Autism Spectrum Disorder in the Primary Care Setting

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Disclosures

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Agenda

1. Autism Spectrum Disorder for the Primary Care Physician
2. Applied Behavior Analysis
3. Patient-Centered Care

1 Autism Spectrum Disorder for the Primary Care Physician

What Is Autism Spectrum Disorder?

Understanding autism

ASD is a **multifactorial neurodevelopmental condition**.

- This means it is a developmental delay caused by differences in the brain that come about due to a combination of environmental, genetic and biologic factors.
- Some children with ASD may have a genetic condition. Most have no known cause.
- It is not an intellectual disability, but people with ASD can have cognitive or intellectual delays.
- It can be a lifelong condition, but symptoms may improve with treatment and age.

Source: Centers for Disease Control and Prevention

What Is Autism Spectrum Disorder?

Signs and symptoms

- ASD can be seen as early as 6 months of age and typically by age 3.
- Some children have typical development until age 18 to 24 months and then either stop or regress.

Key features

- Atypical social communication and interaction skills
- Unable to make or sustain eye contact
- Unable to show emotion through facial expressions
- Restricted or repetitive behaviors and interests
- Must follow certain routines and gets significantly agitated or distressed by minor changes
- Repeats words or phrases over and over (echolalia)

Source: CDC

Comorbidities

Additional diagnoses or delays

- Language disorder
- Fine motor delays
- Cognitive or learning delays (intellectual disability)
- ADHD-impulsive, hyperactive or inattentive
- Epilepsy
- Food aversions or restricted diet
- Anxiety disorder

Source: CDC

Risk Factors

Available evidence

- Having a sibling with ASD
- Fragile X
- Tuberous sclerosis
- Other genetic and chromosomal conditions
- Advanced parental age
- Birth complications

Source: CDC

Our Understanding of ASD Prevalence Is Evolving…

Studies reviewed patient sample ages 3 to 17 years old.

CDC Autism Prevalence Studies

Author	Publication Year	Study Years and Source	Sample Size	Prevalence per 1,000	Male:Female
Yuan et al	2021	2014-2019 *National Health Interview Survey*	52,550	24.9	3.5
Li et al	2022	2019-2020 *National Health Interview Survey*	12,554	31.4	3

Sources: Racial/Ethnic Disparities in the Prevalence and Trends of Autism Spectrum Disorder in US Children and Adolescents. JAMA Netw Open, March 2021

Prevalence of Autism Spectrum Disorder Among Children and Adolescents in the United States from 2019 to 2020. JAMA Pediatr, September 2022

Diagnosing ASD

Diagnostic criteria

American Psychiatric Association's Diagnostic and Statistical Manual, 5th Edition (DSM-5)

- A child must have persistent deficits in each of three areas of social communication and interaction plus at least two of four types of restricted, repetitive behaviors
- Symptoms must be present in the early developmental period
- Symptoms cause clinically significant impairment in social, occupational or other important areas of current functioning
- Symptoms are not better explained by intellectual disability or global developmental delay

Updated classification/nomenclature

Based on severity of symptoms and how much support is needed in everyday life

- ASD Level 1 – requires support
- ASD Level 2 – requires substantial support
- ASD Level 3 – requires very substantial support

Tips for the Primary Care Physician

Screening tools

Modified Checklist for Autism in Toddlers, Revised with Follow-Up

- For age 16 to 30 months
- For low-risk toddlers. There is high sensitivity and specificity for this group
- Most commonly used tool
- American Academy of Pediatrics (Bright Futures) recommendation is for 18-month and 24-month well visits
- If positive, complete follow-up questionnaire and interview
  - Refer to developmental pediatrician or diagnostic psychologist if concerns remain
  - Low threshold for referral if there are parental concerns

Tips for the Primary Care Physician

Screening tools

The Survey of Well-Being of Young Children: Parent's Observations of Social Interactions

- For ages 16 to 35 months
- The parent's observations is a 6-question portion of the survey
- This is a good way to complete developmental screening and autism screening in one tool
- Low specificity; a negative screen doesn't rule out ASD
- Low threshold for referral if there are parental concerns

