

ALABAMA INTERAGENCY AUTISM COORDINATING COUNCIL



2014

Diagnostic Clinics Standards of Practice Recommendations

Autism Spectrum Disorder is a developmental disability that causes substantial impairments in social interaction and communication and the presence of unusual behaviors and interests. Many people with ASD have unusual ways of learning, paying attention, and reacting to different sensations. The thinking and learning abilities of people with ASD can vary from gifted to severely challenged. ASD begins before the age of 3 and lasts throughout the life of a person with the disorder.(Act 2009-295)

The Alabama Interagency Autism Coordinating Council, created by the Alabama Autism Support Act of 2009 (Act #2009-295), is charged with meeting the urgent and substantial need to develop and implement a statewide, comprehensive, coordinated, multidisciplinary, interagency system of care (SOC) for individuals with Autism Spectrum Disorder (ASD) and their families.

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AIACC Membership

The AIACC is composed of the following members:

Governor appointed members include:

Three Adults with Autism Spectrum Disorder
Three Parents or Guardians of a Child with Autism Spectrum Disorder
Five Service Providers
Private Health Insurance Representative

Senate Appointee

House Appointee

The chief executive officer or a representative from each of the following state agencies:

Alabama Council on Developmental Disabilities
Alabama Department of Children's Affairs
Alabama Department of Education
Alabama Department of Human Resources
Alabama Department of Insurance
Alabama Department of Mental Health
Alabama Department of Public Health
Alabama Department of Rehabilitation Services
Alabama Institute for Deaf and Blind
Alabama Medicaid Agency
American Academy of Pediatrics – Alabama Chapter
Autism Society of Alabama
University Center of Excellence in Developmental Disabilities Education, Research, and Service

*The Alabama Department of Mental Health is the lead agency for the AIACC.

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Findings and Recommendations

The recommendations included in this document are in draft form. This report in no way constitutes policy or decision making. Revisions will continue to be made in partnership with stakeholders and appropriate parties.

The Diagnostic Clinics Workgroup has drafted recommendations for 1) a multidisciplinary autism spectrum disorder diagnostic evaluation, 2) autism-specific screening, and 3) implementation of care coordination. The recommendations for the diagnostic evaluation provide “meets standards,” “progressive,” and “best practice” criteria for the following: audiological evaluation; vision screening; psychological evaluations that include measures of the child’s cognitive and adaptive abilities, direct observation of the child’s behaviors using a standardized, validated instrument such as the Autism Diagnostic Observation Schedule: Second Edition (ADOS-2), and a Diagnostic and Statistical Manual of Mental Disorders (DSM) based interview with the caregivers; an assessment of speech and language skills including pragmatic language abilities; evaluations for sensory processing and motor delays; and a comprehensive medical evaluation that includes a medical and 3-generation family history, as well as a physical examination which focuses on the identification of recognizable syndromes that are associated with autism. Our workgroup has drafted recommendations for autism specific screening and we offer suggestions for screening instruments to be used by pediatricians and other primary care providers. Lastly, our workgroup recognizes the need for Care Coordination for children and families affected by autism. A preliminary discussion of models of Care Coordination is addressed in our report and will need further investigation.

The Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) was released in May 2013. The new revision has made changes to the diagnostic criteria and terminology used for the Pervasive Developmental Disorders and has collapsed the previously recognized autism spectrum diagnoses (Autistic Disorder, Asperger Syndrome, Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS), and Childhood Disintegrative Disorder) into one diagnosis of Autism Spectrum Disorder. The DSM-5 changes will likely result in revision of currently used diagnostic instruments, e.g., the ADI, GARS, GADS, etc., which will require the Council to continue to revise recommendations to prevent them from appearing dated.

The cost of an evaluation and determining the payer for these services will also be a challenge. In Alabama, there are a relatively few number of diagnostic clinics that specialize in ASD. Training pediatricians and family physicians in appropriate referrals and initial testing could be of great benefit.

Many children in Alabama are identified once they enter the public school system. It will be important to work with the Department of Education to identify ways to reduce or eliminate unnecessary duplication of diagnostic testing and prevent unnecessary delays in the receipt of services for children affected by autism, as well as to align more clearly the similar goals of evaluation for special education eligibility and the clinical diagnosis/evaluation of ASD for other purposes.

Introduction

Standards of Practice for Autism Diagnostic Clinics will guide providers of diagnostic services in the use of evidence-based best practices and will provide individuals and families who have concerns about autism spectrum disorders with reliable information about what to expect from a diagnostic evaluation, leading to greater confidence in the diagnoses and services rendered by the diagnostic clinics. Adoption of Standards will result in uniformity in the diagnostic evaluations provided across the state, lead to greater efficiency in

the utilization of limited resources, increase accountability, improve the overall quality of services provided, and ultimately improve outcomes for those receiving diagnostic services.

The Diagnostic Clinics Workgroup of the Standards of Practice Committee is comprised of a multidisciplinary team of physicians, psychologists, audiologists, speech and language pathologists, social workers, occupational therapists, and others, all of whom have clinical experience and expertise in autism spectrum disorders. The workgroup members are comprised of volunteers from Alabama’s public and private universities and other service providers from around the state. The process of developing standards has been an open and transparent one. Workgroup members meetings have been open to anyone interested in helping with or observing the process. Members began their task of defining minimum and best-practice standards by reviewing current practices across Alabama. This was followed by a review of the recommendations and standards established by national organizations, e.g., the American Academy of Pediatrics, the American Academy of Child and Adolescent Psychiatry, American Speech and Language Association, etc., reviewing standards implemented by states with regional autism centers, e.g., California and Washington, and by reviewing the scientific literature. In situations in which there were no national or state standards to guide our recommendation, the experts on the panel drew from the clinical experiences and knowledge to make their recommendations.

MULTIDISCIPLINARY AUTISM SPECTRUM DISORDER DIAGNOSTIC EVALUATION RECOMMENDED STANDARDS

Medical Evaluation

Standard	Check all that Apply		
As part of a comprehensive interdisciplinary diagnostic evaluation, all children referred to a Regional Autism Diagnostic Clinic will receive a thorough medical evaluation.	Service: <input checked="" type="checkbox"/> Direct <input type="checkbox"/> Technical Assist <input type="checkbox"/> Consultation	Recipient: <input checked="" type="checkbox"/> Individual w/ASD <input checked="" type="checkbox"/> Family <input checked="" type="checkbox"/> School District <input type="checkbox"/> Other / List:	Location: <input type="checkbox"/> Home <input type="checkbox"/> School <input checked="" type="checkbox"/> Community

Check One: Meets Standard Progressive Standard Best Practice

X Best Practice Standard: The Best Practice Standard consists of a developmental-behavioral pediatrician, child psychiatrist, pediatric neurologist, or other physician with expertise and interest in autism spectrum disorders conducting and/or supervising the medical evaluation. Best practice also incorporates referrals, when appropriate, to other subspecialists, including (but not limited to) medical geneticists, nutritionists, gastroenterologists, allergists, pediatric ophthalmologists, etc.

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Introduction

Autism Spectrum Disorder (ASD) is comprised of behaviorally defined conditions and is neurologically based. Numerous medical, genetic, and metabolic conditions have been associated with ASD.¹⁻⁴ The American Academy of Pediatrics, the American Academy of Neurology, the American Academy of Child and Adolescent Psychiatry, and state Standards of Practice Guidelines have outlined the role of physicians in the diagnosis and subsequent management of ASD.⁵⁻⁸ Though not always possible, determination of the specific etiology of an ASD and its associated medical conditions provide multiple benefits to the individuals and families affected by autism, which include the provision of anticipatory guidance, treatment options, prognosis, and genetic counseling.

Components of the Medical Examination

A comprehensive health, developmental, and behavioral history, along with a family history of medical and psychiatric illnesses, should be obtained on all children evaluated for suspicion of an ASD and/or developmental delay. Completion of a health questionnaire prior to the physician visit is recommended, because it allows the physician to address and clarify relevant issues during the interview. Prenatal and perinatal factors known to affect development should be recorded. Information regarding the achievement of age-appropriate developmental milestones and a history of regression in language, social-emotional, or other developmental domains will be sought during the evaluation. A review of newborn screening test results should be considered. Past and current illnesses, e.g., encephalitis or seizure disorders, medications known to affect central nervous system functioning, and prior hearing and vision screenings, should be noted. Behaviors such as irritability, self-injury, sleep and eating disturbances, inattention, hyperactivity, impulsivity, distractibility, etc., should be recorded. A 3-generation family pedigree should be obtained with regard to both medical and psychiatric illnesses, with emphasis on cognitive disabilities, ADHD and other learning disorders, epilepsy, autism, bipolar disorder, schizophrenia, and deafness.

A comprehensive physical and neurological exam that includes a thorough search for dysmorphic features, aberrations of growth (e.g., microcephaly or macrocephaly), manifestations of neurocutaneous disorders, and abnormalities in tone, muscle stretch reflexes, cerebellar function, gait, and the presence of involuntary movements, is recommended as part of the comprehensive medical work-up of children suspected of autism.

All children evaluated for suspicion of autism should receive an audiology evaluation, vision screening, and dental care. Children diagnosed with an autism spectrum disorder and their families may benefit from

genetic testing that may include a high resolution karyotype, DNA for fragile X, microarray comparative genomic hybridization (CGH), DNA testing for MECP2 mutations in girls with autism and/or developmental regression, and lead levels. The microarray CGH has recently been recommended as the first-tier genetic test for patients with unexplained autism spectrum disorders.⁹ If there is a history of early seizures, cyclical vomiting, dysmorphic or coarse facial features, or if the adequacy of the newborn metabolic screening is in doubt, plasma amino acid chromatography, urine for organic acids, and tests for thyroid functioning may be warranted. Allergy testing and evaluation for primary gastrointestinal disorders should be individualized based on the patient's history and physical findings.¹⁰

Routine neuroimaging is not recommended for the diagnostic evaluation of autism, even in the presence of macrocephaly.⁵ Cranial MRI or CT scanning, however, should be considered if focal findings are present on the neurological exam, or if there is microcephaly or a rapid increase in head circumference. Electroencephalography (EEG) should be considered when there is a suspicion of seizures or a history of language regression.

Medical Differential Diagnosis and Coexisting Conditions Associated with Autism Spectrum Disorders

Autism spectrum disorders (ASD) are biologically based neurodevelopmental disorders that are highly heritable. Chromosomal anomalies and single gene mutation can be identified in 15% or more of individuals with autism, with the highest yields being obtained when microarray comparative genomic hybridization is used. ASD can be subtyped as either idiopathic or secondary.

Idiopathic ASD refer to the condition of individuals that do not have an identifiable co-morbid medical or genetic condition known to be associated with autism. Children with idiopathic ASD demonstrate variable behavioral phenotypes, although they are somewhat less likely to have co-morbid global developmental delay/intellectual disability (i.e., $IQ \leq 70$).

The term syndromic or secondary autism is used to refer to individuals who have a single defined cause, such as fragile X syndrome or tuberous sclerosis, associated with the autism. Coexisting severe intellectual disability, especially in the presence of craniofacial dysmorphism, increases the likelihood of identifying a genetic disorder. The following are examples of well-described neurogenetic syndromes associated with autism.

