AzAAP Consensus Statement on the Care of Children with Autism Spectrum Disorders Related to Arizona HB 2847

PURPOSE: To create a consensus statement by Arizona pediatricians regarding best approaches to the screening, referral, diagnosis, and treatment of children with Autism Spectrum Disorders (ASD) in Arizona.

On July 1, 2009 Arizona House Bill 2847 (Steven's Law), became law. This Bill mandates insurance coverage by Arizona health insurance companies for the provision of services for children with Autism.

Arizona House Bill 2847 provides the following coverage:

1. Fifty thousand dollar maximum benefit per year for an eligible person up to the age of nine.
2. Twenty-five thousand dollar maximum benefit per year for an eligible person between the ages of nine and sixteen.

In an effort to provide medical guidance on operationalizing this statute, the AZ AAP convened an expert panel of developmental pediatricians and primary care pediatricians in consultation with pediatric geneticists, neurologists, psychiatrists, psychologists and parents to develop clinical guidelines for the care of individuals with suspected or confirmed ASD and their families, based on evidence and best practices.

Overview

Beginning in the 1990's, major changes have occurred in how children with ASD are identified, diagnosed, and treated. The state of Arizona must respond to these changes to keep pace with accepted medical and therapeutic practices.

The number of children diagnosed with an ASD has increased from 1 in 1500 25 years ago to 1 in 88 children today[i]. It is not yet clear whether this rise represents a true increase or whether the rise is due to more broadly defined clinical criteria, changes in special educational eligibility criteria, increased physician and public awareness, and/or changes in funding for special education programs.

Autism is a neurobiological condition and the providers and therapists involved in the recognition, diagnosis and management of children with autism should have medically-based expertise. Treatment for autism should fall under the rubric of medical care and covered by medical insurance.

Professionals presently involved in the care of children with ASD include:

a. Primary Care Physicians (PCP) in the Medical Home are responsible for ongoing developmental surveillance and specific screening for autism. PCPs should respond to parental concerns, provide universal developmental screening and refer for appropriate diagnostic evaluation and early intervention those children whose screening results are positive. Because resources for definitive assessment are often limited, PCPs should not delay referral for additional assessments as needed (audiological assessment, Arizona Early Intervention Program (AzEIP) eligibility assessments for developmental delays, neurological referral for evaluations for possible seizure activity, gastroenterological evaluation for feeding, or bowel complaints, referral for evaluation for eligibility for developmental preschool services) or other assessments as appropriate. Medical surveillance should continue throughout childhood and adolescence. Because of the limited number of medical specialists available to diagnose children with autism, PCPs with an interest and expertise in autism can provide initial diagnostic and treatment services, especially in underserved areas of the State. PCPs that provide medical homes and expanded care for children with ASD should be reimbursed for the additional time required. Ongoing training will be necessary to assure clinical expertise.

b. Developmental/Behavioral Pediatricians are primarily involved in the diagnosis and initial treatment of children with ASD in Arizona. DBP perform developmental assessments, diagnose and manage autism spectrum disorders, including ongoing evaluation and monitoring of developmental progress. DBP also coordinate management of multiple needs and provide family support with counseling for parents, siblings and extended family. DBP monitor nutritional, medical, therapy, educational, and behavioral issues and outcomes. The developmental pediatrician should assess the manifestations of ASD and recommend specific treatment interventions as appropriate.

c. Child Psychiatrists diagnose and provide ongoing care for children with ASD and may provide medication treatment to those with co-occurring behaviors, such as aggression, depression, compulsions, and anxiety.

d. Pediatric Neurologists diagnose and provide provide ongoing care for children with autism, particularly for management of seizures, tics, and

other movement disorders that occur as comorbid conditions in children with ASDs.

e. Geneticists evaluate children to determine the etiological basis for the disorder, provide treatment for metabolic and mitochondrial disorders that may cause autism, and provide genetic counseling to those families where autism has been identified.

f. Child psychologists diagnose children with ASD, assess a child's cognitive skills, perform complete psychoeducational evaluations, formulate educational management plans, and provide ongoing assistance to those with behavioral concerns.