Tips for the Primary Care Physician

Screening tools: honorable mentions

Communication and Symbolic Behavior Scales Developmental Profile – Infant/Toddler Checklist

- For ages 6 to 24 months
- Decent sensitivity and specificity but doesn't differentiate between autism and other communication delays/disorders
- Able to screen down to 6 months of age
- Can be used to identify high-risk patients in the practice that may benefit from more specialized screening tools completed by trained professionals if symptoms persist into toddler age, such as the Rapid Interactive Screening Test for Autism in Toddlers
- Low threshold for referral if parental concern in toddler age

Tips for the Primary Care Physician

Screening tools: honorable mentions

Rapid Interactive Screening Test for Autism in Toddlers

- For ages 18 to 36 months
- Must be purchased from Kennedy Krieger
- Users complete training on use of the tool
- Diagnostic if positive
- High specificity and negative predictive value
- Low threshold for referral if parental concern in toddler age

Tips for the Primary Care Physician

Medical Coding

ICD-10-CM

- Z13.40 Encounter for screening for unspecified developmental delays
- Z13.41 Encounter for autism screening
- Z13.42 Encounter for screening for global developmental delays (milestones)
- Z13.49 Encounter for screening for other developmental delays

Current Procedural Terminology (CPT®)

- 96110 Developmental and behavioral screening

CPT is a registered trademark of the American Medical Association.

Tips for the Primary Care Physician

Family-centered care

- Review and understand the screening tool questions and scoring before using the tool
- Be clear about the intention of each question in the screening tool. For example, in the Modified Checklist for Autism in Toddlers, this question is looking for behaviors seen in some children with autism spectrum disorder: “Does your child get upset by everyday noises (scream or cry to noise such as a vacuum cleaner or loud music?)”
- Listen when families voice concerns
- Use family concerns as a guide when reviewing developmental screening results
- Clarify the tool is only screening for signs and symptoms of autism
- Be aware that testing by a developmental professional is needed to diagnose autism
- Understand the diagnosis of autism is a concern for most parents of toddlers. It might be a minimal concern, but it is still there.
- Let the family lead the conversation and support with facts, not opinions

Tips for the Primary Care Physician

After a positive screen

- Refer to Early Childhood Intervention, which offers longitudinal support for the family including transition to preschool when children age out of ECI
- Refer to a developmental pediatrician, pediatric neurologist or psychologist for diagnostic testing. Applied Behavior Analysis providers are great partners in identifying developmental professionals.
- Explain the process to the family
  - By age 2, a diagnosis can be considered reliable.
  - Testing is usually a 4- to 8-hour visit
  - Results are discussed with the family a few weeks after the diagnostic testing. The timeframe depends on the provider.
  - Results will be sent to the family and referring physician. This is a multiple page document that includes patient history, presenting signs and symptoms, results of any screening tools, quantitative and qualitative testing with scores, interpretation, diagnoses and recommendations.
- Schedule a visit with the family to review recommendations and answer questions
  - Typically, the developmental professional doesn't initiate referrals, but some may. Confirm before moving forward with referrals.

Common Recommendations from Developmental Professionals

Referrals and community supports

The following three recommendations are the most important referrals to initiate as soon as possible and can be initiated at the same time:

- Applied Behavior Analysis (a diagnosis of ASD is required for referral)
- Medical therapy: Speech and occupational therapy
- School services when age-appropriate
  - Letter to Special Education office/department may be included (parents can request this)
  - Assessment and letter can be submitted to school district for “Child Find” evaluation

Other common recommendations include:

- Family counseling
- Family support groups or advocacy groups
- Literature on ASD
- Others as appropriate for comorbidities
- Hippotherapy (equine therapy)
- Music therapy

Community Supports

School services

School services address the needs of individuals with physical, medical or cognitive conditions that affect learning.

