



This PowerPoint file is a supplement to the video presentation. Some of the educational content of this program is not available solely through the PowerPoint file. Participants should use all materials to enhance the value of this continuing education program.

## *Supporting Children with Autism Spectrum Disorder and Their Families*



*Elizabeth Sledge, MD, FAAP  
Assistant Professor  
Department of Pediatrics  
Texas Tech University Health Sciences Center  
Lubbock, Texas*

## **Goals**

- **Describe the prevalence of Autism Spectrum Disorder (ASD) and common comorbidities associated with ASD**
- **Identify stressors affecting mental health of family members of children with ASD and examine how these stressors may affect family dynamics and quality of life for all members**
- **Discuss how medical staff can support children with ASD, their siblings, and their caregivers and identify resources to facilitate support**

## **Financial Disclosure**

**I have no professional or personal financial disclosures**

## **Personal Disclosure**

**I am not an expert in ASD  
I am learning more about ASD  
every day**

## **Basics**

- **ASD affects more than 5 million Americans**
- **Prevalence of 1:59 children (approximately 1.7%)**
- **Care needs of children with ASD can be significant**
- **Adequate understanding of these needs facilitates timely and effective intervention**
- **Collaborative care between families, schools, and medical homes leads to best outcomes**

# Prevalence

Prevalence has increased over time

May be attributed to multiple factors:

- Broadening diagnostic criteria
- Increased public awareness
- Universal screening recommendations
- Increased early intervention and school based services

Possible biological risk factors

# Core Symptoms

Neurologically based but manifest as behavioral characteristics

- Present differently depending on age, language level, and cognitive abilities (hence, spectrum)
- Symptoms due to atypical development in several functional areas
  - Social and communication delay
  - Deficits in imitation and sensory processing difficulty
  - Repetitive behaviors and perseveration
  - May be due to atypical processing of sensory information and desire for predictability

# Diagnosis-DSM V Criteria

Divided into 2 domains:

- Social communication and social interaction (all 3 must be met)
- Restrictive, repetitive behaviors (2 of 4 symptoms must be present)

Severity rating

- Based on level of support needed

## DSM V Social Communication Deficits

Social-emotional reciprocity

Nonverbal communicative behaviors used for social interaction

Developing, maintaining, and understanding relationships



## **Restrictive, Repetitive Behaviors**

**Stereotyped or repetitive motor movements, use of objects, or speech**

**Insistence on sameness, inflexible adherence to routines, or ritualized patterns or verbal nonverbal behavior**

**Highly restricted, fixated interests that are abnormal in intensity or focus**

**Hyper- or hyporeactivity to sensory input or unusual interests in sensory aspects of the environment**

## **Primary Treatment Goals**

**Minimize core features and associated deficits**

**Maximize functional independence and quality of life**

**Alleviate family distress**



## **Common Issues/Comorbidities**



**Sleep disorders**



**Developmental or  
behavioral diagnoses**



**Seizures**



**Behavioral disorders**



**GI issues**

**Significant effects on the health and quality of life for children and youth with ASD and their families**

## **Seizures**

**Increased risk for ASD among children and youth with epilepsy**

**Increased risk for seizures in those with ASD**

**Risk factors:**

**Intellectual disability**

**Female sex**

**Lower gestational age**

**Specific genetic disorders associated with ASD (e.g.,  
Tuberous Sclerosis)**

# Seizures

**Children with ASD and seizures tend to have more behavioral challenges**



# GI Symptoms

**More commonly reported in children with ASD than those with developmental delay or typical development:**

- Abdominal pain
- Constipation
- GERD
- Feeding problems

**May present as agitation, sleep disruption, or other behavioral symptoms rather than GI discomfort**

- Due to language delay, atypical sensory perception



## GI Symptoms – Why?

- Resistance to change (feeding and constipation)
- Comorbid anxiety (pain, feeding, and motility disorders)
- Altered sensory perception (pain, feeding, and constipation)
- Restrictive eating patterns
- Ongoing research in areas of immunology, motility, and microbiome



## Atopy

Children with ASD may be more likely to have a food, respiratory, or skin allergy



