

# **Committees Progress Report**

**Submitted to:**

**The Alabama Interagency Autism Coordinating Council**

**October 19, 2010**

*The information contained in this Progress Report is in draft form and in no way constitutes policy.*

Submitted by Caroline R. Gomez, Ph.D., State Autism Coordinator on behalf of the AIACC Committees on October 19, 2010.

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**Introduction**

As State Autism Coordinator, my role is to work with the Alabama Interagency Autism Coordinating Council (AIACC) to meet the urgent need for a statewide comprehensive system of care for individuals with ASD and their families. While searching for dollars to support implementation of the system of care, three committee efforts are underway, (a) Strategic Planning, (b) Standards of Practice, and (c) Special Projects. *The committees continue to encourage new members to join the efforts.* This Progress Report represents a remarkable collaboration by a diverse group of stakeholders all committed to a single goal – improving the lives of Alabamians with ASD, related conditions, and their families.

***The information contained in this Progress Report is in draft form and in no way constitutes policy.***

Please direct any comments, questions, recommendations to the State Autism Coordinator, Caroline Gomez, at [caroline.gomez@mh.alabama.gov](mailto:caroline.gomez@mh.alabama.gov).

<b>Alabama Interagency Autism Coordinating Council</b> <b>Members</b>	
Key: Autism Spectrum Expert Advisor (A.S.E.A.) / Autism Spectrum Family Advisor (A.S.F.A.) Autism Community Advocate (A.C.A.)	
Representative Cam Ward, A.S.F.A., Council Chair	Alabama House of Representatives
Myriam Peralta, M.D., F.A.A.P.	American Academy of Pediatrics- Alabama
Elmyra Jones, A.C.A.	Alabama Council on Developmental Disabilities
Terry Graham, Ph.D.	Alabama Institute for the Deaf and Blind
Carol Steckel, M.P.H.	Alabama Medicaid Agency
Senator Trip Pittman	Alabama State Senate
Melanie Jones, B.S., B.A.	Autism Society of Alabama
Marquita Davis, Ph.D.	Department of Children's Affairs

Joseph Morton, Ph.D.	Department of Education
Nancy Buckner, B.A.	Department of Human Resources
Jim Ridling, M.S.	Department of Insurance
John Houston, M.A., M.S.W.	Department of Mental Health
Don Williamson, M.D.	Department of Public Health
Cary Boswell, Ph.D.	Department of Rehabilitation Services
Fred Biasini, Ph.D.	University Center of Excellence in Developmental Disabilities
<b>Governor Appointees</b>	
Linda Bachus, A.S.F.A.	Julie Brown, A.S.F.A.
Robert Tristan Dunn, A.S.E.A.	Jerimie W. Goike, A.S.E.A.
Bama Folsom Hager, Ph.D., A.S.F.A	Evan Lang Krchak, A.S.E.A.
Jim Mercer, A.C.A	Sandra King Parker, MD
Hanes Swingle, M.D., M.P.H.	Kathy Welch, S.L.P.

The Council is established pursuant to Act 2009-295 of the Alabama State Code, the Riley Ward Alabama Autism Support Act, creating the Alabama Interagency Autism Coordinating Council. The purpose of the AIACC is to work in collaboration with the entities named in Act 2009-295 and other stakeholders to establish a long-term plan for a system of care for individuals with ASD and their families.

### Strategic Planning Committee

Chair: Bama Hager, Ph.D.

Consensus is a critical component of positive change. System level change is required to meet the urgent need for a statewide comprehensive system of care for individuals with ASD and their families. The Strategic Plan process was designed to build consensus needed to guide the system level change. The process seeks to inspire synergy among stakeholders, so that there is a unified strategy that leverages resources and expertise. The purpose of the Strategic Plan final document will be to help guide the AIACC goals and priorities and to communicate the philosophy, values, and intentions of the AIACC.

