Understanding Autism Spectrum Disorder: Creating Inclusive Opportunities

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Our Mission

The Autism Society of North Carolina is committed to providing support and promoting opportunities which enhance the lives of individuals within the autism spectrum and their families.
Objectives:

**Part One**
- Develop a basic understanding of the core features of Autism
- Identify the characteristics of Autism Spectrum Disorder with emphasis on the ways those manifest in the library (and community) contexts.

**Part Two**
- Identify key supportive strategies to apply in such contexts. These will include:
  - Physical structure/environment design
  - Visual schedules and other visual supports
  - Structuring materials and routines to promote participation

- Group Activity
What do you see?
What Is Autism Spectrum Disorder (ASD)?

A neurobiological disorder of development that impacts social communication and behavior.

There are differences in the way individuals process and learn information.

- Understand and use language to communicate
- Understand and relate to people, events and objects
- Understand and respond to sensory stimuli
- Learn and think in the same way as typically developing children
Autism is a Spectrum Disorder

Each individual diagnosed with ASD have different strengths and needs.

Mild ------------------------Severe
Verbal ---------------------Non-verbal
Social Seeking--------------Avoiding
Oversensitive--------------Under sensitive
High IQ---------------------Dev. Delays
Autism Spectrum Disorder

Challenges range from mild to severe

Level 1
“Requiring support”

Level 2
“Requiring substantial support”

Level 3
“Requiring very substantial support”

(DSM V, 2013)
Who Has Autism?

- 1 of every 58 children born today will be diagnosed with Autism Spectrum Disorder (Center for Disease Control & Prevention)
- In NC - 1 in every 57
- Five times as many boys as girls
- Nearly 60,000 North Carolina families are affected
- Autism affects over 1 million children in the U.S.

(Center for Disease Control & Prevention 2018)
Common Misconceptions

- If a child is highly verbal, they must not have ASD
- Most with ASD are savant, “genius” in certain areas
- If you have ASD, then you don’t want to be around other people and you don’t initiate interactions
- Other misconceptions? Not affectionate, poor eye contact, ....
Raise your hand if.... *(you like to be in control)*

And raise your hand if... *(you like to be controlled)*
Four Core Features

- Communication (verbal and nonverbal)
- Play / leisure skills and social interactions
- Thinking and learning
- Behavior and sensory responses
Joint Attention: Foundation of Communication
Differences in Early Forms of Expressive Communication

- Language does not develop as expected
- Does not consistently use words they have
- Limited use of gestures
- Struggles to direct communication to someone
- Struggles to initiate
Differences in Expressive Communication

- May not initiate communication around needs or problems
- May not clearly direct communication
- Difficulty ping-ponging
- Difficulty conceptualizing and conveying complex concepts, internal states such as degree of pain or emotional state; difficulty elaborating
Differences in Receptive Communication

- Difficulty understanding what others are communicating, both nonverbally and verbally
- “I can look at you or talk to you, but I can’t do both at the same time”
- Delayed processing of what is said
- Difficulty “reading between the lines,” social nuances, tone, sarcasm, idioms or puns
- Understanding (and performance) is driven by context
Differences in Social Interaction

- Poorly integrated nonverbal behaviors to communicate and to regulate social interaction
- Limited sharing of affect, emotions, and interests
- Lack of social-emotional reciprocity
- Weakness in reading social cues, faces, perspectives
Limited Flexibility and Creativity in Play
Restricted Patterns of Interest

• Lack of variety in toys, reinforcers, topics and downtime activities

• Some display extensive knowledge around certain peak topics

• Their topic of preoccupation may be an unusual or uncommon interest
Key Social Concepts

• Other people have thoughts that are different from your thoughts
• People have thoughts about other people as they interact
• My behavior affects other people’s thoughts about me
• There are hidden messages in words and actions
Thinking and Learning

- Over-focus on details
- Concept of time may be affected
- Difficulty problem-solving
- Difficulty generalizing concepts or skills learned under one condition to novel conditions
Sensory Processing Difficulties

“When my hormones hit at puberty, my touch sensitivity worsened. Loud noise was like a dentist’s drill hitting a nerve and scratchy clothes were like coarse sandpaper against my skin” Temple Grandin
What Behaviors *Might* We See in Patrons with ASD?