# Feeding Disorders

Up to 3/4 of children with ASD have problems related to eating

- Food selectivity
- Compulsive eating of certain foods
- Behavioral refusal: holding food in mouth, gagging, emesis
- Pica
- Sensory differences, perseveration, oral exploration (monitor for foreign body ingestion, toxicity)
- Rumination
- Delayed oral motor skill development

# Obesity

Greater risk for overweight and obesity than general population

Decreased opportunities or less interest for activities or organized sports

Medications



## **Dental Health**

**Commonly have unmet dental needs**

**May have difficulty cooperating with hygiene and professional care**

**Even when insured, children with ASD have fewer routine care visits**

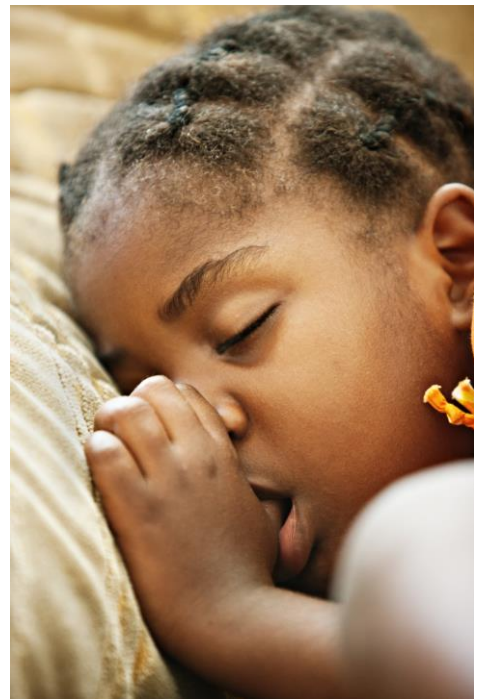
**Behavioral strategies may be helpful**

## **Sleep Problems**

**Sleep disturbance is common in individuals with ASD**

- **50-80% of children have difficulty initiating or maintaining sleep**
- **Sleep problems usually persist**

**May exacerbate problematic daytime behavior**



# Sleep Problems

## Reasons:

- Differences in melatonin metabolism
- Lack of social expectations
- Disruption of critical sleep neurotransmitter systems



# Elopement

Places child at risk for injury

Decreased awareness of social convention/community rules, impulsivity, perseverative interests

Most common perceived reasons: enjoyment of running, attempts to get to a desired location, pursuit of interest, and escape from situations or sensory events that increase anxiety

Prevention is key

## **Motor Disorders**

**Developmental coordination disorders or other neurologic problems**

**Tic disorders - increased frequency in children with ASD**

**Catatonia - possible co-existing condition**



## **Co-Occurring Behavioral Health Conditions**

**Not core features of ASD but commonly interfere with functioning in school, at home, and in the community**

**Effects on quality of life for children with ASD and their families**

**Patients should be regularly screened for behavioral and/or emotional conditions**

**Changes in behavior may be due to physical sources of discomfort**

# ADHD

**½ of children with ASD may also meet diagnostic criteria for ADHD**

**May further compromise social skills function**

**Be aware:**

- **Delayed language may present as inattention**
- **Escape behaviors may be misinterpreted as hyperactivity**



# Anxiety

**40-66% of school-aged children and adults with ASD are reported to also have anxiety disorders**

**Symptoms may presents as behavioral challenges (e.g., over reactivity)**

**Social communication deficit may lead to heightened worry (fear of the unknown)**

**Repetitive behaviors may serve to help with predictability**

**May not be able to fully describe their symptoms**

- **May be associated with GI and sensory symptoms**

## **Mood Disorders**

**Depressive disorders are more common among individuals with ASD (children and adults)**

**Co-existence of ASD and depression may be associated with genetics, neurobiological factors, and environmental factors (chronic stress and difficulty with understanding social situations)**

**May present as changes in affect, participation, sleep habits, and eating**

**Attempted suicide is reported to occur more frequently**

## **Other Behavioral Disorders**

**Disruptive behavior disorders: Aggression, self-injurious behavior, and tantrums**

**Understand behavior in context:**

- Stressful events**
- Medical conditions**
- Functional communication**
- Symptom of co-occurring mental health disorder**

