress Balls
  - Infinity Cube Fidget
  - Sensory Stress Ball and Water Bead Set
  - Bubble Popper
- Weighted Lap Pad**
  - Friendly Cuddle Weighted Lap Pad for Kids - Sensory Weighted Stuffed Animal

"My son was very comfortable getting his booster. The quiet rooms and friendly staff were a huge help. We were all very excited that he handled it so well." - VEI clinic participant

## Appointment Preparation

- Develop Social Narrative to help individuals and families prepare for the appointment.
- Prepare and send a visual schedule ahead of time. Participants can use this at the appointment to walk through the steps of the appointment.
- Ask individualized questions during registration/sign up:
  - How have past vaccine experiences gone?
  - To help us prepare for a positive experience, please list any accommodations you may find helpful at this event below.
  - Or please provide any additional information about how we can provide a successful vaccination experience.
- Send paperwork ahead of time to reduce time spent waiting at check in.
- Prepare a feedback survey to be taken during observation or sent out via email after the event.
- Send a reminder email to participants with tips, resources, and paperwork

## Space Considerations

- Waiting room with sensory fidgets, activities, visual schedules.
- Private rooms for vaccine administration.
- Plan for an extra vaccination room in case someone needs more time.
- When possible, have separate observation and waiting rooms.
- Two separate observation spaces when possible - one with activities for children and one for older teens and adults.
- Allow movement, exploration, and play.
- Clear signs showing where to go.
- Break space for volunteers, nurses, and others to reduce crowds, and noise in other spaces. Consider providing water, coffee, snacks, etc.

## Injection Tools

**Buzz Bee:** "Through a combination of vibration and ice pain-blocking methods, this FDA 510(k) cleared topical product is the most proven way to control pain associated with venipuncture and cosmetic injections. Our solutions use high-frequency, low amplitude vibration, which provides a more subtle sensation than percussive or other e-stimulation vibration therapies. Users should familiarize themselves with the vibration strength before the first application."

**Shotblocker:** "The contact points on the underside saturate the sensory nerves, distracting the patient from the pain signals caused by the needle poke."

How did this clinic promote vaccine access for your family?  
"The different tools used to distract my son and make him as comfortable and relaxed as possible. Also that nobody held him down."

## Other Supports & Accommodations



"Everything was great and although my son wasn't happy about getting the vaccine, this was by far the smoothest vaccination he has ever received. He only wants to get vaccines here now!"

## Other Resources (Clickable Links)

- Prepping a Child for a COVID-19 Vaccine
- Fear of Needles and the COVID-19 Vaccine: A Guide for Caregivers
- To find an adaptive vaccine clinic near you, an educational program, or to learn more about the VEI please visit: [COVID19 Support](#) | [Autism Society](#)

# Accessible Vaccine Clinics

- Pre-registration support
- Sensory and Environmental Considerations
- Links to preparation material
- Communication boards
- Universally Designed



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# Pre-Registration Supports



# Planning Ahead

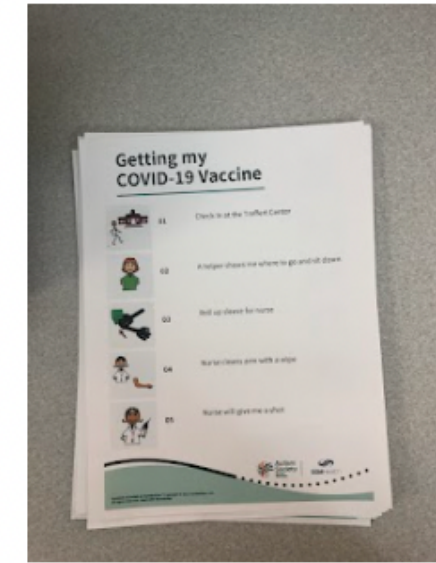
- Include individualized information requests during sign-up
  - Past experiences?
  - Accommodations?
  - Anything else we should know?
- Send paperwork ahead of time
  - Reduce wait-time upon arrival
- Parent/Caregiver Preparation
  - Snacks, Safety Items, etc.
- Patient Preparation
  - Social Story and Visual Schedules

Please check any supports that the person receiving the vaccine might find helpful:

\*



Weighted lap pad



Visual Schedule



Sensory Fidget



Noise Canceling Headphones

**Autism Society** Getting My COVID-19 Vaccine



I want to protect myself and people around me from getting sick from COVID-19.