<b>Committee Members</b>	
Key: Autism Spectrum Expert Advisor (A.S.E.A.) / Autism Spectrum Family Advisor (A.S.F.A.) / Autism Community Advocate (A.C.A.)	
Bama Hager, Ph.D., A.S.F.A.	Committee, Chair; AIACC, Co-chair
Bev Mulvihill, Ph.D.	Committee, Facilitator; University of Alabama at Birmingham, Public Health
Representative Cam Ward, A.S.F.A	AIACC, Chair
Caroline Gomez, Ph.D.	State Autism Coordinator
Brian Anderson, A.S.F.A.	Partners in Policymaking Leader
Fred Biasini, Ph.D.	AIACC member; University of Alabama at Birmingham
Greg Carlson, M.B.A.	Glenwood. Inc, VP Planning & Development
Tracy Cron, A.S.F.A.	Autism Society of Alabama, Network Group Leader
Valerie Gamble, MS Ed., A.S.F.A.	Cleburne Schools
Evan Lang Krchak, A.S.E.A.	AIACC member
Kathryn DeCola, A.S.F.A.	Advocate
Thomas Holmes, A.C.A.	Arc, Executive Director

Laura Klinger, Ph.D.	University of Alabama
Michael Martin, A.S.F.A.	Alabama Department of Mental Health-Intellectual Disabilities Division; Parent
Beverly Marson, A.S.F.A.	Parent Advocate
Jim Mercer, A.C.A.	AIACC member; Glaxo Smith Kline
David Savage, MSC, CCC/SLP	Alabama Department of Rehabilitation Services: Children's Rehabilitation Services
Joe Septer, A.S.F.A.	Advocate
Margaret Stewart, A.S.F.A.	Talk About Curing Autism (TACA) Now, Alabama Coordinator
Alice Widgeon, L.B.S.W., MPA	Alabama Department of Mental Health, Early Intervention
Libby Williams, MBA, PMP	ATT, Project Manager; Family member
Lee Yont, M Ed, FACHE	Glenwood, Inc, President & CEO

**Meeting Dates:** March 23, 2010 / April 21, 2010 / May 11, 2010 / June 2, 2010 / August 30, 2010

### Strategic Planning Summary

#### **Mission Statement** (adopted April 27, 2010)

The Alabama Interagency Autism Coordinating Council guides a collaborative effort to facilitate a lifelong system of care and support for persons and their families living with Autism Spectrum Disorder or associated conditions, so that they enjoy a meaningful and successful life.

#### **Values Statement** (See Appendix A)

We believe that a successful system of care will provide innovative best practices services for individuals with ASD and their families. These services should be ACCESSIBLE to families across the state of Alabama, provide PERSON AND FAMILY CENTERED services, and promote meaningful PUBLIC AWARENESS and COMMUNITY INTEGRATION AND INCLUSION. We value a system of care that is responsive to the current SENSE of URGENCY, is ACCOUNTABLE for providing best practice services, that includes COLLABORATIVE PARTNERSHIPS, and offers HOPE to families and service providers across the state.

Key Issues	Impact
1. Adequate Funding	Level of Services
2. Competent ASD-Specific Trained Providers	Availability and Accountability for Providing Best Practice Interventions
3. Access to Care	Comprehensive Community-Based Services
4. Political Leadership	Advocacy
5. Public Awareness of ASD	Early Identification and Community Inclusion
6. True Cooperation Within the Autism Community	Comprehensive and Coordinated System of Care

Priority	Goal
1	Cultivate an overarching environment of understanding, communication, collaboration, and consensus building among Council membership that extends to the ASD community.
2	Support evidence-based, high quality, cost-effective models and best practices that provide supports to persons with ASD and their families.
3	Raise public awareness of issues/needs affecting persons with ASD and their families across the lifespan.
4	Identify and promote opportunities and create the infrastructure for diversified public and private partnerships that expand needed funding.
5	Increase the number of qualified and competent ASD trained professionals /personnel / providers
6	Increase choice among and access to quality services and supports for persons, families, and providers within ASD community-based systems of care.