**May be a way to escape from a demand or an undesired situation**

**New onset of several behaviors requires consideration of potential medical reasons**

## How Do We Help?

- Collaborative care with medical home
- Refer to appropriate care teams, therapies, and resources in the community
- Emergency plans
- Classroom support - IEP



## Siblings

**Siblings play an important role in family life and are the first significant peer relationships that a child experiences**

**Large impact on socio-cognitive development**

**Source of prosocial behaviors: sharing, cooperation, and empathy**





## How Are Siblings Affected?

**Siblings, like parents, face a number of challenges**

**Some may take on caregiving roles, responsibilities, or chores to alleviate burden**

- Feeding, dressing, bathing siblings

**Parents may be less emotionally or physically available for siblings**



## How Are Siblings Affected?

**Higher levels of separation anxiety, emotional problems, increased risk of adjustment difficulties**

- Behavioral problems in siblings with ASD positively predict depressive symptoms

**Parenting stress is a strong predictor of adjustment**

- Maternal stress was strong predictor of anxiety



# Protective Factors

Decreased parental stress (especially maternal)

Social support

- Family
- Close friends
- Support groups

Increased parental involvement → greater positive sibling adjustment

Higher family income

- Greater access to resources, therapy

Female

Larger family, birth order



## Upside

Studies have also shown that siblings are affected positively

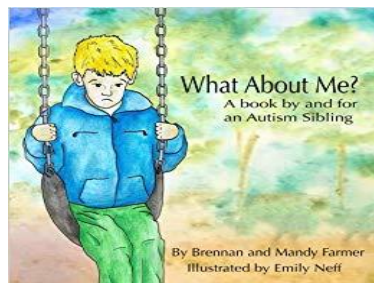
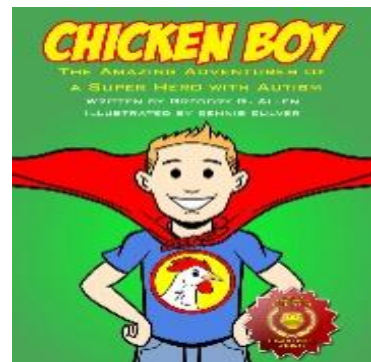
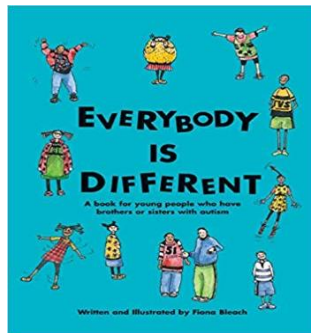
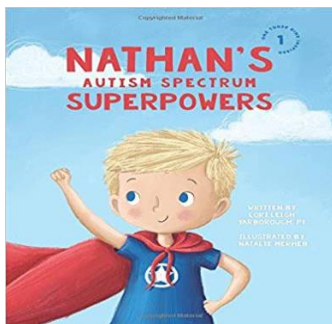
Many report relationship as fun

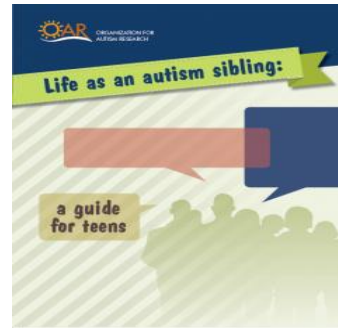
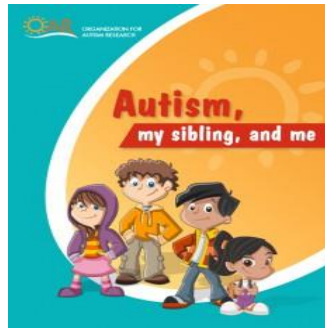
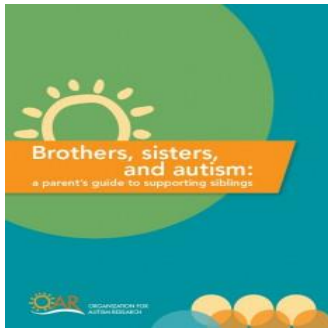
Some studies have shown that siblings of children with ASD were overall well-adjusted when compared to normative samples



# Support for Siblings

- Assess sibling mental health and refer if needed
  - Validate feelings
- Support groups
- Integrate siblings into treatment plan
- Educate
- Listen