g. Other medical specialists may be needed to manage specific manifestations and common co-occurring disorders, such as seizures, tics, stereotypies, movement disorders, gastrointestinal disturbance, immunologic vulnerabilities, mitochondrial disorders, metabolic disorders, feeding disorders, sleep disturbance, aggression, self-injurious behaviors, compulsive behaviors, depression, anxiety, and attention deficits. These might warrant an array of diagnostic studies, pharmacological interventions, individual and family counseling and specific family training and support to manage medical concerns.

h. Board Certified Behavior Analysts (BCBAs) are responsible for the implementation of treatment programs based on applied behavior analysis (ABA), including behavioral assessment of the child and family; identification of target behaviors/intervention goals and development of behavioral treatment plans; ongoing data collection to monitor child progress and modify programs accordingly; and coordination of care with other professionals. To ensure treatment fidelity, ABA-based programs require ongoing supervision and oversight by a BCBA.

Screening (early identification) and Diagnosis

PCPs are commonly the first professionals to identify developmental concerns. Early identification of children with ASD improves outcomes for the individual and family.[ii],[iii] The AAP recommends administering standardized autism-specific screening tools (such as the mCHAT) to all children at the 18- and 24month (well-child) preventive care visits, and at any subsequent health care contact within which parents/caregivers raise concerns regarding a child's developmental progress.[iv] This, along with developmental surveillance and awareness of red-flag warning signs, will support appropriate screening.

Symptoms of autism are often present at this age, and effective early intervention strategies are available. Primary care physicians can be trained in the use of these autism-specific screening tools and need to be reimbursed

accordingly. Over the past several years, Southwest Autism Research & Resource Center (SARRC) has provided an Autism Spectrum Disorders Screening Toolkit to PCPs in Arizona free of charge. SARRC and the AzAAP have provided training on the use of this tool.

Children who screen positive for a possible ASD should receive:

- Audiology evaluation,
- Speech and language assessment,
- Referral to a developmental pediatrician or an expert in the diagnosis and management of autism for comprehensive diagnostic evaluation, treatment planning and ongoing management,
- Referral for early intervention services:
    - Children under 3 years old: AzEIP (Az Early Intervention Program)
    - Children 3 years and older: Local school district (special education department), and to the Division of Developmental Disabilities (DDD)
    - Determine eligibility for early intervention services through medical insurance coverage (e.g., Steven's Law-related coverage for children of any age).

Components of Diagnosis:

The AAP Autism Diagnostic guidelines should be used to guide the diagnostic evaluation for autism.[v],[vi] An etiologic evaluation including genetic testing should be undertaken to distinguish idiopathic from syndromic ASD (Table 1) along with an assessment for co-occurring conditions. (Table 2,3) This evaluation should be individualized to the child's specific needs. It should include an assessment of developmental, behavioral, and psychological functioning, family strengths, limitations and vulnerabilities.

Components of Treatment

Interventions based on applied behavioral analysis are supported by scientific evidence. Research in autism therapies continues and recommendations for therapeutic interventions will evolve as new evidence emerges. For now, recommendations are based on evidence, best practices, standard of care and consensus of expert clinical experience. (Table 4) [vii]

In addition, the AZ Chapter of the American Academy of Pediatrics Autism Consensus Report Task Force recognizes that ABA Therapy as supervised by a BCBA and/or AZ Licensed Behavior Analyst is not "experimental" and is, in fact, part of the established AZ community standard of medical care used as treatment for children with ASD. Further, in the absence of clear scientific data

defining dose-response relationships for ABA therapy, "medical necessity" is best determined on a case by case basis by the child's medical care provider.

Treatment of autism requires collaboration between multiple specialists. Some younger children will not meet the DSM IV criteria for ASD because of their age, along with the subtlety of early symptoms. Nonetheless, these children greatly benefit from early intervention services while ongoing diagnostic evaluations are being completed. These children are considered at risk for ASD and should receive appropriate interventions. Intervention is individualized to each child's needs and follows the principles of accepted interventions based on available evidence or best practices and expert clinical experience.

Complementary and Alternative Medicine

Because of the nature of ASD, parents are often caught between differing world views on treatment options for their children. The following principles are germane in this regard. [viii]

- Ensure that all families have access to evidence-based services and are actively involved in all treatment decisions.
- Be willing to discuss complementary and alternative therapies whenever asked.
- Become knowledgeable about both evidence-based and complementary and alternative treatments and refer families for appropriate consultation.
- Be willing to support a trial of therapy in select situations, and in such situations, provide clear treatment objectives, pretesting, and post-testing.
- Remain actively involved, even if in disagreement with the family's decision.

