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 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

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.

Adapted from @More than one neurotype

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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 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.
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
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.
Accessible Vaccine Clinics

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

What to expect with your Covid-19 Vaccine

Before | During | After

- Make a vaccine appointment online at vaccines.gov.
- Inform & Modesta require two shots so make sure you have two appointments scheduled.

- Do you need help with the application or transportation? Call DEUX: The Disability Information and Assistance Line: 888-677-1599

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

- Wear a mask that covers your mouth and nose.
- Wear a short-sleeved shirt; the shot will be in your upper arm.
- Learn what will happen during and after the appointment; you can plan ahead (bring anything that may help ease anxiety like a fidget, spinner, squishy, comfort items, pencil, red violets, etc.)

Getting the COVID-19 Vaccine

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
Social Narratives

Getting My COVID-19 Vaccine

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.

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.

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!
Symbol-Supports

Letter Boards
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
The Connection Is You.
Provider Supports
Considerations for Immunizers
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Injection Tools
“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.

Contact our National Helpline to speak with a trained Information & Referral Specialist:
800-3-AUTISM
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
Thank you.