Some examples:

- Plugging ears, rocking, flapping, pacing, vocalizations, and other sensory-based repetitive behaviors (not necessarily targets for change!)
- Inappropriate social communication behaviors (e.g., interrupting, inappropriate topic selection, no social filter)
- Poor grooming and hygiene routines
- Arguing, refusals, debate
- Verbal outbursts, yelling
Fear and ANXIETY

- Compulsive-looking behavior
- Need for things to look or be a certain way
- May become upset over minor changes
- Rigidity

The above can be heightened in an unfamiliar setting where the people, food, smell and environment are different.
Common observable triggers of behavior

- Unexpected changes to routine
- "No" "Wait" "Not now"
- Long verbal strings; complex info/instructions
- Socially demanding situations

Behaviors we see on the surface

- Environmental stimuli (sensory)
- End of preferred activity
- Transitions
- Non-preferred activities / demands

Fear, confusion, anxiety
Major Contributors to Challenging Behavior

• Does not communicate what he wants
• Does not communicate what he does not want
• Does not understand what you are communicating
Video clip
Strengths

- Use visual information meaningfully
- Understand and use concrete rules
- Concentrate on topics of specific interests
- Children learn best through play
Keys to Supporting Individuals with Autism

- Make directions and expectations clear
- Provide information visually, not just spoken
- Allow time for processing
- Provide follow up
- Be consistent, flexible, and patient
Visual Support = Success + Independence

People with autism need **visual information** to help them understand and respond in their environment.

• Neurotypicals assume sharing information verbally is best
  • **BUT**

• People with ASD get part of it....
  ▫ Part of social interaction
  ▫ Part of social problem solving
  ▫ Part of communication
  ▫ Part of the rules

• I act on what I know. If I miss key features of social communication, my behavior will be confusing.
Variations of Picture Schedules
Visual Directions

When I go to the library, I will:

• Ask the Librarian for time on the computer
  - She/he will put my name on the list and tell me what time to come back. I will have 30 min to use the computer.
• I will look for 5 books
• When it is time to leave the library, I will check out my books
Using available apps on phones and iPads, like the Paperless app.

THINGS TO DO TODAY

Date_________________________COMPLETED

1) ____________________________
2) ____________________________
3) ____________________________
4) ____________________________
5) ____________________________
6) ____________________________
7) ____________________________
8) ____________________________
9) ____________________________
10) ____________________________

1. Get materials for work
2. Wait for bus
3. Check in with supervisor
4. Remove packaging from stock
5. Hang clothing on correct hangers and put on rack
6. Move rack to correct department and put clothing on rack by size
7. Put rack back in work area
8. Check out with supervisor
9. Wait for bus
There are wonderful apps for iPhones and iPads that provide a simple way to structure and organize daily routines and activities.

Like the Paperless app
Remember, “different, NOT less”

(Quote from the movie, Temple Grandin)
Questions?
15 min BREAK

[Image: A drawing titled "30 Ways to Take a Break," with various ideas such as meditate, call a friend, write in a journal, and spend time in nature.]
Part Two
Core Features Review

- Communication (verbal and nonverbal)
- Play / leisure skills and social interactions
- Behavior and sensory responses
- Thinking and learning
I don’t know what to do:

- Where to start?
- How do I break it down into manageable parts?
- How long do I work on this?
- How do I know when this task is finished? When to stop?
- What is the criteria for “good” and/or complete?
- How do I manage my time to meet short and long-term deadlines?
Six Evidence Based Strategies for Successful Library and Community Experience
1. Arrange the Environment: Set the Stage

People with autism often need visual information to help them understand and respond in their environment.
**Structure**

Modify the environment to enhance meaning for people with autism.
Embed visual cues that clarify boundaries

Photo above courtesy of Manna Church
Arrange the Environment to:

- Convey clear physical and visual boundaries
- Minimize distractions
- Clearly define area/zones

Design the space so that cues support the behavior you want – organization communicates expectations
2. Concretely and visually clarify what will happen and in what sequence

First

Then
Visuals can help establish rules as well as provide a gentle reminder of them.

**Rules for Library**

- Quiet Voice

- Stay with me

- Find 5 books, sit quietly and read them.

- Place the books on the cart, NOT ON THE SHELVES!
• Get out colored pencil and homework
• Correct HW
• Turn in HW
• Get out regular pencil and calculator
• Listen and watch teacher
• Take notes
• Get out agenda
• Write tonight's HW in agenda
• Put binder, pencil, calculator and agenda in backpack.
3. Concretely communicate expectations

- Addresses differences in receptive language skills
- Reduces anxiety
- Addresses differences in how the individual mentally plans, sequences, and organizes
Visuals can help establish rules as well as provide a gentle reminder of them
Visual Directions

When I go to the library, I will:

• Ask the Librarian for time on the computer
  - She/he will put my name on the list and
tell me what time to come back. I will
have 30 min to use the computer.
• I will look for 5 books
• When it is time to leave the library, I will
check out my books
Embed visual cues that convey expectations
“Be good...Be polite...Make good choices...”

Be explicit!