<b>Appendix A. Statement of Values</b>	
<b>Value</b>	<b>Definition</b>
<b>Person and Family Centered</b>	We respect and value the uniqueness of all individuals. The system of care and support that will serve those with an Autism Spectrum Disorder (ASD) is based upon the individual's distinctive strengths, abilities, interests and choices. We recognize when given the opportunity, each person can make a unique contribution to family, community and to society. The individual's needs drive their unique program.
<b>Sense of Urgency</b>	Due to the overwhelming necessity for quality services and knowledgeable, reputable providers, our focus will be on the steps we can take to respond rapidly, efficiently and effectively to the immediate and life-long needs and challenges of people living with an ASD and their families.
<b>Partnerships in Action</b>	We promote improved public awareness and understanding of those living with an ASD and advocate for public policy and funding that expands medical, therapeutic, educational, vocational, recreational, social and residential options.
<b>Spirit of Collaboration</b>	Cooperative partnerships will be created between those living with an ASD and their families and those agencies, organizations and professionals that serve them. These partnerships will encourage collaboration and lead to an enhanced and more efficient service delivery to their clients. We value partnerships founded on honesty, integrity and mutual respect. We will treat all interested parties with respect, listen to diverse views with open minds, discuss submitted public comments and foster discussions where participants can comfortably offer opposing opinions.
<b>Accountability</b>	We will pursue innovative best practices of the highest quality for each individual to protect the safety and advance the interests of people affected by an ASD. We will promote a SMART (Specific, Measurable, Achievable, Realistic and Time-specific) structure for service delivery. This structure will be aligned with the needs of each individual with an ASD and their family. Methods will be used to evaluate and determine the success of service delivery. Services will be adjusted as necessary to promote meaningful and successful lives for those living with an ASD.
<b>Hope</b>	Although autism can be an isolating and involved experience, we will encourage hope for the autism community by endorsing our values

	on each and every service provider, agency and organization that touches them. We will also promote education for family members and those living with an ASD, so that they will be knowledgeable in what the possibilities are for their lives.
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### Standards of Practice (SOP) Committee

Chair: Alice Widgeon, L.B.S.W., MPA

Standards are statements that outline what level of service one can expect to be provided and how the service will be provided. The SOP Committee consists of six work groups addressing standards from screening and diagnosis through the lifespan. The committee's work has been towards developing SOP based on *evidence-based practice*. Evidence-based practice provides a framework for integrating what is known from research into real-world practice. In effect, evidence-based practice bridges the science-to-practice gap by using three core components (a) best research evidence, (b) clinical expertise and judgment, and (c) individual values and preferences.

The final SOP Report will serve three functions related to the Alabama Autism Regional Networks. The SOP will:

1. Advise the AIACC on appropriate standards for programs and services provided or to be provided for individuals with ASD under a Network.
2. Provide information to be used in monitoring the implementation of SOP in programs and services.
3. Be used to recognize the achievement of good standards and quality in the provision of programs and services to individuals with ASD.

For the individual with ASD and his or her family, the SOP will (a) tell them what they can expect from a service, (b) give them greater awareness of their rights and responsibilities, (c) give them confidence in the quality of services, and (d) provide them with the opportunity to have a say in the development and review of services. The SOP Report will assist the service providers as they work to (a) improve outcomes for individuals and families who use their services, (b) provide opportunities for their staff to improve their skills, (c) improve use of resources, (d) plan and improve their processes and systems, and (e) satisfy accountability requirements.

The resulting SOP Report will then (a) inform development of a quality rating system (QRS) for programs and providers that participate in Networks and; and (b) provide parents, policymakers, funders, and the public with information about the level of quality of programs and providers

participating Networks. Quality is meeting (and where possible exceeding) the assessed needs and defined expectations of the service user through efficient and effective management and processes. The QRS will be composed of five common elements including (a) standards, (b) accountability measures, (c) program and provider technical assistance, and (d) parent/consumer education efforts. All of the elements will be addressed in the initial planning for a Standards of Practice QRS.

<b>SOP Work Group Leaders</b>	
Diagnostic Clinics	Hanes Swingle, M.D., M.P.H.
Services Birth-5 Years	Tonya Lee, M.Ed.
Services 6-21Years	Abbie Felder, M.Ed.
Transition Services	Jennifer Sellers, Ph.D.
Adult Services	Jade Carter, Ph.D.
Professional Preparation & Training	Doris Hill, PhD.

**Meeting Dates:** March 29, 2010 / June 21, 2010 / September 2, 2010

### **Work Group Guidelines**

#### **General Principles**

1. The purpose of the Standards development is to ensure best practices in all fields and disciplines serving individuals with ASD, related conditions, and their families under a Network.
2. Standards will be used in accordance with evidence-based practice three core components (a) best research evidence, (b) clinical expertise and judgment, and (c) individual values and preferences.
3. Standards will align with standards established by other major professional organizations (e.g., Alabama State Department of Education, American Academy of Pediatrics, Council for Exceptional Children).
4. Standards will be developed with representation from all stakeholders.