Fragile X syndrome is the most common known genetic cause of intellectual disabilities and is identified in 1-3% of children with autism. As many as 30% to 50% of individuals with fragile X syndrome demonstrate characteristics of ASD. All children with suspected delays should be tested for fragile X.

Tuberous sclerosis, an autosomal dominant neurocutaneous disorder, is characterized by hypopigmented macules, seizures, intellectual disabilities, and benign tumors of the brain, skin, kidneys, and heart. Almost 50% of individuals with tuberous sclerosis manifest ASD.

Down syndrome (trisomy 21), the most common and well-known genetic syndrome associated with intellectual disability, is usually characterized by relatively good social skills compared with other areas of functioning. However, recent studies have reported that 6% to 7% of children meet criteria for an ASD.

Rett syndrome is a postnatal neurodevelopmental disorder, identified almost exclusively in females, due to a mutation in the MECP2 gene. Girls with Rett syndrome typically develop normally for the first 6-18 months, then demonstrate autistic-like regression and manifest acquired microcephaly, seizures, and hand-wringing stereotypies. Rett syndrome should be considered in all girls who present with autistic-like regression.

Microdeletions and duplications are increasingly being identified in children with ASD and are often associated with mild craniofacial dysmorphism. One percent of children with autism have a maternally-derived chromosomal duplication at the 15q 11-13 region. Autism spectrum disorders are also found with increased frequencies among children with Prader-Willi and Angelman's syndrome, which are due to paternal and maternal deletions in the 15q11-13 region, respectively. A 16p11.2 deletion, a deletion that is associated with a variety of other behavioral and psychiatric conditions, has been identified with 1% of children with autism.

Smith-Lemli-Opitz syndrome (SLOS) is a rare autosomal recessive multiple malformation syndrome caused by a deficit of 7-dehydrocholesterol reductase. More than 75% of individuals with SLOS have autistic symptoms, which may improve with dietary cholesterol supplementation.

Landau Kleffner syndrome (LKS), or acquired epileptic aphasia, is a rare childhood epilepsy syndrome characterized by the sudden or gradual development of aphasia, which is the inability to understand or express language. LKS occurs most often in children between the ages of 3-10 years who were developing normally, but then lose language skills. While many of these children have clinical seizures, some only have a distinctive electroencephalographic (EEG) pattern of status epilepticus appearing during slow-wave sleep. Anticonvulsants and corticosteroids may improve symptoms.

Several metabolic disorders, including phenylketonuria, creatine deficiency syndromes, adenylosuccinate lyase deficiency, and metabolic purine disorders, are associated with developmental delay and autism. In the past, phenylketonuria was frequently associated with autistic symptoms, but this association has almost vanished since the introduction of newborn screening and treatment of phenylketonuria.

Mitochondrial diseases are a group of heterogeneous disorders resulting from inborn, or sometimes acquired, defects that impair the function of mitochondria, tiny organelles inside cells that are essential for energy function. A number of recent reports have provided evidence of mitochondrial diseases in a subset of children with autism, and some have even suggested that mitochondrial disease might be one of the most common medical conditions associated with autism. The diagnosis of mitochondrial diseases is a complicated and often lengthy process, usually requiring the expertise of a metabolic specialist.

Children with ASD are at some increased risk of also having sensory impairments. The presence of a sensory impairment does not rule out an ASD. As with genetic disorders, if there is a known genetic disorder (i.e., one not associated with ASD), it does not disqualify ASD from being present.

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Psychiatric Differential Diagnosis and Co-morbidities Associated with Autism Spectrum Disorder

The variability of expression of symptoms of ASD makes the diagnosis difficult. Multiple co-morbidities confound the issue as well. According to the American Academy of Child and Adolescent Psychiatry the differential diagnosis of ASD includes the consideration of the various pervasive development disorders (PDD), intellectual disability not associated with PDD, specific developmental disorders (e.g., of language or sensory impairment), and early onset psychosis as well as various other developmental and psychiatric conditions.

In ASD the apparent onset of the condition is almost always within the first years of life. Parents may initially be concerned that the child is deaf although they also report unusual sensitivities to the nonsocial environment. Language is typically significantly delayed or absent. Unusual behaviors, (e.g., stereotyped movements) are common, particularly after about three years of age.

In Rett syndrome, very early growth and development is normal but is followed by a deceleration in head growth, development of marked intellectual disability, and unusual hand washing stereotypies and other features.

Usually in intellectual disability, social and communication skills are at levels expected given the child's overall development. Individuals with severe and profound intellectual disability may exhibit various autistic-like features, particularly stereotyped movement. It is difficult to differentiate autism from intellectual disability in children with mental ages below two years of age.

Language-related disorders may sometimes mimic autism and related conditions. Usually in the language disorders, the primary deficits are in the area of language/communication, social skills are relatively preserved, and the usual restricted interests and repetitive behaviors associated with autism are not present. In addition, the DSM-5 also includes a category of Social Communication Disorder, intended to describe difficulties with pragmatics, or the social aspects of communication. Diagnostic criteria for this disorder do not include the past or current restricted and repetitive behaviors and interests that are required for an ASD diagnosis.

Unlike ASD, the onset of schizophrenia in children less than 7 is extremely rare. Usually there is a previous history of normal or near normal development although some children later diagnosed with schizophrenia have been described as having findings of language impairment in infancy and early childhood as well as impairments in fine and gross motor functioning. Some authors say these children can be characterized as socially unresponsive as infants who also demonstrated excessive clinginess, mood lability and unexplained rage reactions in early childhood. As the child with schizophrenia approaches adolescence he/she may have increased difficulties with peer relationships, academics, school adaptation and restricted interests. Finally, premorbid social withdrawal aloofness, detachment and developmental disorders of speech, language and motor functioning were found in adolescents with schizophrenia. Usually the appearance of characteristic hallucinations and delusions occurs. In ambiguous cases a high familial loading of psychiatric illness (schizophrenia, bipolar, etc.) indicates a strong possibility of schizophrenia rather than a PDD. Children and adolescents with schizophrenia typically function within the borderline to low normal ranges of cognitive

functioning on standard intelligence tests with nonverbal strengths relative to their language skills. Children with schizophrenia usually have social withdrawal as their social impairment. Their ability to understand nonverbal social cues and the pragmatics of communication (conversational turn-taking, eye gaze to regulate interaction, etc.) may be lower than in typically developing children, but they are generally less impaired than children with ASD.

Children with depression often display social withdrawal and limited interest in their environment. These children show a period of relatively normal functioning preceding the onset of symptoms. These children do not usually show development delay and an examination of family history reveals a greater preponderance of mood disorders than would be expected.

Children and adolescents with anxiety disorders can display extreme social withdrawal, sleep problems, agitation and worry that interfere with social and academic functioning. Children with anxiety disorders show extreme shyness and social avoidance. These children often have normal relationships with their parents and other familiar people. Their deficits become apparent in interactions with peers and/or other situations of which they are extremely fearful or uncomfortable. These children rarely display the developmental delays characteristic of ASD. The social impairment of ASD is apparent throughout the child's relationships.

Selective mutism is sometimes confused with ASD. In selective mutism the child speaks normally in some situations but not others. Children with autism may be mute but their mutism is not selective in nature.

Several features of Obsessive-Compulsive Disorder (OCD) have considerable overlap with behaviors seen in ASD. A fine line often separates obsessions and compulsions from stereotypic movements and restricted/repetitive interests and activities. But other features necessary for the diagnosis of ASD are not present in OCD such as lack of social skills or language/communication skills.

Stereotypic movement disorder is characterized by motor mannerisms (stereotypies), and intellectual disability is often present. A diagnosis of stereotypic movement disorder is not made if the child meets criteria for ASD.

Occasionally a dementia has its onset in childhood. The typical pattern in dementia of childhood onset is one of progressive deterioration in functioning.

When children with ASD grow older, they can potentially meet criteria for or resemble a number of personality disorders (e.g. avoidant, antisocial, obsessive-compulsive, and narcissistic personality disorders).

In reactive attachment disorders, there is usually a history of marked or very severe neglect. The social deficits of reactive attachment disorder tend to remit dramatically in response to a more appropriate environment.

Attention-Deficit/Hyperactivity Disorder (ADHD) can be confused with ASD in some children. Children with ADHD often have the capacity for social relationships but because of their behavior may be socially isolated from peers. Children with ADHD are able to display typical social and communicative behaviors in structured and, often times, novel settings. In contrast children with ASD continue to display nonverbal deficits in social communication in familiar, comfortable and structured situations. Children with ASD are often able to focus on activities that are particularly interesting to them. This is less likely with ADHD children.

Persons with ASD may appear to have Oppositional Defiant Disorder (ODD) or Conduct Disorder. These disorders involve a lack of respect for or willingness to follow norms. Children with these disorders act out purposefully. Physical aggression in persons with ASD is more common in persons who are functioning at lower developmental levels where they are unable to communicate their needs and who have poor

comprehension of the environment. In contrast to children with CD, children with ASD rarely exhibit malicious intent or aggression on another person with explicit intent to cause harm. Children and adolescents with ASD rarely try to conceal or lie about their aggressive or criminal-type behaviors.

Other psychiatric disorders that require clinical attention can be co-morbid with ASD.

Numerous studies have described the co-occurrence of affective disorders in children and adolescents with ASD. The etiology of risk in persons with ASD for coexisting affective disorders is unclear. Children at higher levels of functioning often are included academically with socially adept, typical peers. Children with ASD are at risk for social rejection which can lead to depression and stress. (Some studies show bipolar disorder is more common in persons with ASD).

Anxiety disorders and Tourette’s Disorder, or motor and vocal tics are more common in persons with ASD.

OCD and ADHD symptoms are often seen in persons with ASD.

Circadian rhythm sleep disorder or dysomnia-not otherwise specified may be seen in persons with ASD.

It is important to consider medications the child may currently be taking when considering a diagnosis. Stimulants, alpha-agonists (e.g. tenex and clonidine, which are widely used for children with hyperactivity, aggression, and other behavior problems), and anti-psychotic medications can all blunt a child’s affect and decrease eye contact and social interactions.