A vaccine is a medicine that gets put into my arm to protect me from getting sick from COVID-19




I can get a COVID-19 vaccine at any pharmacy, doctor, or clinic.


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**Autism Society** What to expect with your Covid-19 Vaccine


Before | During | After




- Make a vaccine appointment online @ [vaccines.gov](https://www.vaccines.gov).
- Pfizer & Moderna require two shots so make sure you have two appointments scheduled.




- Do you need help with the application or transportation Call DIAL: The Disability Information and Assistance Line: 888-677-1199



- The Vaccine is free.
- You will need to show your ID.
- You do not need insurance, a driver's license or a social security number.








- Wear a mask that covers your mouth and nose.
- Wear a t-shirt, the shot will be in your upper arm.



- Learn what will happen during and after the appointment and plan ahead: Bring anything that may help ease anxiety like a fidget spinner, squishy, comfort item, preferred video, etc.

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**Autism Society** Getting the COVID-19 Vaccine 1

- 1  Check in at the vaccine clinic
- 2  Follow a helper to a room
- 3  Sit down and roll up sleeve
- 4  Nurse cleans arm with a wipe
- 5  Nurse will give the shot

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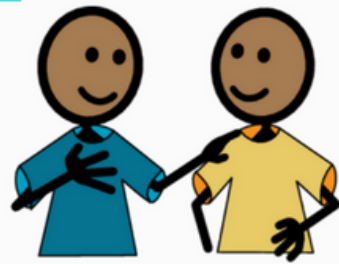
# Social Narratives & Visual Schedules

# Social Narratives

## Getting My COVID-19 Vaccine

Connect to Protect

1



I want to protect myself and people around me from getting sick from COVID-19.

2



A vaccine is a medicine that gets put into my arm to protect me from getting sick from COVID-19

3



I can get a COVID-19 vaccine at the Building for Kids We will drive to the Building for Kids.

4

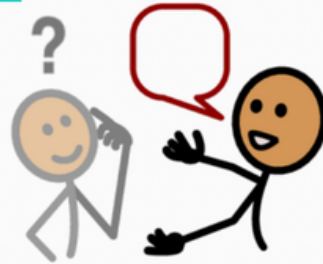


I can put on my mask before entering the Building for Kids.

## Getting My COVID-19 Vaccine

CONNECT TO PROTECT

5



I will go into the building and check in by giving my name, birthday, and answering questions from the helper.

6



My family can help me check in. A helper will show me where to go. I will go with the helper and my family.

7



Helpers may be dressed up in gloves, masks, and face shields.

8

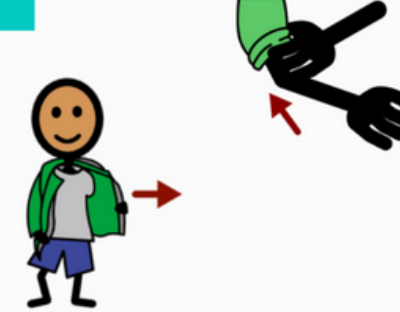


Even though I can't see their faces, the helpers are very happy to see me.

