



Autism 101: Understanding and Supporting Individuals with Autism

By: Rose Sutton

Education & Support Coordinator

Today We Will Cover:



1. What is autism?
2. My loved one has autism,
now what?
3. How can ASNV help?

What is Autism?



Autism is a lifelong
neuro-developmental
disability

Autism is a spectrum disorder,
meaning that it looks different
in everyone. A disorder that
affects the brain's normal
development of social and
communication skills.

The Autism Spectrum



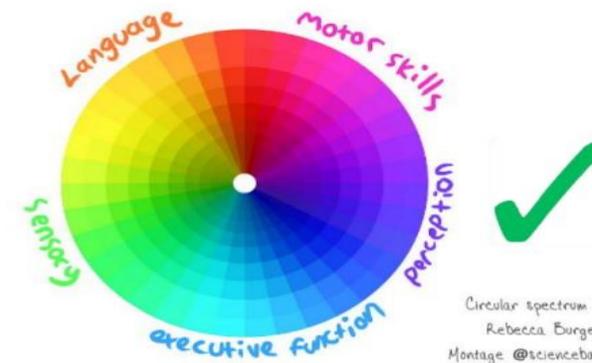
There are similarities found across the spectrum including:

- Unusual communication style
- Challenges with typical social interaction
- Intense interests
- Repetitive behaviors
- Difference in processing sensory input

What does the autism spectrum look like?



VS



Where a person is on the spectrum CAN CHANGE due to a variety of reasons including development, circumstances, and treatment.

Practicing Verbal Respect



- **“Person first”** language means referring to the person before their autism, such as “individual with autism”
- **“Identity first”** language means referring to autism first, such as “an autistic person”
- **“Neurotypical”** (NT) refers to an individual with neural functioning that is *perceived* as normative or typical
- **“Neurodivergent”** refers to someone with atypical neural functioning (autistic, ADHD, etc)
- **“Neurodiverse”** refers to a community or group of individuals with varying neurological or cognitive features
- Not everyone agrees about what kind of language is most respectful

TRY THIS!

We recommend that you ask what language the person prefers. And then use what language *they* feel comfortable with, not the language *you* prefer.