Section 504 of the Rehabilitation Act of 1973

- Protections for individuals with disabilities in programs that receive federal funding such as public schools
- 504 Plan
  - Accommodations and supports to access academic and extracurricular activities
  - For students who do not require special education services

Community Supports

School services

Students with ASD need an Individualized Education Plan. Individuals with Disabilities Act of 2004 identifies students who need an IEP.

- Students who require special education services
- Provides for “Free and Appropriate Public Education” in the “least restrictive environment” for all children with disabilities

IEP outlines a program of specialized instruction and supports that allow children with ASD to access and progress in the curriculum

- Measurable learning goals
- Accommodations
- Tracking progress
- Related services – ABA can be provided in school or out of school. Educate families that IDEA requires public schools to provide ABA therapy when indicated as a necessary service to help the child access or participate in school.

2 Applied Behavior Analysis

Autism Treatment

Behavioral health

There are very few empirically supported treatments for ASD.

- Many treatments are still in the experimental/investigational stage
- Some treatments are ineffective or can even be harmful

Applied Behavior Analysis

An intensive therapy using procedures based on the science of learning and behavior that produces observable changes in skills and behavior

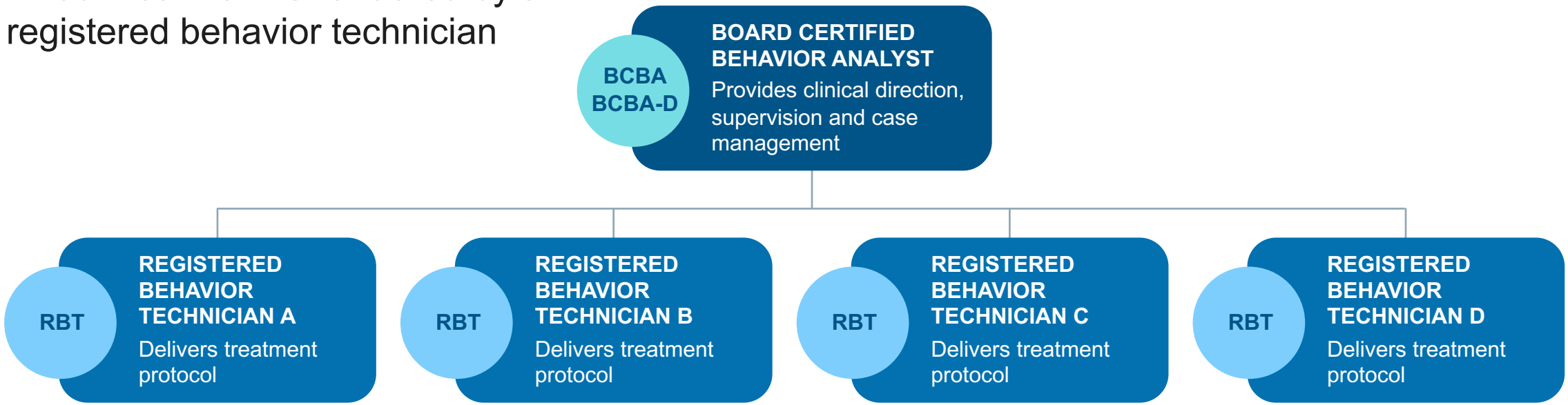
- ABA is a relatively young science, generally recognized as officially established in 1968
- Empirically supported interventions teach new skills and replace maladaptive behavior with more socially acceptable behaviors
- ABA works by identifying the functional relationship between behavior and environment
  - To increase behaviors and teach new skills
  - To maintain behaviors
  - To generalize or transfer behavior from one situation or response to another
  - To restrict or narrow conditions under which interfering behaviors occur
  - To reduce interfering behaviors

Source: Association for Science in Autism Treatment

ABA Model of Care

Tiered service delivery

- ABA is delivered by a team of therapists, at different education and experience levels
- Treatment design, regular oversight and supervision are rendered by master's level or higher clinician
- Direct treatment is rendered by a registered behavior technician