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Audiology Evaluation

Standard	Check all that Apply		
All children suspected of having an autism spectrum disorder should have a comprehensive audiological evaluation that includes a case history, otoscopic exam, pure tone testing, speech audiometry, immitance testing, otoacoustic emissions, and/or an auditory brainstem response (ABR).	Service: <input checked="" type="checkbox"/> Direct <input type="checkbox"/> Technical Assist <input type="checkbox"/> Consultation	Recipient: <input checked="" type="checkbox"/> Individual w/ASD <input type="checkbox"/> Family <input type="checkbox"/> School District <input type="checkbox"/> Other / List:	Location: <input type="checkbox"/> Home <input type="checkbox"/> School <input checked="" type="checkbox"/> Community

Check One: MeetsStandard ProgressiveStandard Best Practice Standard

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Standards for Audiological Assessment In Children Suspected of ASD

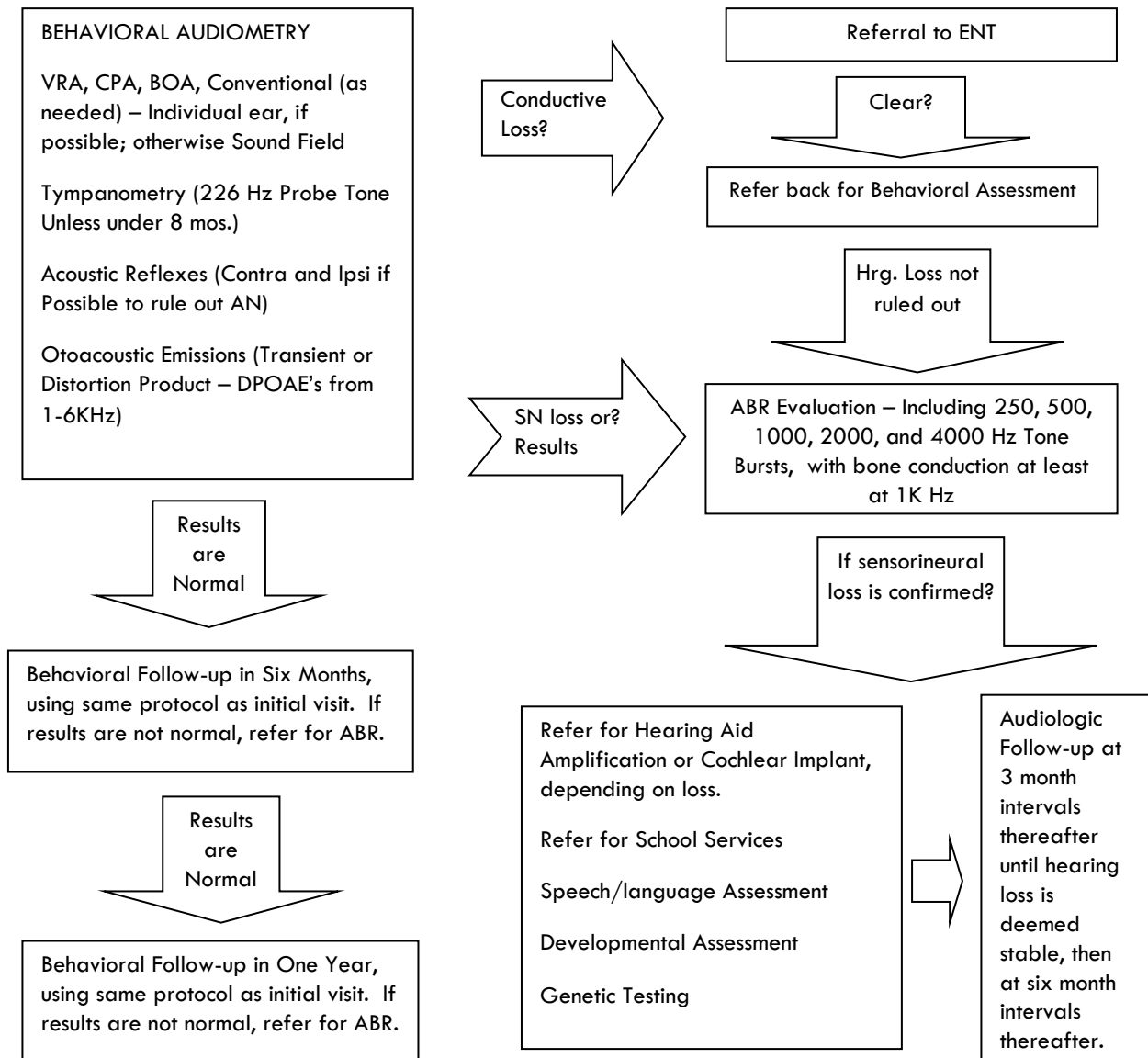
NOTE: *Ultimate goal is to obtain ear specific and frequency specific information*

1. Infants and young children (birth – 3 years developmental age) who cannot be tested behaviorally
 - a. Otoscopy for both ears.
 - b. Tympanometry for both ears (1000Hz probe tone for ages birth to 6 months developmental age – 226 Hz probe tone for 7 months and older)
 - c. Acoustic Reflexes, measured ipsilaterally at 1000 Hz
 - d. DPOAEs @ 1000-6000Hz.
2. Older children (i.e. 3 years & older developmental age) who can be tested behaviorally for individual ear thresholds. NOTE: This could also be applicable for younger children who can be tested behaviorally, although air conduction screening levels may vary, depending on age and developmental level. In the case of older verbal children a hearing test is recommended to rule out the possibility of a late on-set hearing loss, as even a mild loss may have deleterious effects for development.
 - a. Otoscopy for both ears
 - b. Tympanometry for both ears with 226 Hz probe tone
 - c. Acoustic Reflexes, measured ipsilaterally at 1000 Hz
 - d. Air conduction screening for both ears at 15 dB HL for 500, 1000, 2000, and 4000Hz via headphones or insert phones (preferable) using VRA, conditioned play audiometry, or conventional response
 - e. Speech Reception Thresholds (SRT's) for both ears
3. Children who will not cooperate for individual ear testing with inserts or headphones

- a. Otoscopy for both ears
 - b. Tympanometry (if possible) for both ears with 226 Hz probe tone
 - c. Minimum responses to warbled tones or fresh noise in sound field at 500, 1000, 2000, and 4000Hz, or screen at 25 dB HL.
4. For infants and children who cannot be tested or will not cooperate for any type of behavioral or objective testing, a threshold Auditory Brainstem Response (ABR) test for both ears with at least a click stimulus should be scheduled. **Non-verbal children should always have a comprehensive audiologic assessment to rule out hearing loss.**

NOTE: For additional information, please refer to the more comprehensive flow chart.

Flow Chart for Audiologic Assessment of Children Suspected of ASD



Best Practices Standard for a comprehensive audiological evaluation includes the following:

1. **Case history** – To include the following: birth and developmental information; medical history, including history of ear infections and ear problems; family prevalence of hearing loss and patterns of decreased cognitive skills, behavioral concerns; auditory symptoms; and academic performance (when applicable).
2. **Otoscope Exam** – To include the following: visualization of both ear canals and tympanic membranes; assure that both ear canals are unobstructed and free from foreign objects or excessive cerumen (i.e. earwax) buildup.
3. **Pure Tone Testing** – Depending on the age and developmental level of the child, may include the following: Behavioral Observation Audiometry (BOA), Visual Reinforcement Audiometry (VRA), Conditioned Play Audiometry (CPA) or Conventional Pure Tone Threshold Assessment. Individual ear assessment should be attempted, but, if the child is resistant to wearing headphones/inserts, responses to warbled tones or narrow band noise in sound field should be recorded. Responses should be obtained at 250, 500, 1000, 2000, 4000 and 8000 Hz, with the ultimate goal to obtain thresholds for each ear. If a conductive hearing loss is suspected, masked pure tone bone conduction thresholds should be recorded at 500, 1000, 2000 and 4000 Hz for both ears.
4. **Speech Audiometry** – Keeping language function/verbal abilities in mind, may include the following: Speech Awareness/Detection Threshold, Speech Reception Threshold and Word Recognition/Discrimination Testing. As with pure tone testing, individual ear assessment should be attempted, but, if the child is resistant to wearing headphones/inserts, responses should be recorded in sound field, preferably obtaining responses from both right and left sides. As with pure tone testing, the ultimate goal is to obtain thresholds for each ear.
5. **Immittance Testing** – To assess middle ear function, as well as auditory nerve function up to the level of the SOC, tests should include the following: tympanometry, static compliance, and measurement of ipsilateral and contralateral acoustic reflexes at 500, 1000 and 2000 Hz.
6. **Otoacoustic Emissions (DPOAE or TOAE)** – To assess cochlear function and predict the presence of normal or reduced hearing for both ears. May include either Distortion Product or Transient OAE's, measured at 1000-6000 Hz.
7. **Auditory Brainstem Response (ABR)** – If behavioral assessment is not feasible or is inconclusive in ruling out hearing loss for both ears, ABR can be used to estimate hearing thresholds and to assess function beyond the periphery. Auditory neuropathy/auditory dys-synchrony should also be ruled out at the time of ABR testing. In many children suspected of autism, sedation may be required for ABR assessment. ABR assessment should include the following: minimum responses to clicks and tone bursts at 500, 1000, 2000 and 4000 Hz;; a graph of Wave V latency/intensity function using click stimuli; using click stimuli, measurement of absolute latency of Wavelets I, III and V, as well as interpeak latency between Wavelets I and V, and minimum response for a bone conduction click. If auditory neuropathy/dys-synchrony is suspected, verification of a cochlear microphonic should be made using condensation and rarefaction clicks at 80-90 dBnHL.
8. **Monitoring / Follow up** - Children with ASD or suspected of ASD may require subsequent hearing evaluations to monitor hearing status for the following reasons: 1) Risk factor(s) for delayed onset or progressive hearing loss have been identified in the case history; 2) A co-morbid condition of hearing loss has been identified; 3) Individual ear information to confirm normal hearing status bilaterally has not been obtained.

Vision Evaluation

Standard	Check all that Apply		
All children referred for an autism diagnostic evaluation should have an age-appropriate eye examination and vision assessment.	Service: <input checked="" type="checkbox"/> Direct <input type="checkbox"/> Technical Assist <input type="checkbox"/> Consultation	Recipient: <input checked="" type="checkbox"/> Individual w/ASD <input type="checkbox"/> Family <input type="checkbox"/> School District <input type="checkbox"/> Other / List:	Location: <input type="checkbox"/> Home <input type="checkbox"/> School <input checked="" type="checkbox"/> Community

Check One: Meets Standard Progressive Standard Best Practice Standard

Exam conducted by a pediatric ophthalmologist Best Practice Standard

Citation(s) for Evidence-base:

1. Eye examination in infants, children, and young adults by pediatricians: organizational principles to guide and define the child health care system and/or improve the health of all children. *Ophthalmology* 2003; 110:860-5.
2. TINGLEY DH. Vision screening essentials: screening today for eye disorders in the pediatric patient. *Pediatr Rev* 2007; 28:54-61.

Children referred for an autism diagnostic evaluation should have an age-appropriate eye examination and vision assessment. Vision problems, e.g., major refractive errors, strabismus, and amblyopia, occur in 5% to 10% of all preschool children. Children with developmental delays and neurological problems are at even higher risk.^{1, 2}

For children under 3 years of age, an ocular history, external inspection of the eye and lids, ocular motility assessment, pupillary and red reflex examinations, and vision assessments should be performed by a pediatrician or other primary healthcare provider. Vision assessment in children younger than 3 years of age can be accomplished by evaluating the child's ability to fixate on an object, maintain fixation, and then follow the object into various gaze positions. The assessment should be performed binocularly and then monocularly. For children older than age 3, visual acuity testing should be attempted. If an adequate eye examination cannot be obtained or if a visual acuity assessment cannot be accomplished by age 4, then the child should be referred promptly to an ophthalmologist experienced in the care of children.

Because children with who have significant developmental delays or neurological problems are at higher risk for eye problems, autism diagnostic clinics should have a low threshold for referring children with autism to a pediatric ophthalmologist or other ophthalmologist who is experienced in treating young children. Autism diagnostic clinics should develop a working relationship with such ophthalmologists so that these children can receive prompt, specialized eye examinations.