## Getting My COVID-19 Vaccine

CONNECT TO PROTECT

9



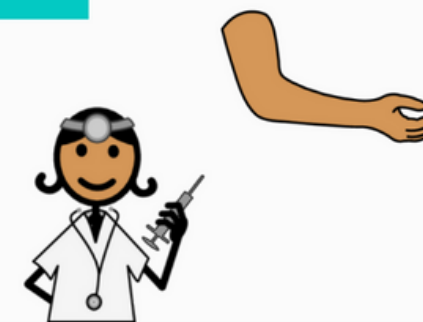
I will roll up my sleeve or take off my jacket when it is my turn.

10



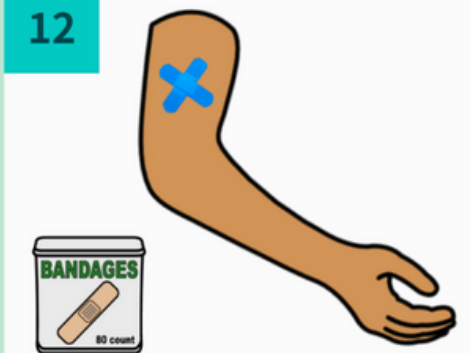
I will sit in a chair. I will try to stay still.

11



A nurse will give me the shot. I might feel a pinch when the needle goes into my arm.

12



The nurse will put a band-aid on my arm. My vaccination is done!

# Communication Supports



# Symbol-Supports

**Autism Society Healthcare Communication Board**

**Pain Scale:**

- 10: Worst Pain Possible
- 9
- 8
- 7: Severe Pain
- 6
- 5: Moderate Pain
- 4
- 3
- 2: Mild Pain
- 1: No Pain

**YES** **NO**

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# Letter Boards

**Autism Society Healthcare Communication Board**

A	B	C	D	E	F	G	H				
I	J	K	L	M	N	O	P				
Q	R	S	T	U	V	W	X				
Y	Z	0	1	2	3	4	5	6	7	8	9
.	,	!	?	YES	MAYBE	NO					

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## **AAC** Alternative Augmentative Communication

- iPhone
- Tablet
- Symbol-supported
- Text-based
- All-of-the-above

"Don't leave my voice on  
the shelf."

# Sensory & Environmental Supports



# Sensory-Friendly Environments

- Reduce fluorescent lights
- Variety of seating options
- Noise cancelling headphones
- Sensory/fidget tools
- Visual supports
- Reduce crowding





# Autism Society

The connection is you.



The Connection Is You.

# Provider Supports

## Considerations for Immunizers



# Injection Tools



Canva

**Forbidden (403)**

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Contact us through our [Help Center](#). Please quote the error

3



Administer the shot through the opening.



