

Understanding Autism in Real Life: From the Clinic to the Hospital Room

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Objectives

- Describe how early neurodevelopmental risk factors influence later autism-related differences.
- Identify early signs and functional presentations of autism across clinical settings.
- Implement practical strategies to support children with autism and their families.



Quick Caveat

- Autism is broad, nuanced, and highly individual
- No single presentation fits every child
- Diagnosis is not always immediate or straightforward
- Today's goal: practical frameworks + take-home strategies



Why This Matters

- “Difficult” behaviors across settings are often connected
- Autism is increasingly encountered in *all* pediatric environments
- Many children, whether they are diagnosed with autism or remain undiagnosed, still need support



Recognize this patient?

- 4-year-old admitted for pneumonia
- Meltdowns during vitals or procedures
- Pulling off monitors
- “Noncompliant”



Autism Spectrum Disorder Basics



Autism Statistics

Prevalence

- About **1 in 31 (3.2%)** children aged 8 years has been identified with ASD.¹
- ASD is reported to occur in **all racial, ethnic, and socioeconomic** groups.¹
- ASD is over **3 times more common among boys** than among girls.¹
- The increase in prevalence is largely attributed to **broadened diagnostic criteria, improved screening and ascertainment, and increased public awareness** rather than a true increase in incidence.



Autism Statistics

Etiology

- ASD arises from a complex interplay of **genetic and environmental factors**, with **genetics** playing the predominant role.²
- **Environmental factors:**²
 - **Advanced parental age**
 - **Maternal metabolic conditions**
 - **Prenatal exposures – valproic acid, extreme prematurity, birth complications**
 - **Maternal immune activation and maternal infections during pregnancy**



What is Autism Spectrum Disorder?

A neurodevelopmental condition characterized by:

- Persistent deficits in social communication/interaction and
- Restricted/repetitive patterns of behavior, interests, or activities



Social Communication Deficits³

- Reduced social/emotional reciprocity
 - Limited joint attention (pointing, showing)
- Difficulty with nonverbal communication
- Challenges developing and maintaining social relationships



Restricted/Repetitive Patterns of Behavior³

- Stereotyped/repetitive speech, motor movements, or use of objects
- Excessive adherence to routines
- Highly restricted, fixated interests – abnormal in intensity or focus
- Hyper or hypo-reactivity to sensory input – pain, heat/cold, sounds, textures, smelling, lights, spinning objects, etc.

Social Communication Deficits

- Social-emotional reciprocity
- Nonverbal communication
- Ability to form and maintain appropriate social relationships

Need symptoms in all three subdomains

Autism Spectrum Disorder

Restricted Interests/ Repetitive Behavior

- Repetitive or stereotyped movements, speech, or play
- Insistence on sameness and need for rituals or routine
- Highly intense or unusual areas of interest
- Oversensitivity or undersensitivity to different sensory experiences or unusual sensory behaviors

Need symptoms in two of four subdomains



What Autism is Not

- Just a speech or language delay
- Defined by eye contact alone
- Caused by parenting
- Always obvious early



Case Introduction





Meet Liam

Birth:

- 30 weeks gestation
- 6-week NICU stay
- Feeding difficulties

Infancy:

- Difficult to soothe
- Sensitive to noise/touch

2 Years:

- Limited speech
- Not pointing/showing
- Repetitive play (spinning objects)
- Tantrums with transitions



Starting in the NICU

- Prematurity → increased neurodevelopmental risk⁵
- Longer NICU stays associated with higher risk of developmental delay⁶
- High sensory environment (lights, noise, procedures)
- Repeated stress exposure



Early Signs in Clinic

- Speech delay + limited gestures
- Reduced joint attention
- Repetitive behaviors
- Sensory sensitivities
- Difficulty with transitions

***Developmental screening** recommended at 9, 18, and 30 months, with **autism-specific screening** at 18 and 24 months



Inpatient Setting

Liam at Age 5 (Hospitalized)

- Refuses vitals
- Pulls off monitors
- Escalates with staff

May become labeled:

- Noncompliant
- Behavioral

Instead think:

- Sensory overload
- Fear + unpredictability
- Communication mismatch



Practical Strategies





3 Core Principles:

1. Communication

- Presume competence
- Use simple, direct language
 - Clear, concrete statements
- Allow processing time
- Use a lower-volume, non-threatening tone of voice
- Show > tell when possible



3 Core Principles:

2. Sensory Support

- **Reduce noise/light** when possible
- **Prepare before touch**
- **Be mindful of sensory triggers**
- **Limit the number of people entering the room (when possible)**



3 Core Principles:

3. Predictability

- **Explain** what will happen
- Use **routines** when possible
- Offer **choices**
- Use **social stories** to prepare for new or stressful experiences



Social Stories

Useful for:

- Clinic visits
- Hospital admission
- Therapy sessions
- School transitions
- New routines at home

Blood Pressure



This story is about how the nurse will measure my blood pressure. I can tell the nurse anytime if I need a break. The nurse needs to do her job so I can stay healthy.



Blood Pressure



I will sit down. The nurse will wrap a cloth around my arm. It might feel tight.