Speech and Language Evaluation

Meets Standard

Standard	Check all that Apply		
As part of an interdisciplinary team assessment for autism spectrum disorders, a qualified Speech-Language Pathologist should provide evaluation of the following aspects of	Service: <input checked="" type="checkbox"/> Direct <input type="checkbox"/> Technical Assist <input type="checkbox"/> Consultation	Recipient: <input checked="" type="checkbox"/> Individual w/ASD <input type="checkbox"/> Family <input type="checkbox"/> School District	Location: <input checked="" type="checkbox"/> Home <input checked="" type="checkbox"/> School <input checked="" type="checkbox"/> Community

<p>communication:</p> <p>MeetsStandard:</p> <ul style="list-style-type: none"> • A thorough case history of language should be obtained that includes information regarding babbling (age began and description), age and descriptions of first words, and any noted regression in language and/or social skills. • A standardized measure of receptive and expressive language that encompasses all areas of language structure (phonology/morphology/syntax/semantics) • Informal or formal evaluation of social communication skills, appropriate for age and/or cognitive level, such as rate and use of gestures, eye gaze, gaze shifts, joint attention, conversational turn-taking, topic maintenance etc. These skills may be observed during autism-specific assessments such as the ADOS-2 (Lord, 2012) or by obtaining a natural language sample. • Evaluations of articulation, oral motor skills, intelligibility, fluency, and voice should be completed if warranted <p>The SLP is considered qualified by the following characteristics:</p> <ul style="list-style-type: none"> • Holds the ASHA Certificate of Clinical Competence in Speech-Language Pathology (CCC SLP) • Demonstrates continued professional development in the area of autism spectrum disorders <p>As mandated by ASHA standards, “Each practitioner must evaluate his or her own experiences with preservice education, clinical practice, mentorship and supervision, and continuing professional development . . . Speech-language pathologists may engage in only those aspects of the profession that are</p>		<p>___Other / List:</p>	
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within their scope of competence.” (ASHA 2007).			
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Check One: Meets Standard Progressive Standard Best Practice Standard

Citation(s) for Evidence-base:

1. American Speech-Language-Hearing Association. (2007). *(Scope of practice in speech-language pathology.* Available from <http://www.asha.org/policy>.
2. American Speech-Language-Hearing Association. (2006a). *Guidelines for speech-language pathologists in diagnosis, assessment, and treatment for autism spectrum disorders across the life span.* Available from <http://www.asha.org/policy>
3. American Speech-Language-Hearing Association. (2006b). *Knowledge and skills needed by speech-language pathologists for diagnosis, assessment, and treatment for autism spectrum disorders across the life span.* Available from <http://www.asha.org/policy>.
4. American Speech-Language-Hearing Association. (2006c). *Roles and responsibilities of speech-language pathologists in diagnosis, assessment, and treatment of autism spectrum disorders across the life span: Position statement.* Available from <http://www.asha.org/policy>.
5. Luyster, R., Kadlec, M.B., Carter, A., & Tager-Flusberg, H. (2008). Language assessment and development in toddlers with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 38,* 1426-1438.
6. Paul, R., & Wilson, K. (2008). Assessment of communication in autism spectrum disorders. In S. Goldstein, Naglieri, & S. Ozonoff (Eds.) *Assessment in Autism Spectrum Disorders.* NY: Guilford Press.
7. Tager-Flusberg et al., (2009). Defining spoken language benchmarks and selecting measures of expressive language development for young children with autism spectrum disorders. *Journal of Speech, Language, and Hearing Research, 52,* 643-652. Available from http://www.nidcd.nih.gov/funding/programs/vsl/language_benchmarks.htm.

Best Practice Standard

Standard	Check all that Apply		
<p>As part of an interdisciplinary team assessment for autism spectrum disorders, a qualified Speech-Language Pathologist should provide evaluation of the following aspects of communication:</p> <p>Best Practice Standard:</p> <ul style="list-style-type: none"> • A thorough case history of language should be obtained that includes information regarding babbling (age began and description), age and descriptions of first words, and any noted regression in language and/or social skills. • A standardized measure of receptive language that encompasses all areas of language structure 	Service:	Recipient:	Location:
	<input checked="" type="checkbox"/> Direct <input type="checkbox"/> Technical Assist <input type="checkbox"/> Consultation	<input checked="" type="checkbox"/> Individual w/ASD <input type="checkbox"/> Family <input type="checkbox"/> School District <input type="checkbox"/> Other / List:	<input checked="" type="checkbox"/> Home <input checked="" type="checkbox"/> School <input checked="" type="checkbox"/> Community

<ul style="list-style-type: none"> • A standardized measure of expressive language that encompasses all areas of language structure (phonology/morphology/syntax/semantics) • Informal or formal evaluation of social communication skills, appropriate for age and/or cognitive level, such as rate and use of gestures, eye gaze, gaze shifts, joint attention, conversational turn-taking, topic maintenance etc. These skills may be observed during autism-specific assessments such as the ADOS-2 (Lord, 2012) or by obtaining a natural language sample. • In individuals who are verbal, standardized evaluation of articulation, including statement regarding overall intelligibility. • Evaluation of oral motor skills. • In individuals who are verbal, statement regarding fluency should be made. A descriptive statement of prosody should be included. • In individuals who are verbal, descriptive statement regarding vocal pitch, quality and loudness should be made. <p>The SLP is considered qualified by the following characteristics:</p> <ul style="list-style-type: none"> • Holds the ASHA Certificate of Clinical Competence in Speech-Language Pathology (CCC SLP) • Demonstrates continued professional development in the area of autism spectrum disorders <p>As mandated by ASHA standards, “Each practitioner must evaluate his or her own experiences with preservice education, clinical practice, mentorship and supervision, and continuing professional development . . . Speech-language pathologists may engage in</p>			
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only those aspects of the profession that are within their scope of competence.” (ASHA 2007).			
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Check One: MeetsStandard ProgressiveStandard Best Practice Standard

Citation(s) for Evidence-base:

1. American Speech-Language-Hearing Association. (2007). *(Scope of practice in speech-language pathology.* Available from <http://www.asha.org/policy>.
2. American Speech-Language-Hearing Association. (2006a). *Guidelines for speech-language pathologists in diagnosis, assessment, and treatment for autism spectrum disorders across the life span.* Available from <http://www.asha.org/policy>
3. American Speech-Language-Hearing Association. (2006b). *Knowledge and skills needed by speech-language pathologists for diagnosis, assessment, and treatment for autism spectrum disorders across the life span.* Available from <http://www.asha.org/policy>.
4. American Speech-Language-Hearing Association. (2006c). *Roles and responsibilities of speech-language pathologists in diagnosis, assessment, and treatment of autism spectrum disorders across the life span: Position statement.* Available from <http://www.asha.org/policy>.
5. Luyster, R., Kadlec, M.B., Carter, A., & Tager-Flusberg, H. (2008). Language assessment and development in toddlers with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 38,* 1426-1438.
6. Paul, R., & Wilson, K. (2008). Assessment of communication in autism spectrum disorders. In S. Goldstein, Naglieri, & S. Ozonoff (Eds.) *Assessment in Autism Spectrum Disorders.* NY: Guilford Press.
7. Tager-Flusberg et al., (2009). Defining spoken language benchmarks and selecting measures of expressive language development for young children with autism spectrum disorders. *Journal of Speech, Language, and Hearing Research, 52,* 643-652. Available from http://www.nidcd.nih.gov/funding/programs/vsl/language_benchmarks.htm.

Cognitive and Developmental Evaluation

Standard	Check all that Apply		
<p>As part of a comprehensive interdisciplinary diagnostic evaluation, it is essential that all children referred to a Regional Autism Diagnostic Clinic receive an assessment of their cognitive/developmental functioning. Intellectual assessments should be conducted under the supervision of a licensed psychologist. Developmental assessments for toddlers and preschool-aged children can be conducted under the supervision of a licensed psychologist or a credentialed professional in a related developmental field (e.g., education).</p> <p>In accordance with the Alabama State Department of Education requirements, a measure of adaptive behavior is also considered essential.</p>	Service:	Recipient:	Location:
	<input checked="" type="checkbox"/> Direct <input type="checkbox"/> Technical Assist <input type="checkbox"/> Consultation	<input checked="" type="checkbox"/> Individual w/ASD <input type="checkbox"/> Family <input type="checkbox"/> School District <input type="checkbox"/> Other / List:	<input type="checkbox"/> Home <input checked="" type="checkbox"/> School <input checked="" type="checkbox"/> Community

Check One:

COGNITIVE ASSESSMENT: X MeetsStandard ___ ProgressiveStandard ___ Best Practice Standard

ADAPTIVE ASSESSMENT: X MeetsStandard ___ Progressive Standard ___ Best Practice Standard

Citation(s) for Evidence-base:

Klinger, L.G., O’Kelley, S.E., & Mussey, J.L. (2009). Assessment of Intellectual Functioning in Autism Spectrum Disorders. In S. Goldstein, J.A. Naglieri, & S. Ozonoff (Eds.), *Assessment of Autism Spectrum Disorders* (pp. 209-252). New York: Guilford.

PROFESSIONAL PREPARATION AND TRAINING:

The examiner is considered qualified by the following characteristics:

- The examiner/supervisor is licensed as a psychologist (clinical, counseling, or school psychology) by the Alabama Board of Examiners in Psychology (i.e., earned a doctoral degree and completed one year clinical internship) or the examiner has been credentialed by their respective discipline.
- The professional has at least two years previous experience working with individuals with autism spectrum disorders including individuals within the age range and developmental level of the person being evaluated.

Cognitive/Developmental Assessment Instruments:

Cognitive/developmental testing is an essential part of an ASD interdisciplinary diagnostic evaluation (Filipek et al., 1999; Johnson et al., 2007). Klin, Saulnier, Tsatsanis, & Volkmar (2005) described developmental testing for infants and preschool-aged children and intellectual assessment for school-aged children as a frame for interpreting the results of diagnostic testing. This “frame” can be used to evaluate whether a child’s social and communication delays are greater than expected given the child’s developmental level or whether they are equivalent to the child’s developmental level. In order to receive a diagnosis of ASD, a child’s social and communicative skills must be delayed below a child’s developmental level.