**“I’ve worked in peds for 25 years and I’ve never seen anything like this.”**

**“There’s no reason why we couldn’t do this in every clinic. We can.”**

# Whole-Family Support





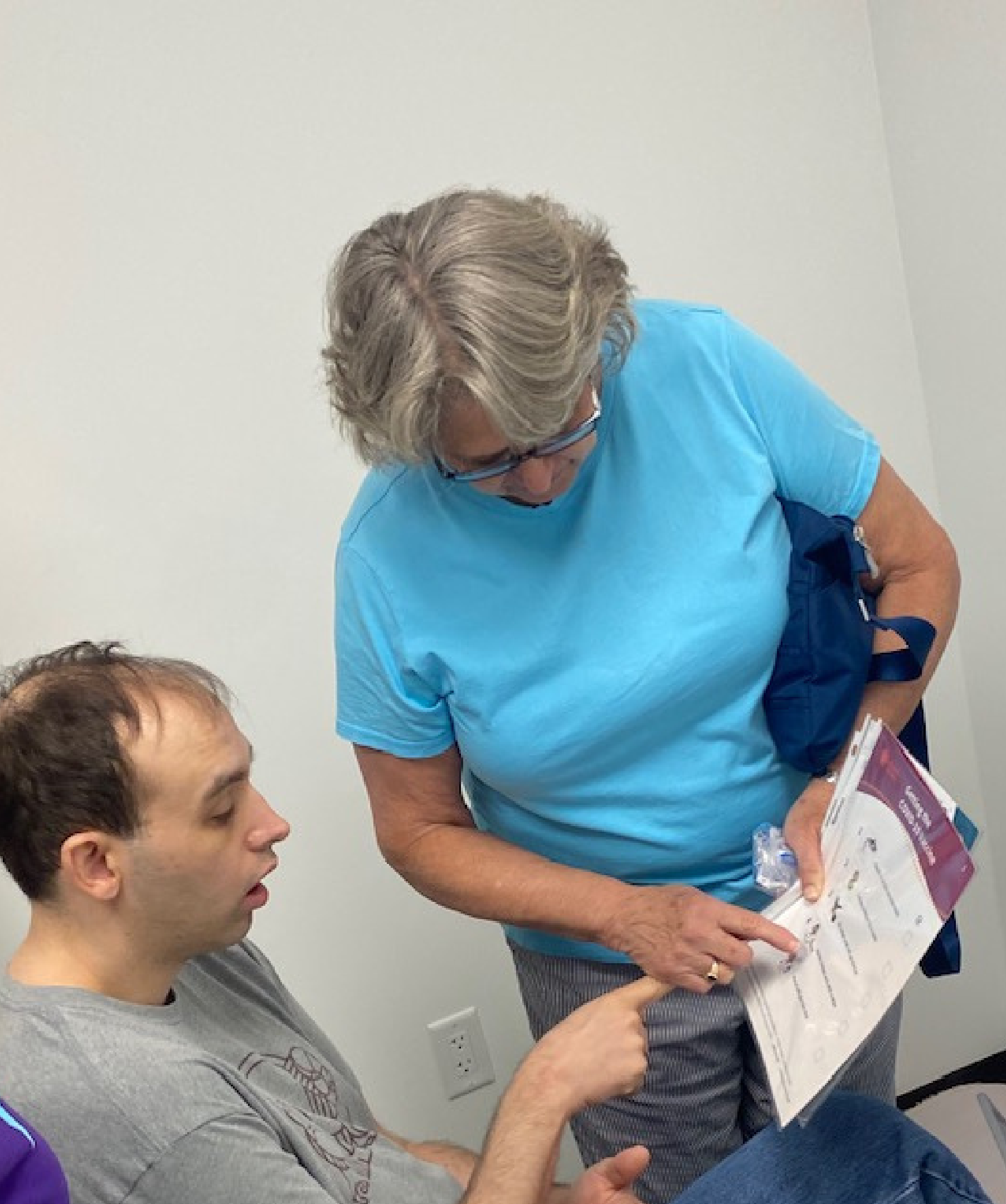
# Caregiver Testimonials

"Getting this done in a low stress, guilt free environment was great! It alleviated my own stress as a parent... about being judged for my child's behavior."

"I appreciate the patience my children were shown and getting to play afterwards helped create a more positive memory of the event, which will hopefully help the next time a vaccine is needed."

"This clinic was a game changer for my family."





**What one person may need**

**ALL can benefit from.**



# Meaningful, substantial, and replicable impact

Messaging that Matters

National Reach, Local Focus

Powerful Collaborations

- (1) the Autistic community
- (2) national and local organizations
- (3) experts across disciplines
- (4) policymakers.





# Get Connected

Get connected to the resources and support you need.  
Visit our website at [AutismSociety.org](https://AutismSociety.org).

Contact our National Helpline to speak with a trained Information & Referral Specialist:  
[800-3-AUTISM](tel:800-3-AUTISM)  
[info@autism-society.org](mailto:info@autism-society.org)

[Connect with a local affiliate.](#)

Discover how you can [get involved](#) or [give](#) today.

**The connection is you.**

**If you'd like further information or have any questions, please reach out to Allie Tasche at [atasche@autism-society.org](mailto:atasche@autism-society.org)**



**Autism  
Society**

**Thank you.**