• Concretely define rules

• Concretely define behaviors

• Concretely convey outcomes / consequences of behavior

• Concretely describe social nuances (for some)

• Don’t emphasize the “don’ts...”
4. Concretely and visually structure activities to answer these questions:

- What am I supposed to do?
- How much / how long am I going to do it?
- When will I be finished?
Sunscreen

1. Face and Neck
2. Arms
3. Chest
4. Back
5. Legs
6. All done! Great job!
Concretely and visually clarify how long, when finished
5. Present choices in a visual modality that the individual can understand

How does the individual communicate wants and needs?

How does the individual understand options and indicate choice?

* Imagine how upset you might get if you could not express your needs all of the time and if you could not assert choice. What behaviors would you use to get your message across?
POND CHOICE

COLORING BOOKS

FISHING

BUBBLES
Go to Non Fiction

600 section is Rocketry

610-15

Take books to sitting area

Leave them on the cart if you decide you don’t want to check them out
Also consider: How does s/he say...

I need to go too
a quiet place
please
What questions should we answer?

- What am I supposed to do?
- How do I do it?
- For how long do I do it?
- How much do I have to do?
- When will this be over?
- What’s the criteria for finished?
- What do I do when I finished?
- When can I have...?
6. Make a plan for meltdowns.
What can you do?

• Give physical space and wait time
• Reduce / eliminate verbal direction
• Withhold emotional reactions
• Distract, redirect
• Have an alternative plan
• Reduce participation in “group” activities
• Stay calm and redirect to a safe place
Possible indicators of stress or anxiety

- Repetitive movements (pacing, flapping)
- Repetitive speech (questions, echolalia)
- Might handle situations as if they were a younger person
- Decreased eye contact
- Banging on tables, stomping feet
Managing *our* emotions

The individual’s behavior is not intended to simply challenge your authority.

It’s a reflection of the individual’s lack of coping skills.

In these challenging moments, our coping skills are crucial.
Reframing our assumptions and our language:

• Instead of “He’s being rude” we might say “He does not seem to understand the social rules in this situation”

• Instead of: “He can do it, but he is just choosing not to”… we might say “He is not responding to things that typically reinforce him right now.”

• Instead of “She’s not even trying it...” we might say “There is some aspect of this activity that she does not seem to understand.”
Identify areas to support self-regulation

GO TO
Small Conference Room
Instructions to support routines

When I am upset, I can:

- Put on my headphones
- Walk down the hall to get water
- Go to the bathroom

**After 5 minutes, I need to return to work**
Warning: I’m stepping on my SOAPBOX

Yes, you are not ultimately responsible for the 6th strategy...but you have a choice and an opportunity.

An opportunity to shape how others may respond and react by watching how YOU respond and react.

I am first and foremost a person.

Autism is only part of who I am.

I am first and foremost a child.

I am first and foremost a person.
ASNC Appreciates Support By:

• Participation in *Autism Awareness Month* each April
• Participation in the *Annual Triangle Run/Walk* event in Raleigh during October
• Look for other events across the state throughout the year.
• Donations
• Sharing knowledge with others about autism
ASNC resources

• Workshops: www.autismsociety-nc.org/workshops
  (Building on Strengths to Overcome Challenges expands on strategies to address the core features.)

• Autism Resource Specialists: www.autismsociety-nc.org/resourcespecialists

• Toolkits: www.autismsociety-nc.org/toolkits

• Blog: www.autismsociety-nc.org/blog
Founded in 1970 to connect families, professionals, and individuals with autism. We are a lifelong partner on the journey with autism.

- We provide support and promote opportunities which enhance the lives of individuals with autism spectrum disorders
- We provide ongoing public education and awareness about the needs of the autism community
- We advocate with legislators, policy makers, and state departments for the needs of the autism community
Our services cover the lifespan and across North Carolina. We offer a menu of supports including:

- Parent to parent consultation through Autism Resource Specialists.
- In person and online workshops by Autism Resource Specialists for individuals with autism, parents and other caregivers, and professionals.
- Chapters and support groups - More than 50 Chapters and eight Hispanic Support Groups around the state.
- Medicaid and private pay services in a person’s home, the community, center-based, and residential and vocational offerings to children and adults with in five regions.
- Social recreation programs for children and adults with ASD at Camp Royall, through eastern social recreation programs (3 locations), and the IGNITE program for young adults in Davidson.
- Individualized, intensive consultation to families and professionals; comprehensive behavior analytic program development and oversight; curriculum development, workshops and site-based coaching to professional groups, delivered by Clinical Department’s psychologists and behavior analysts.
Social Recreation Programs

• Summer Camp and year-round programming at Camp Royall in Pittsboro

• Eastern NC social rec locations:
  ▫ Newport – Afterschool, summer camp, adult options
  ▫ Wilmington - Afterschool, summer camp, adult options
  ▫ Winterville - Afterschool, summer camp, adult options
  ▫ Brunswick and Onslow Counties – summer camp