The traditional standardized assessment paradigm is often a challenge for children with ASD and for the examiner administering the assessment. Thus, the examiner often needs to structure the session using schedules and rewards to maintain motivation and decrease behavioral difficulties (see Klinger et al., 2009 for ideas on how to structure an intellectual assessment). At a minimum, the examiner should have experience administering intellectual assessments to children and have some knowledge about how the symptoms of ASD may interfere with test administration and performance. Ideally, the examiner will have experience interacting with individuals with ASD, and additional understanding of the symptoms and treatment approaches for ASD will assist the examiner in choosing an appropriate test and structuring the testing session to ensure that the child’s performance is representative of his or her true abilities. The choice of an intellectual/developmental assessment depends on the child’s chronological age, mental age, language abilities, and severity of autism symptoms. The attached list of recommended intellectual assessment instruments is based on Klinger et al. (2009) although other measures may also be considered appropriate. **A comprehensive cognitive/developmental evaluation is essential (i.e., meets standards) as part of an interdisciplinary diagnostic evaluation.**

Adaptive Behavior Assessment Instruments

A measure of adaptive behavior is recommended for both diagnostic and clinical reasons. First, in order to diagnose ASD and concomitant Intellectual Disability, delays must be present in intellectual ability and in adaptive behaviors. Second, poor adaptive behaviors are common among even individuals with high

functioning ASD. These delays in adaptive behaviors including daily living skills such as self-care, money management, and employment skills often interfere with long-term success of individuals with ASD. Thus, a measure of adaptive behavior is considered important for making recommendation to insure long-term outcome. Finally, the State of Department of Education requires a measure of adaptive behavior to determine eligibility for services under the diagnostic category of Autism. The attached list of recommended intellectual assessment instruments is based on Klinger et al. (2009) although other measures may also be considered appropriate. **An adaptive behavior evaluation is considered best practices in an autism spectrum disorder evaluation, is required by the Alabama State of Department of Education, and is essential in order to diagnose Intellectual Disability.**

RECOMMENDED COGNITIVE AND ADAPTIVE MEASURES FOR USE WITH INDIVIDUALS WITH ASD

COGNITIVE MEASURES				
Measure	Age range	Standard Score Range	Administration Time (minutes)	Required Level of Verbal Ability
Preschool Age				
Bayley-III	1 to 42 m	40 to 160	30 to 90	V & NV
DAS-II (Early Years)	2 y, 6 m to 3 y, 5 m	30 to 170	20	V & NV
WPPSI-IV(young level)	2 y, 6 m to 3 y, 11 m	40 to 160	30to 45	V
Mullen	Birth to 5 y, 8 m	49 to 155	15 to 60	V
School Age				
DAS-II (School-Age)	3 y, 6 m to 17 y, 11 m	30 to 170	30	V & NV
WPPSI-IV(older level)	4 y, 0 m to 7 y, 7 m	40 to 160	45 to 50	V
WISC-IV	6 y, 0 m to 16 y, 11 m	40 to 160	65 to 80	V
Adult				
WAIS-IV	16 to 89 y	45 to 155	65 to 95	V
Lifespan				
SB5	2 to 85 y	40 to 160	45 to 75	V & NV
Leiter-3	3 y, 0 m to 75 y	30 to 170	25 to 40	V & NV
ADAPTIVE MEASURES				
Measure	Age range		Administration Time	Administration Format
Vineland-II	Birth to 90 y	XX	20 to 60	Interview or Checklist
ABAS-II	Birth to 89 y	40 to 120	20	Checklist
SIB-R	Infancy to over 80 y	XX	15 to 60	Interview or Checklist
BASC-II	2 to 21 y	10-100 (mean of 50)	10 to 20	Checklist

Note: Bayley-III = Bayley Scales of Infant and Toddler Development – Third Edition; DAS-II = Differential Ability Scales – Second Edition; WPPSI-IV= Wechsler Preschool and Primary Scale of Intelligence – ForthEdition; Mullen = Mullen Scales of Early Learning; WISC-IV = Wechsler Intelligence Scale for Children – Fourth Edition; Leiter-R = Leiter International Performance Scale – Third Edition; WAIS-III = Wechsler Adult Intelligence Scale – Fourth Edition; SB5 = Stanford Binet Intelligence Scales – Fifth Edition; Vineland-II = Vineland Adaptive Behaviors Scales – Second Edition; ABAS-II = Adaptive Behavior Assessment System – Second Edition; SIB-R = Scales of Independent Behavior Revised ; BASC-II = Behavior Assessment System for Children – Second Edition; m = months; y = years; NV = Nonverbal; V = Verbal; Unless otherwise noted, mean of all instruments if 100 with a standard deviation of 15.

Psychological Evaluation

Standard	Check all that Apply		
<p>As part of a comprehensive interdisciplinary diagnostic evaluation, it is essential that all children referred to a Regional Autism Diagnostic Clinic receive an assessment of their autism symptoms including:</p> <ol style="list-style-type: none"> Autism Diagnostic Observation Schedule: Second Edition (ADOS-2) - a standardized, validated instrument that includes direct observation. DSM based clinical interview with a caregiver. The Autism Diagnostic Interview-Revised (ADI-R) is considered best practice. In accordance with the Alabama State Department of Education requirements, a norm-referenced autism-specific rating scale is considered essential (i.e., minimal standards) to an interdisciplinary diagnostic evaluation in the state of Alabama. Consider whether an alternative or comorbid diagnosis is appropriate. 	Service:	Recipient:	Location:
	<input checked="" type="checkbox"/> Direct <input type="checkbox"/> Technical Assist <input type="checkbox"/> Consultation	<input checked="" type="checkbox"/> Individual w/ASD <input checked="" type="checkbox"/> Family <input type="checkbox"/> School District <input type="checkbox"/> Other / List:	<input type="checkbox"/> Home <input checked="" type="checkbox"/> School <input checked="" type="checkbox"/> Community

Check One:

Autism Diagnostic Observation Schedule-2: Meets Standard Progressive Standard Best Practice Standard

DSM-IV Based Caregiver Interview: Meets Standard Progressive Standard Best Practice Standard

Autism Specific Rating Scale: Meets Standard Progressive Standard Best Practice Standard

PROFESSIONAL PREPARATION AND TRAINING:

- Autism diagnostic and screening instruments should be administered by or under the supervision of a professional licensed within their respective field.
- Diagnoses should be made by a licensed professional with at least two years “hands on” experience working with individuals with autism spectrum disorder including those within the age range and developmental level of the person being tested.

- Diagnoses should be made by a licensed professional with at least one year of previous experience in conducting autism diagnoses, including “hands on” training and onsite mentoring with the instruments being administered to make the diagnosis.

Diagnostic and Symptom Screening Instruments:

Autism Spectrum Disorder diagnostic evaluation should include ASD-specific diagnostic instruments. Until recently, the diagnosis of ASD has been based on clinician observation and intuition rather than a score on a standardized instrument. However, more objective diagnostic measures are now available. Best practices autism diagnostic evaluations go beyond caregiver rating scales to include standardized assessments including a structured play observation and a caregiver interview.

AUTISM DIAGNOSTIC OBSERVATION SCHEDULE: SECOND EDITION (ADOS-2; LORD ET AL., 2012)
 The ADOS-2 is a semi-structured play session (or conversation for adults) that creates an environment in which to assess an individual’s social skills, communication skills, and the presence of restricted or repetitive behaviors. The ADOS-2 takes approximately 40-60 minutes to administer and is appropriate for individuals from 12 months of age through adulthood; a developmental level of 18 months is necessary for standardized use and interpretation. There are five different ADOS-2 modules based on the individual’s expressive language level and chronological age. The Toddler Module is appropriate for children between 12 and 30 months of age. Module 1 is appropriate for nonverbal children over 31 months who do not consistently use phrase speech, Module 2 is appropriate for children using phrase speech, Module 3 is appropriate for children and adolescents with fluent language, and Module 4 is designed for older adolescents and adults with fluent language. Based on behaviors during the session, a series of algorithm items are rated to yield a classification of Autism, Autism Spectrum, or Non-spectrum. The Toddler Module algorithms indicate “ranges of concern” instead of classifications. The original ADOS scoring algorithm and classifications were based only on social and communication skills because repetitive behaviors and restricted interests were less likely to be observed during a short period of time. During ADOS observation, if repetitive behaviors and restricted interests are observed, the examiner can feel confident that they are present. If behaviors in this symptom area are not observed, a caregiver interview is necessary to assess these behaviors rather than incorrectly assuming these behaviors do not occur, thereby limiting diagnostic accuracy. However, a recent revised scoring algorithm includes scores related to repetitive behaviors and interests (Gotham et al., 2008). This revised algorithm has a greater predictive value (i.e., sensitivity of the measure to yield a classification predictive of eventual diagnosis) than the previous algorithm. Because of the difficulty in assessing repetitive behaviors and interests, a parent interview is an important component of making an accurate diagnosis and it is not recommended that the ADOS-2 be used in isolation for diagnosing ASD. **The use of the ADOS-2 as part of a diagnostic evaluation is considered to be essential (i.e., minimal requirement).**

AUTISM DIAGNOSTIC INTERVIEW – REVISED (ADI-R; LORD, RUTTER, & LECOUEUR, 1994).
 The ADI-R is a semi-structured caregiver interview appropriate for individuals between the ages of 18 months of age and adulthood. The caregiver would need to be familiar with the individual’s early childhood development, as well as their current behaviors. The interview focuses on the individual’s social skills, communication skills, and the presence of any restricted and repetitive behaviors. Because diagnostic symptoms change across the lifespan, an ADI-R classification of ASD is based on caregiver report of symptoms during the preschool years when symptoms tend to be the most severe and differentiated from other developmental disorders. However, current behaviors are also assessed to obtain an accurate picture of each individual’s current skills. This is a lengthy interview; the short version takes approximately 1 ½ hours to administer. Because it is so lengthy, many general practitioners find the ADI-R difficult to administer in their

daily practice. However, it is typically included in an ASD assessment in clinical settings specializing in ASD. **While a DSM-IV based caregiver interview is considered essential (i.e., minimal standards), the use of the ADI-R is considered best practices.**

ASD-Specific Rating Scales

An autism-specific norm-referenced rating scale is required by the Alabama Department of Education criteria for an ASD diagnosis. It is important to note that these rating scales were intended as screening instruments and are never intended as stand-alone diagnostic tools. **Because of the Alabama State Department of Education requirements, a norm-referenced autism-specific rating scale is considered essential (i.e., minimal standards) to an interdisciplinary diagnostic evaluation in the state of Alabama.** As with other parts of the evaluation, clinical judgment should be exercised in interpreting the results of these rating scales.

CHILDHOOD AUTISM RATING SCALE - SECOND EDITION (CARS-2).

The CARS-2 actually consists of two separate scales---the original standard (ST) form which includes the same items from the first edition of the CARS, and the new scale which includes items relevant to verbally fluent individuals (CARS-HF). The CARS-ST may be used with children younger than 6, as well as lower functioning older individuals. The CARS-HF is appropriate for use with verbally fluent persons over the age of 6, with IQ scores above 80. While there is a Questionnaire for Parents or Caregivers (CARS2-QPC), this is a non-scored tool to assist the clinician in making clinical judgments on the CARS-ST or the CARS-HF with regard to a particular individual. The latter instruments should not be completed by parents. While it may only take 5 to 10 minutes to complete the CARS-2, it can require a much longer time to gather the information necessary to do so in a valid manner. Immediately following completion of intellectual or behavioral observation measures may be the most beneficial time to make these clinical judgments. Cut-off scores and percentiles may be obtained for the CARS-2.

AUTISM SPECTRUM RATING SCALES (ASRS).

These teacher and parent rating scales are available in two separate forms---one for preschoolers and the other for elementary and high school students. Using a 5-point Likert response scale, parents and teachers rate the frequency of specific behaviors. Completion time for the full scales is approximately 20 minutes, and the ASRS is normed on children from 2 to 18 years of age. Scoring yields standard scores and percentile ranks for the overall score, as well as the following subscales: Peer Socialization, Adult Socialization, Social/Emotional Reciprocity, Atypical Language, Stereotypy, Behavioral Rigidity, Sensory Sensitivity, Attention/Self-Regulation (ages 6-18) and Attention (ages 2-5).

GILLIAM AUTISM RATING SCALES - SECOND EDITION (GARS-2).

This 42-item scale takes 5-10 minutes to complete, the GARS-2 can be used for ages 3 to 22 years. Separate scores are obtained for Stereotyped Behaviors, Communication, and Social Interaction, as well as a total Autism Index to estimate severity of impairment. Instructional objectives assist in educational planning for students who are rated by the GARS-2.

GILLIAM ASPERGER'S DISORDER SCALE (GADS).