Understanding the Numbers: An Increase in Prevalence



1990- 1 in 2,500

2000- 1 in 250

2005- 1 in 166

2010- 1 in 110

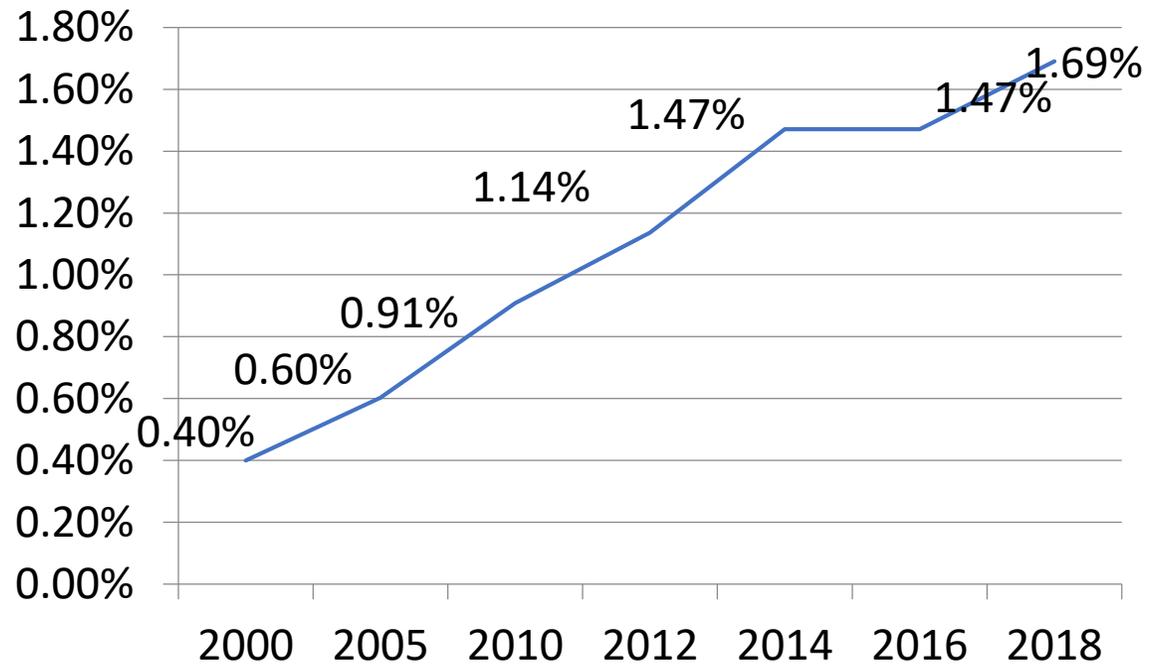
2012 – 1 in 88

2014- 1 in 68

2016 – 1 in 68

2018 – 1 in 59

Autism Prevalence in the US



From the Centers for Disease Control
and Prevention (CDC) April 27, 2018

Basic Facts About Autism



- One in 59 children has a diagnosis
- Lifelong neuro-developmental disorder
- Children and adults can learn and improve
- Early diagnosis is important
- Genetic link, can run in families
- More common in males (approximately five times more common)
- Looks different at different ages, developmental delay
- Frequently occurs with other diagnoses (this is called co-morbidity)
- Autism-related costs are \$1.4 million - \$2.4 million over a person's lifetime



10 Myths about People with Autism



All people with autism

1. Are savants (Rain Man stereotype)
2. Don't have feelings, have no empathy
3. Don't build relationships, can't get married or have families
4. Are violent and a danger to society
5. Have no language skills
6. Can't have jobs
7. Can't go to school or be in standard classrooms
8. Are entirely dependent on a caretaker
9. Are miserable and suffering
10. Need help and want a cure for autism

The truth? Every person with autism is a unique individual. Everyone has different needs, wants, abilities, strengths, lifestyles, and goals.

Possible Causes?



We don't know exactly what causes autism. What we DO know for sure is that autistic individuals, their families, and their communities need:

- ✓ SUPPORT
- ✓ RESOURCES
- ✓ ACCEPTANCE
- ✓ KNOWLEDGE
- ✓ SOCIAL OUTLETS
- ✓ FUNDING & MEDICAL ASSISTANCE
- ✓ THERAPY AND BEHAVIORAL INTERVENTIONS

This is what ASNV strives to provide. We especially think that more work should be done to find more effective, safe, inexpensive, local, and easily available therapy to support individuals in achieving their goals.



Some Early Signs

The earlier the diagnosis, the earlier supports can be provided!

- Lack of typical social engagement - eye contact, cuddling, smiling back, pointing at objects to show interest, prefers to play alone, no meaningful gestures by 12 months
- Unusual responses to sensory input - Stares at lights, only eats certain foods, cover ears
- Repetitive body movements - rocking, spinning, or flapping
- Difficulty with change or transition
- Communication impediments - Stops using speech or sign language (regressive autism); May be non-verbal or hyper-verbal; Echoes words or phrases (echolalia)

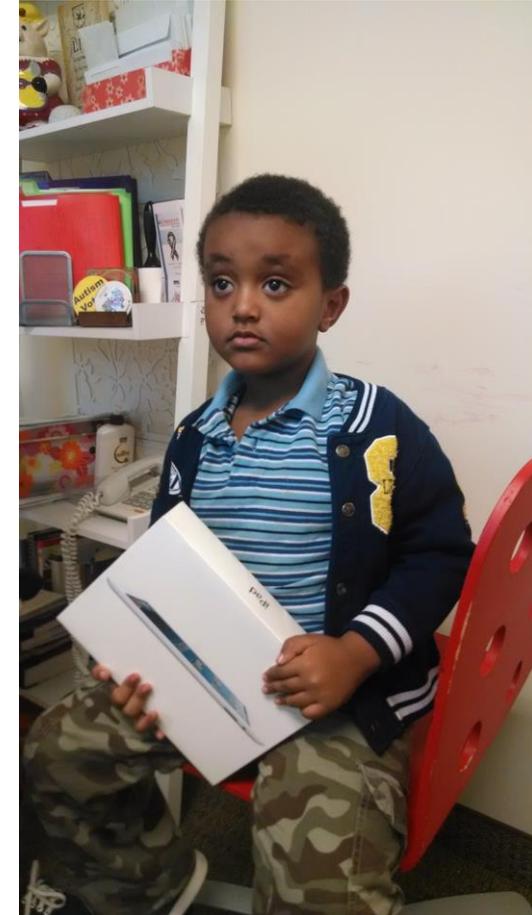
<http://www.cdc.gov/ncbddd/actearly/>

My Child/Adult has Autism, Now What?