ABA Treatment Programs

Comprehensive Program

- 30 to 40 hours of direct treatment per week
- Addresses skills deficits in multiple areas, including communication, executive function, social skills, play skills, motor imitation, and activities of daily living
- Research indicates most effective in children prior to age 8

Focused Program

- 10 to 20 hours of direct treatment per week
- Addresses a narrower scope of deficits that are higher priority
- More common in older individuals
- Appropriate as a step down after comprehensive programming

Conventional Location

- Home or clinic
- The therapist controls the environment and systematically delivers care

Nonconventional Location

- Community settings, school, recreational programs, vocational programs, day programs and camps
- There can't be aide support or respite care

ABA Treatment Goal Examples*

John independently asks for help instead of engaging in crying or tantrum behavior in at least eight out of 10 opportunities for three consecutive sessions.

Amirah takes turns and share with peers without requiring prompts or reminders at least two times during a five-minute play interval for three consecutive sessions.

Carlos follows directions to go to a specific location and retrieve a specific object for at least five items with 100% accuracy across three consecutive sessions.

Kalani independently requests items and activities using functional communication in four out of five opportunities for three consecutive sessions.

*These examples are not real cases and are for illustrative purposes only.

Early Intensive Behavioral Intervention

Scientific research

Comprehensive behavioral treatment originated in the work of OI Lovaas in 1987 on Early Intensive Behavioral Intervention: Behavioral treatment and normal educational and intellectual functioning in young autistic children

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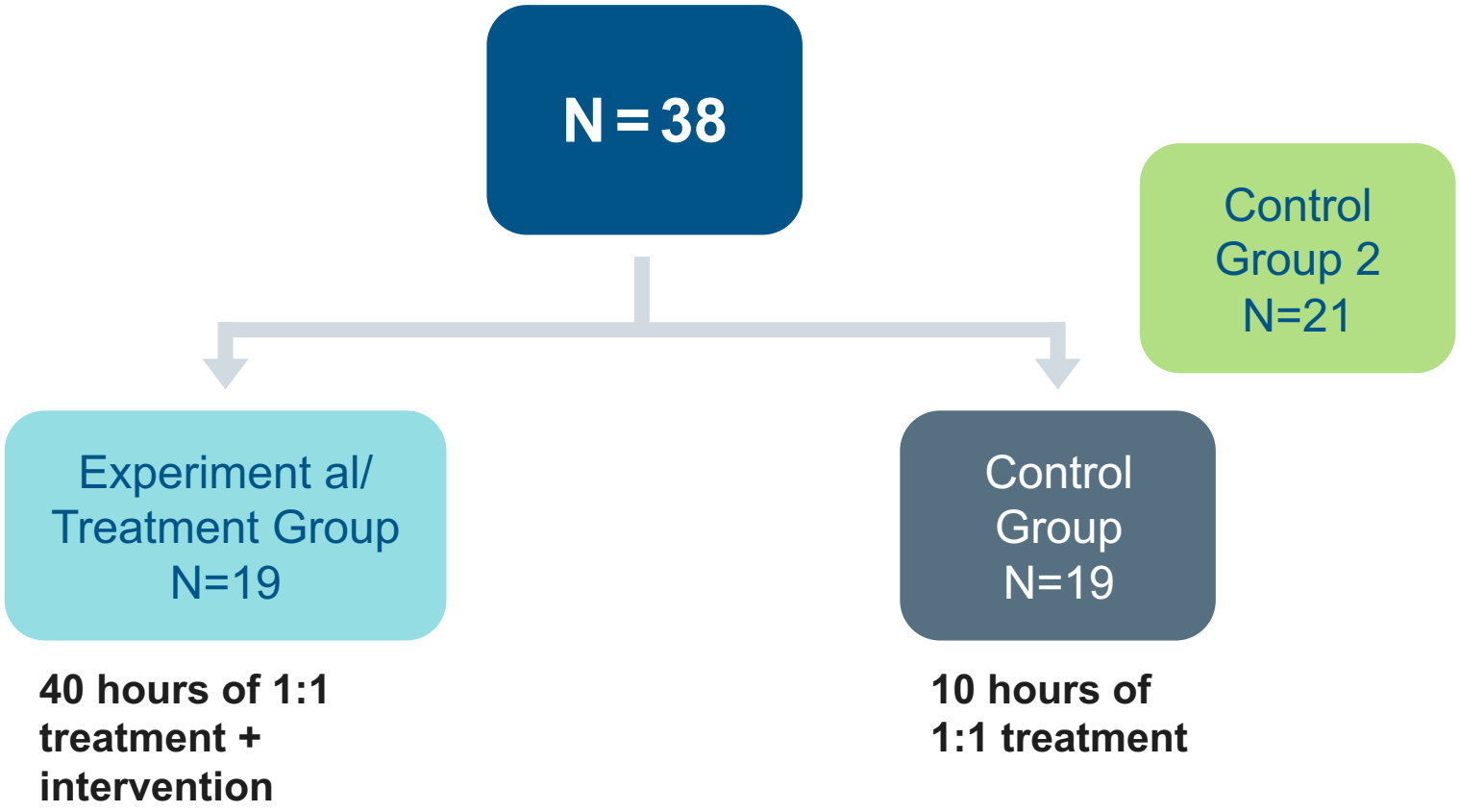
Recent reviews of the literature suggest that the effectiveness of early intensive behavioral intervention is considered well established, according to commonly used criteria for evidence-based practices. Refer to S. Eikeseth 2009; S. Eldevik et al. 2010; S.J. Rogers and L.A. Vismara 2008.