Similar to the GARS-2, the GADS may be used with ages 3 to 22 and can be administered and scored in 5 to 10 minutes. The GADS, however, has a unique norm reference group of individuals diagnosed with Asperger's Disorder. This normative basis facilitates discrimination between Asperger's Disorder and other autism spectrum disorders, with standard scores and percentiles ranking the subject in comparison to persons diagnosed with Asperger's.

SOCIAL RESPONSIVENESS SCALE, SECOND EDITION (SRS-2)

The SRS-2 (Constantino, 2012) is a 65-item questionnaire developed to measure social skills, communication, and repetitive or stereotyped behavior. The SRS-2 is appropriate for individuals four years of age through adulthood. There are separate caregiver and teacher rating scales for the Preschool, School-Age, and Adult Forms that each take approximately 15-20 minutes to complete. An Adult Self-Report Form uses data provided by the individual. Behaviors are rated on a Likert scale. Cut-off scores are provided for use of the SRS-2 as either a population-based screening measure or for use as a screening tool when individuals are suspected of having ASD. In addition to a total T score, subscale scores of Social Awareness, Social Cognition, Social Communication, Social Motivation, and Restricted Interests and Repetitive Behavior may be calculated. Constantino and colleagues (2003) reported that all children receiving ADI-R scores above the clinical cut-off also had elevated SRS scores. Thus, the SRS-2 is useful as a screening instrument and as a measure of ASD symptom severity (see Naglieri & Chambers, 2009 for a more comprehensive review).

Recommended Autism Spectrum Rating Scales				
Measure	Age range	Scores provided	Administration Time (minutes)	Rater
Autism Spectrum Rating Scale	2-18 years	Standard scores and percentiles	20 minutes	Parent, Teacher
Childhood Autism Rating Scale, Second Edition	2+ years	Cut-off scores, percentiles	5-10 minutes after observation completed	Teacher, Clinician
Gilliam Autism Rating Scale, Second Edition	3-22 years	Cut-off scores and percentiles	5-10 minutes	Parent, Teacher, Clinician
Gilliam Asperger's Disorder Scale	3-22 years	Standard scores and percentiles	5-10 minutes	Parent, Teacher, Clinician
Social Responsiveness Scale	4-adult	Standard scores and percentiles	15-20 minutes	Parent, Teacher, Self

Assessment of Alternative and Comorbid Disorders

It is the role of a licensed psychologist, ideally with the support of an interdisciplinary team, to examine whether social communication difficulties and repetitive behaviors can be better explained by alternative diagnoses (e.g., selective mutism) or whether a comorbid diagnosis exists (e.g., anxiety, depression). It may be helpful to consider whether other behavioral and/or emotional rating scales (e.g., BASC-II) or caregiver interviews (e.g., Diagnostic Interview Schedule for Children) should be administered to differentiate between ASD and other diagnoses or to determine comorbidity.

Making a Diagnosis: Integrating Interdisciplinary Results

It is the role of the diagnostician to integrate information from the autism specific measures discussed above, with the information provided by other disciplines in order to make a clinical diagnosis. That is, a diagnosis of an autism spectrum disorder should never be made based on a single score on a single measure. Instead, information about the individual's developmental history, intellectual/developmental ability, language ability,

health/physical concerns, and mental health concerns should be integrated with the autism measures to make a final diagnosis.

Occupational Motor and Sensory Evaluation

Standard	Check all that Apply		
<p>As part of a comprehensive interdisciplinary diagnostic evaluation, all children suspected of having an autism spectrum disorder should, as a minimum, have an occupational therapy screening for fine motor and sensory processing delays. Best practice consists of a comprehensive occupational therapy evaluation that includes the following:</p> <ul style="list-style-type: none"> • Occupational Profile • Motor skills • Sensory processing abilities • Play • Self-care skills. <p>The assessment should include structured interview, observation, direct assessment that include multiple measures which include standardized instruments.</p> <p>Occupational therapy intervention decisions will be based on evidence-based best practices, individualized analysis of the child, and the premise that caregivers are central to the intervention process. Interventions will promote active engagement of the child.</p>	<p>Service:</p> <p>X Direct ___ Technical Assist ___ Consultation</p>	<p>Recipient:</p> <p>X Individual w/ASD ___ Family ___ School District ___ Other / List:</p>	<p>Location:</p> <p>X Home X School X Community</p>

Check One: Meets Standard Progressive Standard ___ Best Practice Standard

Citation(s) for Evidence-base:

1. AOTA (2009). Occupational Therapy Practice Guideline for Children and Adolescents with Autism.
2. Cohen, H., Amerine-Dickens, M. & Smith, T. (2006). Early intensive behavioral treatment: Replication of the UCLA model in a community setting. *Developmental and Behavioral Pediatrics*, 27, S145-S155.
3. Dunst, C., Hamby, D., Trivett, C. M., Raab, M. & Bruder, M.B. (2000). Everyday family and community life and children's naturally occurring learning opportunities. *Journal of Early Intervention*, 23, 151-164.
4. Greenspan, S. I. & Wieder, S. (1997). Developmental patterns and outcomes in infants and children with disorders of relating and communicating: A chart review of 200 cases of children with autism spectrum diagnoses. *Journal of Developmental and Learning Disorders*, 1, 87-142
5. Rogers, S. & DiLalla, D. L. (1991). A comparative study of the effects of a developmentally based instructional model on young children with autism and young children with other disorders of behavior and development *Topics in Early Childhood Special Education*, 11(2), 29-47.
6. Turnbull, A.P., Turbiville, V. & Turnbull, H.R. (2000). Evolution of family-professional partnership models: Collective empowerment as the model for the early 21st century. In S. J. Meiseld J.P. Shonkoff (Eds.) *Handbook of early intervention* (pp. 640-650). New York: Cambridge University Press.

PROFESSIONAL TRAINING AND PREPARATION

All occupational therapists who are on a Regional Diagnostic Clinic Interdisciplinary Diagnostic Team will have graduated from at least a bachelor's degree OT program accredited by ACOTE, have passed the nationally recognized NBCOT examination, and fulfill state license requirements for the Alabama State Board of Occupational Therapy

These recommendations are based on best practice from the American Occupational Therapy Association, The California Best Practices, and in consideration of the logistical limitations for the evaluation process, and the needs of the families.

A proposed change to the diagnostic criteria for autism spectrum disorders in DSM V reads as follows:

“Hyper- or hypo-reactivity to sensory input or unusual interest in sensory aspects of environment; (such as apparent indifference to pain/heat/cold, adverse response to specific sounds or textures, excessive smelling or touching of objects, fascination with lights or spinning objects.”

(<http://www.dsm5.org/ProposedRevisions/Pages/proposedrevision.aspx?rid=94>)

Sensory processing disorders are well documented in the literature (Ornitz, 1989, Ornitz, Lane, Sugiyama, & de Traversay, 1993, Yenug-Courchesne&Courchesne, 1997. Ertmer& Dunn, 1998; Kientz& Dunn, 1997; Watling, Deitz, & White, 2001) as well as supported by first-person accounts (Cesaroni& Garber, 1991; Grandin, 1995). Children being evaluated for possible autism spectrum disorders should be screened for fine motor and sensory processing delays. The Sensory Profile Short Form is one instrument that can be used for screening. However, best practice dictates that if the Sensory Profile Short Form identifies dysfunction in any subsection and/or in the total score, a referral should be made to an occupational therapist for a thorough evaluation and therapeutic recommendations.

The Short Sensory Profile is a 38-item caregiver report measure that takes about 10 minutes to administer to parents. Items are scored on a five-point scale. There are seven sections: tactile sensitivity, taste/smell sensitivity, movement sensitivity, under responsive/seeks, sensation, auditory filtering, low energy/weak, and visual/auditory sensitivity. The total score is the most sensitive indicator of sensory dysfunction, however, section scores are interpreted as independent variables. The SSP isolates sensory processing from social and motor items. Validity is at >95% in identifying children with and without sensory modulation difficulties (McIntosh et al, 1999). Tomchek and Dunn (2007) found that children with ASD performed differently than normally developing children on the SSP .

The Best Practice Occupational Therapy evaluation should include all of the following:

PLAY SKILLS- Play is the child's primary occupation and is an essential component of the occupational therapy evaluation. Observation of play often provides a rich amount of information regarding performance skills of a child. Assessment of play is an essential component of the diagnostic process because children with autism spectrum disorders lack spontaneous, varied make-believe play (DSM-IV). Observations should describe the child's level of play skills, qualitative aspects of the play performance, social and interactive aspects of the play performance, as well as variability of play skills, transitions from one activity to another, and ability to engage in creative and pretend scenarios. Information related to play preferences, routines, engagement, environments, ability to play with peers, ability to engage in pretend play, imitation, initiation, and shared enjoyment should be noted. Evaluation includes direct assessment, observation, caregiver interview, and structured and unstructured play opportunities. Frequently used assessment tools include the Revised Knox Preschool Play Scale (Knox, 2008), Test of Playfulness (Skard& Bundy, 2008), and the Transdisciplinary Play Based Assessment 2nd Edition (Linder, 2008). The information gathered during the

evaluation should be interpreted to determine play levels, typical and preferred play activities, ability to engage in play interactivity, and hindrances to play skills.

OCCUPATIONAL PROFILE-The occupational profile identifies the child's occupational history, current occupations in various contexts, discusses typical routines, and the child's interests and motivations. The profile also explores problematic daily routines, social supports, and parent concerns. Assessment tools commonly used include the Canadian Occupational Performance Measure (Law et al., 2005), Perceived Efficacy and Goal Setting System (PEGS; Missiune, Pollock, & Law, 2004), Children's Assessment of Participation and Enjoyment and Preferences for Activities (CAPE/ PAC; King et al., 2005) and caregiver interview. If the child is school age, additional communication may be needed to determine school based performance and concerns and may include additional testing.

MOTOR SKILLS- A motor skills evaluation includes fine motor, gross motor, and visual motor skills. Observation of motor performance should include postural stability, mobility, neuromotor development, and skill performance. The evaluation can include observations of play as well as structured or standardized assessments. Performance of typical age appropriate skills such as walking, running, stair climbing, hopping, skipping, kicking a ball, riding a bicycle, swimming, and participation in structured activities (i.e., recreational sports, team sports, etc.) should be included. The evaluation should assess both the quality of movements and the precision of skills. Fine motor and visual motor evaluation should include typical grasp and prehension patterns, hand dominance, finger dexterity, and manipulation of play items. Performance of typical age appropriate skills such as block play, coloring, writing, cutting, puzzle play, catching, throwing, and manipulation and activation of various toys should be included. Assessment tools commonly used include the Peabody Developmental Motor Scales- Second Edition (Folio & Fewell, 2000), the Bruininks-Oseretsky Test of Motor Proficiency-Second Edition (Bruininks & Bruininks, 2005), the Miller Function and Participation Scales (Miller, 2006), the Developmental Test of Visual Motor Integration 5th Edition (Berry et al., 2004), Test of Visual-Motor Skills Revised (Gardner, 1998), The Evaluation Tool of Children's Handwriting (Amundson, 1995), Minnesota Handwriting Assessment (Reisman, 1999) and the Test of Handwriting Skills (Gardner, 1998). The evaluation should include an interpretation of motor abilities and underlying issues impacting performance.