5. Standards progress reports will provide (a) sufficient documentation to enable an assessment of the process used in development, (b) literature review with annotation of evidence cited, and (b) credentials of work group contributors to include Autism Spectrum Expert Advisor (A.S.E.A.), Autism Spectrum Family Advisor (A.S.F.A.), and Autism Community Advocate (ACA).
6. Standards include disclaimers and/or discussion of limitations of the recommendations specific to clinical conditions or context.
7. While developed to guide the practice of professionals serving the ASD community, the Standards are hoped to be relevant and helpful to other professionals who provide services to individuals with disabilities.

### **Process**

1. First progress report will be presented at quarterly AIACC meeting (target date October 1, 2010).
2. State Autism Coordinator and the committee chair will present updated progress reports at quarterly AIACC meetings and invite Council recommendations.
3. Draft Standards will undergo extensive review by key constituent groups, acknowledged experts in the topic areas, members of AIACC, and other ASD organizations and stakeholders.
4. Following extensive review and revision, draft standards will be posted on the AIACC website and presented at other forums for comments.
5. State Autism Coordinator and committee chair will incorporate comments into Standards final draft.
6. The final draft Standards will be reviewed by a Standards Consensus Group convened by the AIACC.
7. The Standards Consensus Group will be comprised of (a) AIACC chair and co-chair, (b) State Autism Coordinator, (c) Standards Committee Chair, (d) work group leaders, (e) two additional AIACC members, and five ASD community members (i.e., individuals with ASD and family members).
8. Following the Consensus Group approval, the final draft Standards will be sent for professional editing.
9. Edited draft Standards must then be adopted by the Council. It is anticipated that the Council will only make substantive changes in extraordinary circumstances. Any substantive changes suggested by the Council after professional editing will be submitted to the Standards Consensus Group for consideration. However, final adoption of standards rests with the Council.
10. The target timeline for this entire process should be no more than 12 months (target date October 1, 2011).
11. Adopted Standards will be disseminated widely and made available to all who may be affected by the requirements.
12. Adopted Standards will be updated at a minimum of every 5 years with a process in place to consider addendums between updated versions.

**SOP: Diagnostic Clinic Work Group**

Leader: Hanes Swingle, MD, MPH

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 reviewing 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, which was the case in the audiology evaluation of children suspected of autism, the audiology experts on the panel drew from the clinical experiences and knowledge to make their recommendations.

<b>SOP: Diagnostic Clinic Work Group Members</b>	
Key: Autism Spectrum Expert Advisor (A.S.E.A.) / Autism Spectrum Family Advisor (A.S.F.A.) / Autism Community Advocate (A.C.A.)	
Hanes Swingle, MD, MPH	University of South Alabama Children's and Women's Hospital, Department of Pediatrics
Alice Widgeon, L.B.S.W., MPA	Alabama Department of Mental Health, Early Intervention
Caroline Gomez, Ph.D.	State Autism Coordinator
Stephanie Anderson, MD	University of South Alabama Children's and Women's Hospital, Department of Pediatrics
Kirstin Bailey, Ph.D.	Advocate
Rusty Becker, OTR/L	Excel Rehabilitation, Owner
Debbie Frame, M.A., A.S.F.A.	Cleburne Schools, Psychometry
Bridget Hannahan, Ph.D.	University of South Alabama, Clinical Psychologist
Ingrid Hartman, LPC	AltaPointe, Children's Outpatient Services Coordinator
Tim Holston, Au.D., CCC-A, FAAA	University of South Alabama, Audiology
Amy Mitchell, M.S., CCC-SLP	University of South Alabama, Autism Diagnostic Clinic
Sandra King Parker, MD	AltaPoint Health Systems, Medical Director
Teri Pinto, B.A.	Alabama Department of Mental Health, Early Intervention
Olivia Nettles, L.C.P	AltaPoint Health Systems
Alice Sette, MPA, Au.D.CCC-A/ABA	Alabama Department of Rehabilitation Services Children's Rehabilitation Services
Kathy Welch, M.A., CCC S.L.P.	Easter Seals Central Alabama, Autism Diagnostic Team
Martha Wilder Wilson, Au.D., CCC-A	Auburn University, Audiology
Julie Woodruff, Au.D., CCC-A	Pediatric Audiologist, Civitan-Sparks Clinics

Donna Wooster, M.S., OTR/L, BCP	University of South Alabama, Department of Occupational Therapy
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**Meeting Dates:** April 28, 2010 / June 9, 2010 / July 21, 2010 / September 1, 2010