Conclusion

This consensus statement regarding best approaches in the screening, referral, diagnosis, and treatment of children with ASD has been developed by an expert panel of practitioners convened by the Arizona Chapter of the American Academy of Pediatrics. These clinical guidelines are based on evidence and best practices.

Through this initiative we seek to:

- Provide clarity to the roles of primary care pediatricians, developmental and behavioral pediatricians and the other professional involved in the care of children with autism

- Identify best practices and evidenced based treatments addressing the medical, educational and developmental challenges facing children and adolescents with ASD
- Support the families caring for children with ASD in a compassionate, respectful and culturally competent fashion, recognizing the diversity of treatment options as well as the constancy of family in the children's lives

Table 1. Genetic Testing recommended for children with an ASD

Test	Population
Comparative Genomic Hybridization (CGH), Chromosomal Microarrays (CMA)	All children with Intellectual Disability and ASD[ix]
Fragile X molecular analysis	All children with Intellectual Disability and ASD[x]
MECP2/CDKL5 (Rett syndrome) sequencing and deletion testing	Based on clinical features
Angelman syndrome methylation studies and *UBE3A* sequencing	Based on clinical features
Tuberous Sclerosis DNA	Based on clinical features
PTEN DNA sequencing and deletion testing	Based on finding of macrocephaly
Metabolic Testing	Based on clinical features
Methylation studies	Based on clinical features
Sequencing studies	Based on clinical features

Table 2. Conditions that may co-occur with autism

Seizures
Sleep Disorders
Feeding Disorders
Undiagnosed hearing, dental and vision disorders
Gastrointestinal Disorders
Inattention
Hyperactivity
Anxiety
Irritability
Aggression
Tic
Depression
Intellectual Disability

Children with autism are at the same risk of experiencing common childhood conditions as any child, regardless of diagnosis.

Table 3 Syndromes that may be associated with Autism

Fragile X syndrome
Tuberous sclerosis
Neurofibromatosis 1
Angelman syndrome
Prader-Willi
Smith Lemli-Opitz syndrome
Down syndrome
CHARGE syndrome
Mitochondrial disorders
Metabolic disorders

Table 4 Treatments for Autism

I. Treatments supported by evidence
Interventions based on applied behavior analysis (ABA) • Discrete Trial Training • Pivotal Response Treatment • Learning Experiences: An Alternative Program for Preschoolers and Parents [LEAP])[xi] Interventions reviewed by National Autism Center's National Standard's Project[xii] • Antecedent Package • Behavioral Package • Comprehensive Behavioral Treatment for Young Children • Joint Attention Intervention • Modeling • Naturalistic Teaching Strategies • Peer Training Package • Pivotal Response Treatment • Schedules • Self-management • Story-based intervention package

II. The treatments identified as emerging or promising practices by clinical consensus

Interventions reviewed by National Autism Center's National Standard's Project [xiii]

- Augmentative and Alternative Communication Device
- Cognitive Behavioral Intervention Package
- Developmental Relationship-based Treatment (FloorTime)
- Exercise
- Exposure Package
- Imitation-based Interaction
- Initiation Training
- Language Training (Production)
- Massage/Touch Therapy
- Multi-component Package
- Music Therapy
- Peer-mediated Instructional Arrangement
- Picture Exchange Communication System
- Reductive Package
- Scripting
- Sign Instruction
- Social Communication Intervention
- Social Skills Package
- Structured Teaching (TEACCH)
- Technology-based Treatment
- Theory of Mind Training

Interventions identified after National Autism Center's National Standards Project was published

- Early Start Denver Model for Young Children with Autism[xiv]

Occupational Therapy[xv],[xvi]

Speech-Language Therapy [xvii],[xviii]

III. Unestablished Treatments
Interventions reviewed by National Autism Center's National Standard's Project [xix] • Academic Interventions • Auditory Integration Training • Facilitated Communication • Gluten- and Casein-Free Diet • Sensory Integrative Package Vitamin/mineral therapy[xx] Hyperbaric oxygen [xxi],[xxii]
IV. Treatments proven ineffective
Secretin [xxiii],[xxiv] Intravenous Gammaglobulin (without evidence of underlying immunodeficiency) [xxv] Chelation[xxvi]

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