SENSORY PROCESSING ABILITIES- Evaluation of sensory processing abilities includes gathering information regarding sensory processing within daily life situations, measuring the child's responsiveness to varied sensory experiences, and include assessment of behavior, praxis, and emotional lability. Assessment tools commonly used include the Sensory Profile (Dunn, 1999); Infant Toddler Sensory Profile (Dunn et al., 1999), Adolescent/ Adult Sensory Profile (Dunn et al., 1999), Sensory Integration Inventory-Revised (Reisman & Hanschu, 1992), Sensory Processing Measure, Home Form (Parham & Ecker, 2007), Main Classroom and School Environment (Miller-Kuhaneck et al., 2007). The evaluation should include an interpretation of the sensory processing, including a description of sensory behaviors with hyper and hypo sensitivities clearly indicated.

SELF-CARE SKILLS- An assessment of self-care skills should include feeding, grooming, dressing, bathing, and toileting. Particular emphasis should be placed on the feeding performance when this is a concern. Feeding assessments should include feeding history, and typical performance related to volume and variety of foods and preference for particular textures, flavors or temperatures of foods or rituals related to feeding and mealtimes. Typical assessment tools utilized include the Pediatric Evaluation of Disability Inventory (Haley et al., 1992), parent interview, BAMBI and Vineland Adaptive Behavior Scale-Second Edition (Sparrow et al., 2005). The assessment should include a description of any specific rituals that are currently followed for completion of specified self-care skills. An interpretation of the child's current status should be included to prioritize skills that will be targeted for intervention.

BEHAVIORS DURING THE EVALUATION- From initial contact with the family and throughout the evaluation process, the child's behaviors are noted.

Observations should note the following: (a) ritualistic and rigid behaviors, (b) vocalizations (echolalia, sounds, humming, high pitched screams, non-purposeful noise), (c) quality of eye contact, (d) response to name calling, (e) self-stimulating behaviors, (f) self-injurious behaviors, (g) ability to remain seated when requested, (h) frustration tolerance, (i) ability to handle transitions, (j) withdraw or aversive responses to touch or auditory stimuli, (k) distractibility, and (l) social appropriateness.

Best Practice Occupational Therapy for evaluation of ASD should include:		
Area:	Include:	Recommendations
Occupation	Occupational profile- occupational history and current occupations in various contexts, typical routines, interests, and motivations, problematic routines and social functions, family concerns, questions and priorities	Parent/caregiver interview Chart review Observations during evaluation
Self-care	Feeding Grooming Undressing and dressing Bathing Toileting	Pediatric Evaluation of Disability Inventory Skilled Clinical Observation BAMBI (optional) Parent interview to probe for details that promote participation and hindrances in the process
Sensory Processing	Full evaluation of sensory processing abilities	Sensory Profile or Infant/Toddler Sensory profile Or Adolescent/adult sensory profile as age appropriate And description of sensory behaviors with hyper and hypo sensitivities clearly indicated and interpreted
Motor	Gross motor Fine motor Visual Motor (if appropriate)	Peabody Developmental Motor Scales - 2 (PDMS-2) or Bunininks-Osteretsky Test of Motor Development-2 (BOT-2) And if appropriate: Berry-Buktenica Developmental Test of Visual- Motor Integration
Leisure/play	Assessment of play is an essential part of this diagnostic process and should include play preferences, routines, engagement, environments, peers as much as possible, ability to engage in pretend play or only routine play behaviors -requesting -shared enjoyment -level of play -quality/appropriateness of play -imitation -initiation -etc.	Analysis of information gathered to determine play behaviors that are typical and preferred for this child, those that are indicative of stereotypical behaviors or routines, interaction with others, play environments available, ability to engage

General Behaviors	Observation of ritualistic, rigid, and self-stimulating behaviors should be noted including: <ul style="list-style-type: none"> • hand flapping • humming • non-purposeful noise production vocally • eye contact or lack of • odd eye gazes • rocking • other non-purposeful movements such as tics. • ability or inability to transition between tasks • tolerates/acknowledges unfamiliar person 	Observations should be made during both structured (with expectations and desired outcome) and unstructured play (without expectations and no particular desired outcome) opportunities
Other	At times, other concerns are identified and therefore may be addressed during the OT Evaluation Concerns regarding handwriting, visual perceptual skills, sensory integration and other concerns within the domain of occupational therapy are appropriate to be addressed when needed	Choose as needed and appropriate: Sensory Integration and Praxis Test Test of Visual Perceptual Skills Evaluation Tool of Children's Handwriting Others as developed may be appropriate

SCREENING AND SURVEILLANCE

Universal Screening and Surveillance

Standard	Check all that Apply		
Alabama Regional Autism Network providers will encourage and assist pediatricians and other primary healthcare providers who care for young children to implement and provide universal surveillance and screening for developmental delays/disabilities and for autism spectrum disorders.	Service:	Recipient:	Location:
	<input checked="" type="checkbox"/> Direct <input checked="" type="checkbox"/> Technical Assist <input checked="" type="checkbox"/> Consultation	<input checked="" type="checkbox"/> Individual w/ASD <input checked="" type="checkbox"/> Family <input type="checkbox"/> School District <input type="checkbox"/> Other / List:	<input checked="" type="checkbox"/> Home <input checked="" type="checkbox"/> School <input checked="" type="checkbox"/> Community

Check One: Meets Standard Progressive Standard Best Practice Standard

Citation(s) for Evidence-base:

1. Identifying infants and young children with developmental disorders in the medical home: an algorithm for developmental surveillance and screening. *Pediatrics* 2006; 118:405-20.
2. JOHNSON CP, MYERS SM. Identification and evaluation of children with autism spectrum disorders. *Pediatrics* 2007; 120:1183-215.
3. CARBONE PS, FARLEY M, DAVIS T. Primary care for children with autism. *AmFam Physician* 2010; 81:453-60.
4. BARBARO J, DISSANAYAKE C. Prospective identification of autism spectrum disorders in infancy and toddlerhood using developmental surveillance: the social attention and communication study. *J Dev Behav Pediatr* 2010; 31:376-85.

5. WETHERBY AM, ALLEN L, CLEARY J, KUBLIN K, GOLDSTEIN H. Validity and reliability of the communication and symbolic behavior scales developmental profile with very young children. *J Speech Lang Hear Res* 2002; 45:1202-18.
6. WETHERBY AM, BROSINAN-MADDOX S, PEACE V, NEWTON L. Validation of the Infant-Toddler Checklist as a broadband screener for autism spectrum disorders from 9 to 24 months of age. *Autism* 2008; 12:487-511.
7. ROBINS DL, FEIN D, BARTON ML, GREEN JA. The Modified Checklist for Autism in Toddlers: an initial study investigating the early detection of autism and pervasive developmental disorders. *J Autism Dev Disord* 2001; 31:131-44.
8. KLEINMAN JM, ROBINS DL, VENTOLA PE, et al. The modified checklist for autism in toddlers: a follow-up study investigating the early detection of autism spectrum disorders. *J Autism Dev Disord* 2008; 38:827-39.
9. *Ages & Stages Questionnaires: Social-Emotional*, A parent-completed child-monitoring system for Social-Emotional behaviors. Jane Squires, Dian Bricker, & Elizabeth Twombly. 2002. Paul H Brookes Publishing Co.

Alabama Regional Autism Network providers will encourage and assist healthcare practitioners who provide primary care to young children to implement and provide universal surveillance and screening for developmental delays/disabilities and for autism spectrum disorders (ASD), in accordance with American Academy of Pediatrics (AAP) recommendations (AAP, 2006; Johnson and Myers, 2007). The AAP currently recommends that physicians provide developmental surveillance at all well-child health supervision visits and conduct general developmental screening at the 9-, 18-, and 30-month visits, and whenever surveillance demonstrates that a child may be at risk for developmental delay. In addition, ASD-specific screening is recommended at the 18 and 24 month well-child visits.

The AAP views surveillance and screening in the primary care physician's office as the appropriate mechanisms to identify ASD early and to refer children for the appropriate intervention services. The AAP defines surveillance as "the ongoing process of identifying children who may be at risk of developmental delays" and screening as "the use of standardized tools at specific intervals to support and refine the risk." Both mechanisms offer opportunity to observe the developmental trajectory and potential unfolding of developmental concerns, including ASD, over the first years of life. The routine use of developmental surveillance and screening tools increases the chance of earlier ASD diagnosis and earlier intervention (Carbone et al., 2010).

Surveillance

Alabama Regional Autism Network providers will conduct and promote developmental surveillance that includes the following components: eliciting and attending to the parents' concerns about their child's development; documenting and maintaining a developmental history; making accurate observations of the child; identifying risk and protective factors; and maintaining an accurate record of documenting the process and findings. Use of longitudinal developmental surveillance has been shown to increase the accuracy of identifying children with an ASD at 2 years of age and younger (Barbaro et al., 2010).

Screening

Alabama Regional Autism Network providers will encourage health care practitioners to conduct ASD-specific screening at the 18 and 24 month well-child visits using instruments with good sensitivity, specificity, and positive predictive value. Currently, three instruments that meet these criteria are: *The Communication and Symbolic Behaviors Scales Infant Toddler Checklist* (ITC), the *Modified Checklist for Autism in Toddlers* (M-CHAT) with the associated caregiver interview, and the *Ages and Stages Social-Emotional Questionnaire* (ASQ-SE).

The COMMUNICATION AND SYMBOLIC BEHAVIOR SCALES INFANT TODDLER CHECKLIST (CSBS ITC; Wetherby&Prizant, 2002) is currently the most accurate ASD screening instrument. In a recent study of approximately 5,000 children, the CSBS ITC successfully identified children with communication delays including those later diagnosed with ASD at high rates during the 15-24 month well-child visits (Wetherby et al., 2008). The CSBS ITC measures developmental milestones of social communication, sounds and words, understanding, and object use.

- Age Range: 6-24 months of age
- Positive Predictive Value (accurately identifying children with autism without incorrectly identifying children who do not have autism) at 15-24 months: 76%
- Availability: Free to providers and is a brief (5-10 minutes, 24 items) caregiver checklist (<http://firstwords.fsu.edu/pdf/checklist.pdf>).

The MODIFIED CHECKLIST FOR AUTISM IN TODDLERS (M-CHAT; Robins et al., 2001) is another successful screening instrument. In a recent study of approximately 3,800 16-30 month old children, the M-CHAT was most successful at screening for ASD during a well-child visit *if* it was combined with a follow-up caregiver interview (Kleinman et al., 2008). Robins is currently investigating a new approach for scoring the M-CHAT, which may reduce the need for the follow up interview. (IMFAR, 2010; oral presentation by Diana Robins) The M-CHAT specifically measures symptoms associated with ASD.

- Age range: 16-30 months of age
- Positive Predictive Value without interview: 11%
- Positive Predictive Value with Interview: 65%
- Availability: Free to providers and is a brief (5-10 minutes, 23 items) caregiver checklist. The follow-up interview takes about 15 minutes (www.firstsigns.org/downloads/m-chat.PDF).

The AGES AND STAGES QUESTIONNAIRE: SOCIAL EMOTIONAL (ASQ:SE; Squires, Bricker, & Twombly, 2002) assess social emotional abilities in children ages 6-60 months across 7 areas: self-regulation, compliance, communication, adaptive functioning, autonomy, affect, and interaction with people. Sensitivity of the ASQ:SE to detect social-emotional delays ranged from 71% to 85% and specificity ranged from 90% to 98% when results of approximately 3,000 children were analyzed (www.agesandstages.com). Ninety-seven percent of parents rated the questionnaire as easy to use. The ASQ:SE is available commercially at a reasonable cost.