Early Intensive Behavioral Intervention

Lovaas 1987 Young Autism Project

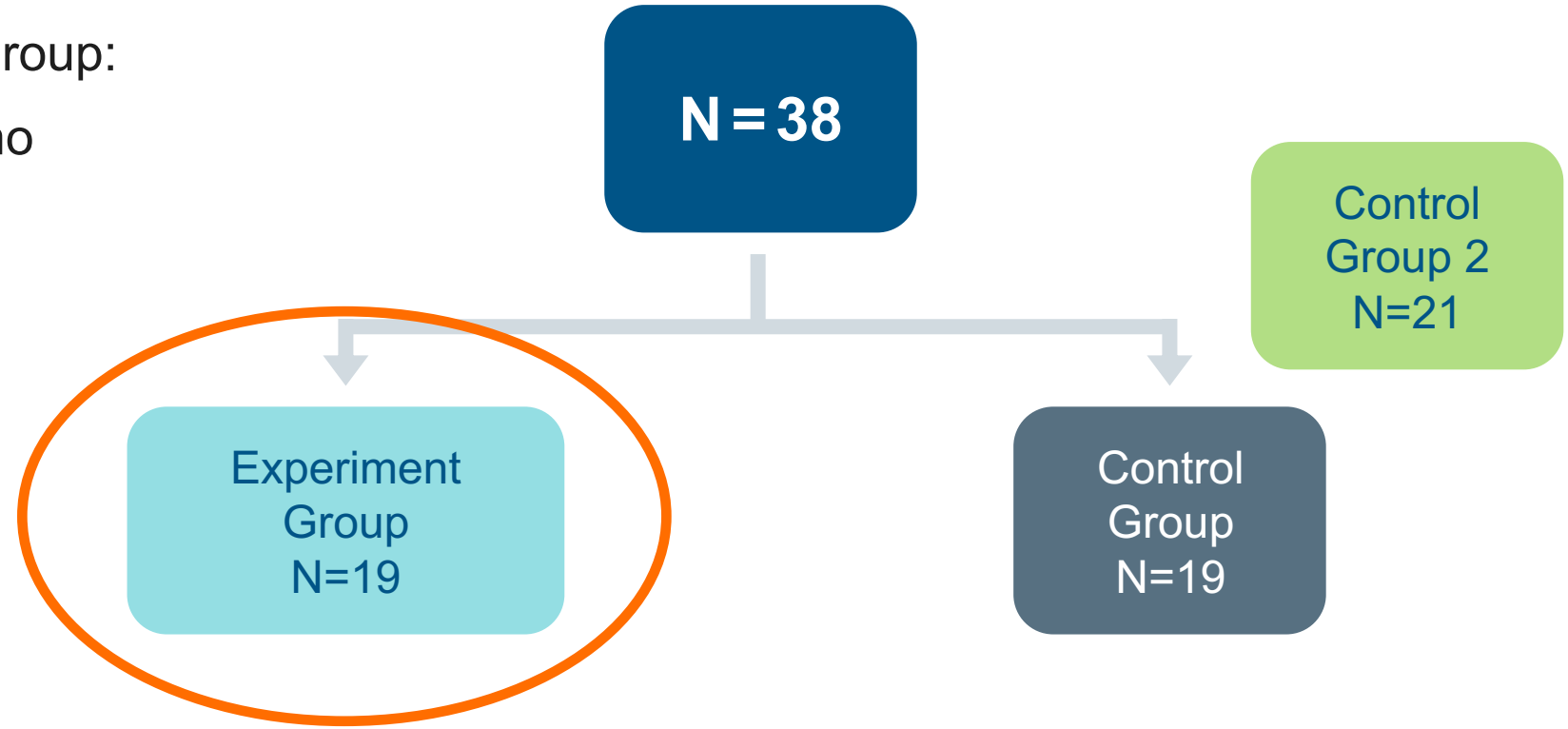


Early Intensive Behavioral Intervention

Young Autism Project Results

Of the 19 in the experimental group:

- 9 achieved average IQ and no longer met criteria for autism diagnosis after two years of intervention
- 8 made some gain but did not remediate all symptoms and retained the autism diagnosis
- 2 did not benefit from treatment at all



ABA

Measurement of outcomes

- The terms “recovered,” “cured,” “indistinguishable from peers” and “no longer meet diagnostic criteria” have been replaced in outcome and meta-analysis literature with “optimal outcome.”
- Replication studies at 3 years and 4 years of treatment did not find significantly different results. Longer duration of treatment did not yield greater number of patients with optimal outcome.
- Diagnostic instruments PDD Behavior Inventory™ – Tricare 10-year Autism Demonstration Project
- Standardized assessments Vineland 3 and SRS-2 – International Consortium for Health Outcomes Measurement
- Problem behavior: Dangerous to self or others. Near zero rates or can access lower level of care.
- Lack of progress

3 Patient-Centered Care

Patient-Centered Care Tips to Consider

Care plan

- The medical home is the hub for the care plan
- Families should receive referrals necessary to access various therapies and services
- Referrals may need to be updated periodically
- Medication management may require a psychiatrist or neurologist with experience treating individuals with autism