**Diagnostic Clinic Standards** (to date)

Standard # 1 Interdisciplinary	Check all that Apply		
	Service:	Recipient:	Location:
As part of a comprehensive interdisciplinary diagnostic evaluation, all children referred to a Regional Autism Diagnostic Clinic will receive a thorough medical evaluation.	<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 checked="" type="checkbox"/> School District <input type="checkbox"/> Other / List:	<input type="checkbox"/> Home <input type="checkbox"/> School <input checked="" type="checkbox"/> Community
Check One: <input checked="" type="checkbox"/> Minimum Standard <input type="checkbox"/> Best Practice Standard <input type="checkbox"/> Gold Standard			
Citation(s) for Evidence-base:			
1. CHRISTIAN SL, BRUNE CW, SUDI J, et al. Novel submicroscopic chromosomal abnormalities detected in autism spectrum disorder. Biol Psychiatry 2008;63: 1111-7.			
2. LANDRIGAN PJ. What causes autism? Exploring the environmental contribution. Curr Opin Pediatr; 22:219-25.			
3. ZECAVATI N, SPENCE SJ. Neurometabolic disorders and dysfunction in autism spectrum disorders. Curr Neurol Neurosci Rep 2009;9:129-36.			
4. CAGLAYAN AO. Genetic causes of syndromic and non-syndromic autism. Dev Med Child Neurol; 52:130-8.			
5. JOHNSON CP, MYERS SM. Identification and evaluation of children with autism spectrum disorders. Pediatrics 2007; 120:1183-215.			
6. VOLKMAR F, COOK E, JR., POMEROY J, REALMUTO G, TANGUAY P. Summary of the Practice Parameters for the Assessment and Treatment of Children, Adolescents, and			

Adults with Autism and other Pervasive Developmental Disorders. American Academy of Child and Adolescent Psychiatry. J Am Acad Child Adolesc Psychiatry 1999;38: 1611-6.

7. FILIPEK PA, ACCARDO PJ, ASHWAL S, et al. Practice parameter: screening and diagnosis of autism: report of the Quality Standards Subcommittee of the American Academy of Neurology and the Child Neurology Society. Neurology 2000;55:468-79.
8. Autistic Spectrum Disorders Best Practice Guidelines for Screening, Diagnosis, and Assessment; California Department of Developmental Services, 2002.
9. MILLER DT, ADAM MP, ARADHYA S, et al. Consensus statement: chromosomal microarray is a first-tier clinical diagnostic test for individuals with developmental disabilities or congenital anomalies. Am J Hum Genet;86:749-64.
10. BUIE T, CAMPBELL DB, FUCHS GJ, 3RD, et al. Evaluation, diagnosis, and treatment of gastrointestinal disorders in individuals with ASDs: a consensus report. Pediatrics 2010;125 Suppl 1:S1-18.

### **Introduction**

Autism spectrum disorders (ASD), which in this report comprises the terms *autism*, *autistic disorder*, *Asperger's disorder*, and *pervasive developmental disorder - not otherwise specified*, are a heterogeneous group of behaviorally defined conditions that are neurologically based. Numerous medical, genetic, and metabolic conditions have been associated with the autism spectrum disorders.<sup>1-4</sup> 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.<sup>5-8</sup> 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 (Table). 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. Past and current illnesses, e.g., encephalitis or seizure disorders, medications known to affect central nervous system functioning, and prior hearing and vision screening 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 one, 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.<sup>9</sup> 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.<sup>10</sup>

Routine neuroimaging is not recommended for the diagnostic evaluation of autism, even in the presence of macrocephaly. 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.

<b>Standard # 2 Audiology</b>	Check all that Apply		
	Service:	Recipient:	Location:
All children suspected of having an autism spectrum disorder should have a comprehensive	__x__ Direct	_x_ Individual w/ASD	__ Home
	__ Technical Assist	__ Family	__ School

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).	<input type="checkbox"/> Consultation	<input type="checkbox"/> School District <input type="checkbox"/> Other / List:	<input checked="" type="checkbox"/> Community
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Check One:  Minimum Standard    Best Practice Standard    Gold Standard

Citation(s) for Evidence-base:

1. American Speech-Language-Hearing Association. (2006). Roles and Responsibilities of Speech-Language Pathologists in Diagnosis, Assessment and Treatment of Autism Spectrum Disorders Across the Life Span (Position Statement). Available from [www.asha.org/policy](http://www.asha.org/policy).
2. Prelock, P. (2001) Understanding Autism Spectrum Disorders: The Role of Speech-Language Pathologists and Audiologists in Service Delivery. The ASHA Leader.
3. Davis, R. & Stiegler, L. (2010) Behavioral Hearing Assessment for Children with Autism. The ASHA Leader.
4. Johnson, C.P., Myers, S.M. & the Council on Children With Disabilities (2007). Identification and Evaluation of Children With Autism Spectrum Disorders. Pediatrics, Vol. 120, No. 5, pp. 1-33.
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6. Englehof, K. et al. What Audiologists Need to Know About Autism Spectrum Disorders. *Seminars in Hearing*: 2005; Vol 26, no 4.
7. Rabidoux, P. Early Identification of Autism: Roles of the Speech Language Pathologist and Audiologist on a Transdisciplinary Team. *Seminars in Hearing*: 2005; vol 26, no 4.
8. Downs, D. et al. Auditory Behaviors of Children and Adolescents with Pervasive Developmental Disorders. *Seminars in Hearing*: 2005; vol 26, no 4.
9. Cloppert, P et al. Evaluating an Enigma: What People with Autism Spectrum Disorders and their Parents Would Like Audiologists to Know. *Seminars in Hearing*: 2005; vol 26, no 4.
10. Tharpe, A et al. Auditory Characteristics of Children with Autism. *Ear & Hearing*: 2006.
11. Legler, L. Asperger’s Syndrome: The Role of the Audiologist. *Educational Audiology Review*. 2008; 27-30.

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. Otoloscopic 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 indicated, 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.

<p align="center"><b>Standard # 3 Speech and Language</b></p>	<p align="center">Check all that Apply</p>		
<p>As part of a multidisciplinary team assessment for autism spectrum disorders, a qualified Speech-Language Pathologist (SLP) should provide evaluation of the following aspects of communication:</p> <ul style="list-style-type: none"> <li><input type="radio"/> Language structure(phonology/morphology/syntax/semantics)</li> <li><input type="radio"/> Pragmatics</li> <li><input type="radio"/> Nonverbal communication (gestures, eye gaze etc.)</li> <li><input type="radio"/> Articulation</li> <li><input type="radio"/> Fluency</li> <li><input type="radio"/> Voice</li> <li><input type="radio"/> Oral Motor skills</li> </ul>	<p>Service:</p> <p><input checked="" type="checkbox"/>_x_Direct</p> <p><input type="checkbox"/>_Technical Assist</p> <p><input type="checkbox"/>_Consultation</p>	<p>Recipient:</p> <p><input checked="" type="checkbox"/>_x_Individual w/ASD</p> <p><input type="checkbox"/>_Family</p> <p><input type="checkbox"/>_School District</p> <p><input type="checkbox"/>_Other / List:</p>	<p>Location:</p> <p><input checked="" type="checkbox"/>_x_Home</p> <p><input type="checkbox"/>_x_School</p> <p><input checked="" type="checkbox"/>_x_Community</p>
<p>Check One: <input type="checkbox"/>_Minimum Standard    <input checked="" type="checkbox"/>_Best Practice Standard    <input type="checkbox"/>_Gold Standard</p>			
<p>Citation(s) for Evidence-base:</p> <p>1. American Speech-Language-Hearing Association. (2007). <i>(Scope of practice in speech-language pathology</i>. Available from <a href="http://www.asha.org/policy">http://www.asha.org/policy</a>.</p>			

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. 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](http://www.nidcd.nih.gov/funding/programs/vsl/language_benchmarks.htm).

**Professional preparation and training**

The SLP is considered qualified by the following characteristics:

1. Holds the ASHA Certificate of Clinical Competence in Speech-Language Pathology (CCC SLP)
2. Demonstrates continued professional development in the area of autism spectrum disorders
3. As mandated by ASHA standards, "Each practitioner must evaluate his or her own experiences with pre-service education, clinical practice, mentorship and supervision, and continuing professional development. Speech-language pathologists may engage in only those aspects of the profession that are within their scope of competence." (ASHA 2007).
4. Possesses knowledge of ASD red flags and the appropriate assessment tools to evaluate red flags in the communication domain.