Healthcare providers should receive continuing education on screening and surveillance instruments for autism and developmental delays. CDC's *Learn the Signs. Act Early*. curriculum offers continuing education opportunities for in-person trainings and online use for healthcare providers (www.cdc.gov/ActEarly).

MODELS OF CARE COORDINATION

Care Coordination and Medical Home

Standard:	Check all that Apply		
Agency is able to provide evidence that demonstrates a care coordination/medical	Service: <input checked="" type="checkbox"/> Direct	Recipient: <input checked="" type="checkbox"/> Individual w/ASD	Location: <input type="checkbox"/> Home

<p>home model in which there is a single point of entry to access services, develop a centralized plan of care, and implement organized treatment by those serving the child and family. Services (1) are comprehensive, planned, and asset based, (2) strengthen families and promote self-management skills, (3) are family centered and based in the community in which all providers work together and share responsibility and (4) promote cross-organizational linkages and partnerships to ensure that practices are individualized and address medical, social, developmental, educational, behavioral/emotional, and financial needs. Agency is also able to demonstrate that care coordination efforts are fiscally efficient and outcome oriented.</p>	<p><input type="checkbox"/> Technical Assist <input checked="" type="checkbox"/> Consultation</p>	<p><input checked="" type="checkbox"/> Family <input type="checkbox"/> School District <input checked="" type="checkbox"/> Other / List:</p>	<p><input type="checkbox"/> School <input checked="" type="checkbox"/> Community</p>
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Check One: Meets Standard Progressive Standard Best Practice Standard

Citation(s) for Evidence-base:

1. Best Practice Guidelines for Screening, Diagnosis, and Assessment _CA_2002.
http://www.ddhealthinfo.org/documents/ASD_Best_Practice.pdf
2. DEC Recommended Practices in Early Intervention and Early Childhood Special Education: Chapter 4: Recommended Practices in Family Based Practices by Carol Trivelle and Carl Dunst.
3. *Washington State Autism Diagnostic Teams Survey of Service Models* sponsored by the Washington State Combating Autism Advisory Council Training Subcommittee.
4. "Family-Centered Care Coordination for Children and Youth with ASD," Power Point Presentation by Richard Antonelli, Children's Hospital Boston, Harvard Medical School, AMCHP Teleconference, October 2009.
5. Waisman Center's National Medical Home Autism Initiative, Medical Home System Guidelines for ASD
6. <http://www.waisman.wisc.edu/nmhai/>.
7. National Center for Medical Home Implementation. American Academy of Pediatrics.
www.medicalhomeinfo.org.
8. Tools for assessing and improving quality of care delivery, including the Medical Home Index, and Medical Home Family Index.www.medicalhomeimprovement.org

Because ASD is a multifactorial condition, optimal care coordination and service processes should be holistic, multifaceted, family-centered and culturally sensitive. *Pediatric care coordination* is defined as a patient- and family-centered, assessment-driven, team-based activity designed to meet the needs of children and youth while enhancing the care giving capabilities of families. Care coordination, using a centralized medical home model, addresses interrelated medical, social, developmental, behavioral, educational, and financial needs in order to achieve optimal health and wellness outcomes and maximize community and provider utilization and linkages.

Care coordination for ASD should focus on the following strategies:

- Linking access to a family-centered, community-based Medical Home system of primary care, integrated with necessary service delivery components
- Develop and sustain collaborative care models aligning families, Medical Homes, and various community providers, including mental/ behavioral health providers

Core components of care coordination:

- Family-centered and based in the community in which all providers work together and share responsibility
- Proactive, planned, asset based comprehensive care
- Care strengthens families and promotes the development of self-management skills
- Facilitation of cross-organizational linkages and partnerships to ensure that practices are individualized yet centralized

A family-centered frame of reference reinforces the concept of parents and caregivers as the most knowledgeable source of information about the child, acknowledges that the child is part of a larger family system and sets the stage for ongoing collaboration and communication between professionals and family members. The needs, priorities and resources of the family should be the primary focus and be respectfully considered. Social-emotional factors must be considered because they influence coping and conceptualization of the individual with ASD.

Care Coordination efforts must serve as a bridge between service providers in order to minimize service delays and duplication. Parental stress is heightened as parents worry about their child while also spending time and energy trying to arrange for needed intervention services. Often, information is extremely difficult for families to find, locate and use. Timely referral, integration, and coordination of services lead to more streamlined and efficient service delivery.

Care coordination efforts need to offer families both informal and formal resources, including intrafamily, peer to peer, and community supports. Having a social support has a positive effect on parental well-being – which can have a positive effect on the parent’s interaction with the child and child development/behavior. Providing or helping families negotiate supports and services, ensures that they have the resources necessary for time and physical/mental energy to engage in good child rearing. Practices should strengthen the parent’s competency and empower rather than build dependency on professionals and systems.

Care coordinators need to meet regularly and work collaboratively with families and share information in a way that matches the family’s style of understanding, literacy, and overall intellectual functioning so they can make informed choices. All efforts should be strength based to increase family functioning which in turn will increase compliance with recommendations and interventions. This means obtaining a comprehensive profile of strengths, skills and deficits soon after diagnosis. Practices should also be individualized to the specific family in order to minimize stress and assumptions as to what and how interventions are provided. Flexible resources should match each family’s priorities and values.

EXAMPLE: if a diagnosis of ASD is confirmed after the intake, screening, and evaluation, a Care Coordinator would be assigned to meet with the family. Evaluation results should be shared verbally and in writing with the parent. The family and Care Coordinator would attend a separate conference with the family and Developmental Pediatrician, Pediatric Psychologist, etc.

Care Coordination should provide the following to families in a clinic, community, and/or home based setting/visit:

- Family education, training, and coaching (both written and verbal) during and after appointments based on service needs/assessment and a written service care plan
- Delivery or arrangement of clinically necessary transportation
- Manages continuous communications, linkage and monitors usage of community supports and providers
- Referrals for special education evaluation with documentation of diagnosis
- Referrals to community providers for supplemental speech, occupational therapy, social skills
- On-going follow-up/management/coordination of care with a Developmental Pediatrician, including psychopharmacologic treatment and medication monitoring/compliance
- Referrals for behavior problems to Pediatric Psychology/Counseling
- Consultation with PediatricNeurology, Genetics, Psychiatry if warranted
- Information on family support groups in the community
- Supports/facilitates care transitions and team meetings
- Uses health information technology

Some providers offer care coordination (referrals and resources) if a diagnosis of ASD is not confirmed but there are other developmental delays of a different etiology, but this should be carefully considered due to the volume of referrals and financial implications.

Examples

MISSOURI

The Missouri Rapid Response Project was created out of a need to help parents of autistic children access comprehensive and coordinated care. Parents and providers reported that service systems were fragmented and families faced significant problems in navigating the system of care. In 2008, Missouri was one of six states to be awarded a State Implementation grant to improve comprehensive and coordinated care for children and youth with ASD and other developmental disorders (Health Resources and Services Administration [HRSA] funding from 2008-2011).

The focus areas of the project included creating and implementing a care coordination and family support model that included:

Family Resource Specialists to:

- identify unmet child and family needs,
- link families to needed information and resources, and
- support effective communication among families, primary and specialty care providers, and other community professionals.

Family Mentors to:

- provide emotional support through parent-to-parent mentoring
- partner with the statewide Sharing-Our-Strengths (SOS) program at the University of Missouri-Kansas City for sustainability. SOS is Missouri's parent to parent/peer support network for parents of children

with developmental disabilities or special healthcare needs, individuals with disabilities, and professionals.

Another focus was building family and professional partnerships in which the project created a model program to enhance family-professional partnerships through:

- ASD Family-Centered Care Survey developed and tested.
- ASD Family-Professional Task Force formed to identify common goals for quality improvement in clinical settings.
- ASD Quality Improvement strategies under development that measure outcomes of activities that aim to improve child- and family-centered care.
- preparing families for leadership and advocacy roles

The *Thompson Center*, which was a result of this project, offers a range of health, educational and behavioral services in one location for individuals with autism and other developmental concerns.

Source:

<http://thompsoncenter.missouri.edu/morr/MORR.php#Care>

WISCONSIN:

The *National Medical Home Autism Initiative* is a project at the University of Wisconsin's Waisman Center and uses a medical home model in order to identify, serve and integrate autistic children and families into the community and services. Families reported frustration trying to obtain a timely and accurate diagnosis while gaining entry info and negotiating appropriate intervention programs. Professionals also reported feeling challenged in knowing what services were available, where to go, criteria for admission, etc. Like others, this model was created in order to address these struggles.

The medical home model offers a single point of entry is used for access to services and a specific plan of care and treatment is designed and implemented in an organized way among all those that are serving the family and child. As a result, no matter where the family enters the system, they will be connected to a medical home that will provide medical care, support and care coordination.

For instance, a pediatric clinician works in partnership with the family and child to assure that the entire medical and non-medical needs of the child/family are met. The provider helps the family/child access and coordinate specialty care, educational services, out of home care, family support, and other community resources that are available.

Source:

<http://www.waisman.wisc.edu/nmhai/>

MARYLAND:

Founded in 1983, *The Coordinating Center for Home and Community Care, Inc.*, (CCHCC) is a nonprofit corporation that was first organized as a consortium and was initially funded by a federal Maternal Child Health Bureau (MCHB) Special Projects of Regional and National Significance (SPRANS) grant. The original purpose of this grant was to develop a care coordination model designed to effect the transition from hospital to home of children who were then hospitalized with complex medical diagnoses requiring ventilator support. However,

it quickly expanded to other areas and programs, *including* an Autism Waiver program, which provides necessary community services to children with severe autism at risk for institutionalization.

Maryland was the first state to implement an autism waiver, which covers intensive family support and training, therapeutic integration services, respite care and home modifications. Maryland's waiver also covers intensive individual support in the home, at school or in the community.

The program is built on care coordination principles and designed to help members and their families receive early intervention and support while navigating services and benefits. The program is designed to increase overall well-being of the family as a whole.

The Coordinating Center's prototype model for care coordination reflects the following characteristics, including

- Family and person centered practice
- Comprehensive, holistic perspective
- Multidisciplinary team function
- Community resource utilization
- Fiscal and resource efficiency

The core service at The Coordinating Center, care coordination, is characterized by

- A person and family centered approach
- Individualized planning
- Personal contacts between clients, families and the professional care coordinator
- Interdisciplinary team expertise
- Community resource development
- Quality improvement tracking and evaluation
- Outcome oriented strategies

The Center offers a holistic approach by coordinating all of the services a person needs to be fully included at home and in the community. Because coordinators use appropriate community resources to help people build networks of support, the staff is able to promote more effective, more cost efficient strategies to reach positive outcomes. Based on the child's needs and the requirements of the program, families and children may be eligible to receive the following supportive services:

- Respite care
- Environmental accessibility adaptations
- Family Training
- Supported Employment
- Intensive Individual Support Service
- Residential habilitation
- Targeted case management, including working with several school systems to provide care management through this program

Source:

<http://www.coordinatingcenter.org/index.html>