## Parents

**Families caring for CYSHCN experience more significant financial and caregiving demands than families of children without special healthcare needs**

- **More pronounced in ASD**

**Behavioral health (of patient and family) strongly influences health and wellness outcomes for all children, especially CYSHCN**

**Risk of adverse childhood experiences (ACEs), abuse, toxic stress**

- **Increased risk if parents lack respite, coping skills, or adequate social and community support**

# Parents

**Families of children with special needs experience more stress compared with neurotypical children**

**More pronounced in children with ASD**

**Parents may feel overwhelmed due to lack of knowledge or resources needed to support their child**

**Lack of social and organizational support**

**High parenting burden and stress, poor quality of life and marital adjustment and poor family dynamics**

**Increased likelihood of mental health disorders**

## Why All the Stress?

**High caregiving demands**

**Feelings of frustration and isolation**

**Less time to attend to their own career, health, and community involvement**

**Atypical behaviors, possible aggression**

**Stigmatizing societal attitudes**

**Uncertainty about the future**

**Grief/loss**

**Sleep deprivation**



# Protective Factors

**Medical home**

**Cohesive and involved families**

- Involvement in intervention decreases parenting stress and increase parent self-efficacy

**Good caregiver physical and mental health**

- More likely to care for and support the development of their child

**Positive caregiver adjustment**

# Protective Factors

**Social support: help from family members, friends, and the community**

- Respite and caretaking

**Financial support**

**Positive quality of marriage**

**Involvement in parent training**



## Types of Support

**Natural:** spouses, extended family members, neighbors, religious community, and friends who can help with caregiving

**Informal:** social networks; community agencies that provide training, respite, social events and recreation



## Types of Support

**Formal:** publicly funded, state-administered programs

- ECI
- Special education
- Vocation and residential/living services
- Respite services
- Medicaid
- SSI
- Other financial subsidies

## **Access to Care**

**Children with ASD have more physician and hospital use but have difficulty accessing needed services**

**Children with autism more likely to have unmet needs for healthcare services, family support services, delayed or foregone care, difficulty receiving referrals and care that is not family centered**

- **Greater risk of unmet needs if lower income, lack of insurance, and limited functional ability**

**Unmet needs, financial burdens, and time impacts associated with increased parental stress**

## **Resources**

**Organization for Autism Research**

**<https://researchautism.org/>**

**Autism Speaks**

**Burkhart Center for Autism Education and Research**

**South Plains Autism Network**

**Navigate Life Texas**

**<https://www.navigatelifetexas.org/en>**

**PEN Project**

**<https://prntexas.org/texas-ptis/pen-project/>**



## **Medical Home**

**Receipt of primary care in a medical home may  
reduce burdens and unmet needs**

**Family-centered care**

**Improved coordination of medical and community  
based services**

## **Advocate**

**For the child**

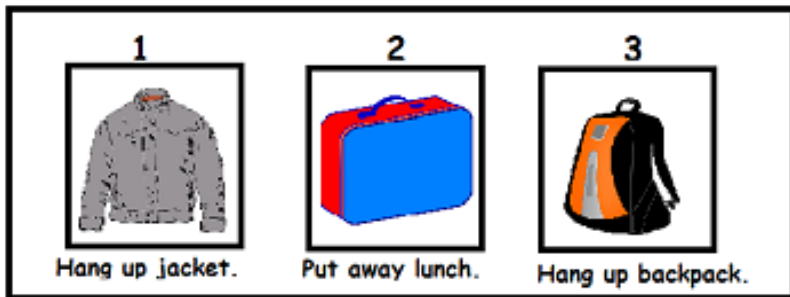
**For the siblings**

**For the parents**

**For the underserved**

# Decreasing Anxiety with Medical Care

- Familiarize the patient with office and staff
- Allow ample time for talking before touching the patient
- Allow child to touch instruments and materials
- Keep instructions simple
- Visual cues and supports (visual organizers)
- Slow down
- Exaggerate social cues
- Involve family and familiar staff





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## Social Stories

Combine pictures (most of the time pictures of individual) and a short story to explain how a child should respond or what is expected in a situation

Used to anticipate changes, events, and adapting behaviors

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**Elizabeth Sledge, MD, FAAP**

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