Blood Pressure



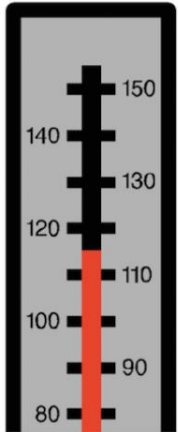
The cloth will get tighter, but that's okay. It is important that I sit still.



Blood Pressure



The cloth will stop feeling tight. The nurse will read my blood pressure from the machine.



Blood Pressure



The nurse will remove the cloth. I can ask the nurse to tell me my blood pressure.



Blood Pressure



I did a great job learning how to get my blood pressure taken!



Autism Friendly Social Stories

Getting to the doctor's office

Getting a shot

Blood draw

Blood pressure

Height and weight

Dentist appointment

Physical exam



about app | BMC Autism Program



Neonatal Strategies

- Prevent brain injury (neuroprotective care bundles)⁸
- Optimize nutrition
- Reduce sensory stress
- Support parent-infant interaction⁹
- Emphasize developmental follow-up¹⁰



Outpatient Strategies

- Environmental modifications
- Communication strategies
- Preparation for procedures
- Provide positive re-enforcement throughout visit
- Staff training
- Engage families as experts
- Validate parent concerns
- Refer early
- Screen for and manage common co-occurring conditions
- Evaluate organic causes



When a Child Is Referred for Autism Evaluation

Developmental-Behavioral Pediatrics (DBP):

Pediatrician with 3 years of specialized fellowship training focused on evaluating and treating children with complex developmental, learning, and behavioral difficulties (including autism).

Autism evaluation often includes:

- Detailed developmental and medical history
- Behavioral observation
- Standardized assessments – Childhood Autism Rating Scale (CARS), Developmental Profile, 4th Edition (DP-4)
- Review of school / therapy information when available



Inpatient Strategies

- Cluster care
- Prepare before procedures (e.g., social stories)
- Prioritize essential interventions (pick your battles)
- Use caregiver as partner



Building Autism Friendly Systems

- This might include:
 - Standardized staff training
 - Sensory supports
 - Communication accommodations
 - Environment modifications



Example – Boston Medical Center “Autism Friendly Initiative”⁷

1. Individualizing patient care
2. Modifying the sensory environment
3. Training clinicians, staff, and students
4. Providing support in preparation of visits

Autistic Patient Bill of Rights




I have the right to

- be treated with equal respect.
- advocate for what I need.
- have my individual preferences and needs considered.
- understand what will happen before, during, and after my visit.
- have all my questions answered.
- information to be explained in a way that I can best understand.
- be offered a quiet alternate waiting space whenever possible.
- accommodations for my individual sensory and communication needs.
- make requests that will help make my experience more positive.
- a satisfactory healthcare experience.



Developed by the Autism Friendly Initiative's TEACH Board
(Teens Educating, Advocating, and Consulting in Healthcare)



Liam, age 5, admitted for pneumonia

Autism-Friendly Initiative Approach:

- Before the Visit / Admission
 - Chart flag for autism / individualized needs
 - Social story sent before admission or procedure
- During Hospital Stay
 - Quiet room when possible
 - Limit unnecessary room entries
 - Explain steps before touch
 - Use clear, concrete language
 - Allow comfort item/headphones
 - Cluster care when possible
 - Ask caregivers “What helps Liam when he is stressed?”



Liam

- Diagnosed with autism
- With supports:
 - Improved communication
 - Better regulation
 - More successful medical encounters



Take Home Points

- Autism is a **trajectory**, not a moment
- Behavior is often a form of **communication**
- Small changes in approach → big impact
- Every role in this room matters

References

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Resources to Explore

1. Boston Medical Center – Autism Friendly Initiative - <https://www.bmc.org/visiting-us/autism-friendly-initiative>
2. BMC Social Stories Library - <https://bmcautismfriendly.github.io/socialstories/>
3. Autism Speaks Tool Kits - <https://www.autismspeaks.org/autism-speaks-tool-kits>
4. Oklahoma Autism Center - <https://autismcenterok.org/>

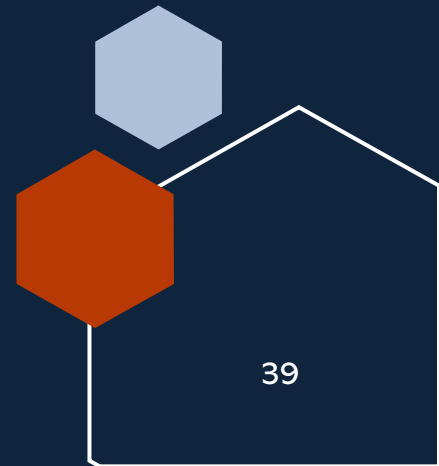
Applied research and training to improve the quality of life for children with autism spectrum disorders and their families. Current projects are Early Access, school support services, and Early Foundations.

5. Oklahoma Autism Network - <https://okautism.org/>

Center of excellence at OUHSC committed to improving quality of life for individuals with autism and their families. They organize the Oklahoma Statewide Autism Conference as well as trainings and events focused on autism spectrum disorders.

6. Oklahoma Family Network - <https://oklahomafamilynetwork.org/>

Nonprofit organization that supports families of children with special needs through resource navigation and mentoring relationships.





Questions?