- 1- Get a diagnosis/evaluation**
- 2 – Learn and connect**
- 3 – Begin supports and interventions**
- 4 – Think long-term**
- 5 – Take care of yourself**

You are in this for the long haul



Get a diagnosis/evaluation



1- Get a diagnosis/evaluation

-Medical Diagnosis

- Find local doctors
- Developmental Pediatricians
- Neurologists
- Neuropsychiatrists
- Psychiatrists/psychologists
- Multidisciplinary Centers

Educational Label

- Infant Toddler Connection
- Child Find - > PACs
- School system

-How is autism diagnosed?

- Multi-stage testing based on behaviors as observed or reported
- No genetic/biological tests
- Rule out hearing and vision loss

Learn and Connect



Attend Autism 101 – **You're HERE!!**

ASNV runs Lunch Bunch, TAP, and Safety Trainings

Read books, websites, blogs

Learn the lingo

Join local groups

ASNV, Arc, RAAC,

Support Groups, Find Mentors

Attend conferences/workshops/vendor fairs

Autism Walks

Educational Rights

Wrights Law

Resources

Other parents, teachers, therapists, etc.

Thinking Person's Guide to Autism

Disability Scoop – News

Wrong Planet

“Ask An Autistic”:



Supports and Interventions



Behavioral/Educational Interventions

- Applied Behavioral Analysis (ABA)
- Relationship Development Intervention (RDI)
- Speech Therapy
- Occupational Therapy
- Physical Therapy
- Sensory Integration therapy
- Auditory therapies
- Vision training
- Social Skills groups/camps

Tangible Supports

- Environmental Modifications
- Assistive Technology
- Service Animals

Biomedical interventions

- DAN! Doctors
- Dietary supplements or restrictions
- Allergy testing
- Gluten and Casein-Free Diets
- Medication

Therapeutic Recreation

- Therapeutic Horseback Riding
- Aquatic Therapy
- Music Therapy
- Dance Therapy
- Adapted Sports and Recreation
- Special Olympics
- Best Buddies

The Autism Society subscribes to the Options Policy –

We firmly believe that no single type of program or service will fill the needs of every individual with autism and that each person should have access to support services. Selection of a program, service or method of treatment should be on the basis of a full assessment of each person's abilities, needs and interests. We believe services should be outcome-based to ensure they meet the individualized needs of a person with autism.

Supports and Interventions cont.



Working with the school system to build a collaborative team

Autism at School

Prepare drafts in advance
Communicate before and after
Know your rights
Document everything
Bring an ally to all your meetings



Educational Rights

Annual IEP, or, 504 Meeting
Tri-annual evaluation
May request additional at any time
IEE – Independent Educational Evaluation
LRE – Least Restrictive Environment
FAPE – Free and Appropriate Public Education
BIP/FBA – Behavioral Assessment and Plan

Resources

Special Education PTA
Parent Resource Center
PEATC
disAbility Law Center of Virginia
Wrightslaw

Think Long Term



Set Goals

Get to know autistic adults, or,
find a mentor

Down the Road –

*Social Security

*Guardianship/Power of

Attorney/Supported decision making

*Vocational Rehabilitation – Vocational
and rehabilitative services to individuals
with disabilities to help them prepare
for, secure, regain or retrain
employment.