- Many services have wait lists. Encourage families to sign up even if they are unsure if the service will be needed. They can always decline should it not be needed when it's their turn.
- Case management and/or service coordination may be available through their insurance plan or county intellectual or developmental disabilities authority.
- Clinical best practice includes periodic re-evaluation. Every two to three years is typical. This ensures awareness of current symptoms, changing needs and screening for any comorbid conditions.

Patient-Centered Care

Autism through the lifespan

Early Intervention

- Initiation of various therapies
- Feeding
- Toileting

School Age

- Educational supports, IEP and 504
- Behavioral supports
- Social skills programs
- Life skills

Adolescence

- Puberty
- Healthy sexuality and body image
- Safe internet use
- Life skills

Adult Services

- Transitional programs and vocational supports
- Specialized university programs
- Day programs
- Integrated, community-based settings, such as housing choice

ABA Resources

- Autism Speaks Resource Guide
- Medicaid waiver programs
- State-specific resources:
  - Illinois Department of Human Services Division of Developmental Disabilities: Prioritization for Urgency of Need for Services
  - Texas Department of Aging and Disability Services Local IDD Authority
  - Early Childhood Intervention
  - Texas Community Resource Coordination Groups
  - Texas Health and Human Services Navigate Life Texas
- Other local resources may include Autism Resource Centers, Easterseals and Special Olympics

Questions?