Stay Organized

Keep a binder/file cabinet

Start right

Special Needs Trust

ABLE account

Consider a microboard
or other Circle of support

Long term services and supports

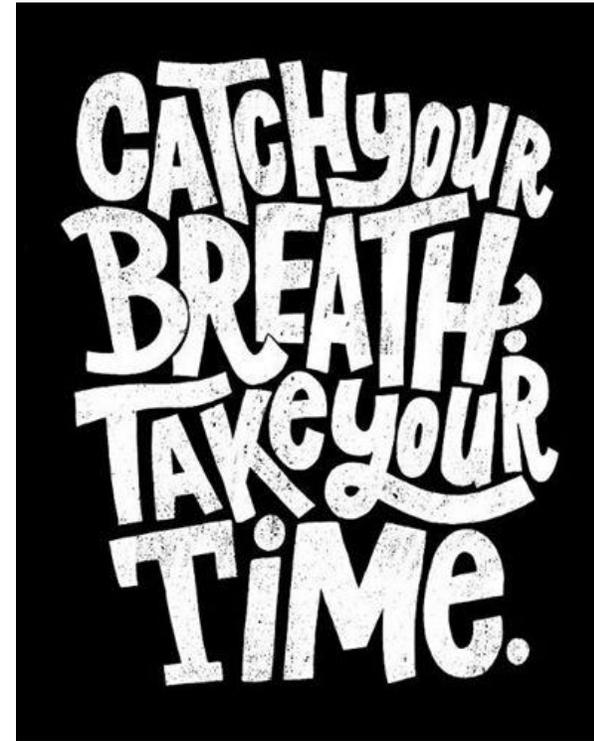
Apply for a Waiver



Take Care of Your Self



- Be sure to use respite (babysitters) to get out and do the things you loved before you entered the world of autism.
- Remember to spend one-on-one time with each family member.
- Remember your other children – they need your love and attention too.
- Be sure to have a hobby of your own, exercise, and even read for pleasure!
- Don't forget to laugh.
- Even though there is a lot to handle with a child, or adult, with Autism, you have to remember that **this is a marathon and not a sprint.**



How to support someone with autism



Top Tips

Be Patient.

Listen.

Avoid sudden change.

If you don't know, ask.

Presume Competence.

Ten things to think about in supporting individuals with autism

1. Sensory issues
2. Anxiety / Trauma
3. Visual supports
4. Literal language
5. Behavior is communication
6. Time for breaks – for you and them
7. Transition points
8. Choice – empowerment
9. Won't vs. Can't
10. Having autism means your brain works differently.

Everyday Tips



- Use a soft voice
- Call them by name
- Be calm
- Give them space
- Do not touch or hug without permission
- Allow time for a response
- Do not expect eye contact
- Help the person learn that they are safe with you
- Make accommodations for sensory challenges
- Be patient; it may take a long time to feel that you are making a connection
- Accept the person's quirks
- If the person is having a hard time, ask how you can help
- Communicate in the way that works best for the person
- If you're speaking to a child, ask the parents for some tips

How Are We Doing?



- VA ranks 39th out of 51 states (and DC) on disability inclusion (United Cerebral Palsy, 2016)

- Autistic adults struggle with employment, housing, bullying and social isolation.



- The waitlist for long-term services has over 12,000 people on it and the wait for services averages 8-10 years. Waiting lists vary by waiver program.

Autism Acceptance



Initiated by the Autism Society of Northern Virginia's autistic board member, autism acceptance as an unambiguously positive response to the negativity frequently associated with autism.

Autism Acceptance is actively offering autistic individuals the supports they need to be fully included as valuable members of our families, schools, workplaces, neighborhoods and faith communities.



Our Mission



To build community for over 5,000 individuals and families through education, advocacy, & support



We believe that no individual should walk this journey alone.

What do we do?



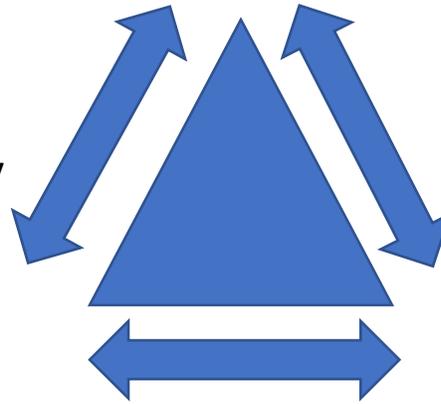
EDUCATE

Provide all affected by autism with knowledge, resources, & acceptance
*Lunch Bunch • Autism 101 • Online support group • Monthly Newsletter
Safety trainings • Resource directory •*

SUPPORT

Provide resources and community for autistic individuals and their families

Social nights • YouToo Tennis • Mini-grant program • Assistive Technology Program • The Autism Partnership (TAP) Program



ADVOCATE

Build a welcoming, inclusive, & supportive region

Autism Advocate Forums • Workplace presentations • Acceptance Walk • Arts for Autism • Local, state, and federal advocacy



The Autism Society of Northern Virginia is here for YOU!

We advocate, inform and...share the journey

Contact us:

Rose Sutton

Support@asnv.org

571-328-5770

www.asnv.org