<b>Standard # 4</b> <b>Cognitive and Adaptive Functioning</b>	Check all that Apply		
	<b>Service:</b> <input checked="" type="checkbox"/> Direct <input type="checkbox"/> Technical Assist <input type="checkbox"/> Consultation	<b>Recipient:</b> <input checked="" type="checkbox"/> Individual w/ASD <input type="checkbox"/> Family <input type="checkbox"/> School District <input type="checkbox"/> Other / List:	<b>Location:</b> <input type="checkbox"/> Home <input checked="" type="checkbox"/> School <input checked="" type="checkbox"/> Community
As part of a comprehensive interdisciplinary diagnostic evaluation, all children referred to a Regional Autism Diagnostic Clinic will receive assessments of their cognitive and adaptive functioning. Diagnostic evaluations for autism spectrum disorders will include use of a			

standardized, validated instrument that includes direct observation, such as the Autism Diagnostic Observation Schedule (ADOS).			
Check One: <input checked="" type="checkbox"/> Minimum Standard <input type="checkbox"/> Best Practice Standard <input type="checkbox"/> Gold 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.), <i>Assessment of Autism Spectrum Disorders</i> (pp. 209-252). New York: Guilford.			

<b>Cognitive and Adaptive Measures for Use with Individuals with ASD</b>				
<b>COGNITIVE MEASURES</b>				
Measure	Age range	Standard Score Range	Administration Time (minutes)	Required Level of Verbal Ability
<i>Preschool Age</i>				
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-III (young level)	2 y, 6 m to 3 y, 11 m	45 to 155	25 to 35	V
Mullen	Birth to 5 y, 8 m	49 to 155	15 to 60	V
<i>School Age</i>				
DAS-II (School-Age)	3 y, 6 m to 17 y, 11 m	30 to 170	30	V & NV
WPPSI-III (older level)	4 y, 0 m to 7 y, 3 m	45 to 160	40 to 50	V
WISC-IV	6 y, 0 m to 16 y, 11 m	40 to 160	65 to 80	V
Leiter-R	2 y, 0 m to 20 y, 11 m	30 to 170	25 to 40	NV
<i>Adult</i>				
WAIS-III	16 to 89 y	45 to 155	65 to 95	V
<i>Lifespan</i>				
SB5	2 to 85 y	40 to 160	45 to 75	V & NV
<b>ADAPTIVE MEASURES</b>				
Measure	Age range		Administration Time	Administration Format

Vineland-II	Birth to 90 y		20 to 60	Interview or Checklist
ABAS-II	Birth to 89 y		20	Checklist
SIB-R	Infancy to over 80 y		15 to 60	Interview or Checklist

Note: Bayley-III = Bayley Scales of Infant and Toddler Development – Third Edition; DAS-II = Differential Ability Scales – Second Edition; WPPSI-III = Wechsler Preschool and Primary Scale of Intelligence – Third Edition; Mullen = Mullen Scales of Early Learning; WISC-IV = Wechsler Intelligence Scale for Children – Fourth Edition; Leiter-R = Leiter International Performance Scale Revised; WAIS-III = Wechsler Adult Intelligence Scale – Third Edition; SB5 = Stanford Binet Intelligence Scales – Fifth Edition; WASI = Wechsler Abbreviated Scale of Intelligence; KBIT-2 = Kaufman Brief Intelligence Test – Second Edition; Vineland-II = Vineland Adaptive Behaviors Scales – Second Edition; ABAS-II = Adaptive Behavior Assessment System – Second Edition; SIB-R = Scales of Independent Behavior Revised ; m = months; y = years; NV = Nonverbal; V = Verbal

<b>Standard # 5</b> <b>Fine Motor and Sensory Processing</b>	Check all that Apply		
	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 checked="" type="checkbox"/> School <input checked="" type="checkbox"/> Community
Children diagnosed with autism spectrum disorders will receive occupational therapy evaluations that include assessments of their fine motor skills, sensory processing abilities, play and self care skills. 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.			

Check One:  Minimum Standard  Best Practice Standard  Gold 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 21<sup>st</sup> 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 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

<p align="center"><b>Standard # 6</b> <b>Primary Healthcare Providers</b></p>	Check all that Apply		
	Service:	Recipient:	Location:
<p>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.</p>	<p><input checked="" type="checkbox"/> Direct</p> <p><input checked="" type="checkbox"/> Technical Assist</p> <p><input checked="" type="checkbox"/> Consultation</p>	<p><input checked="" type="checkbox"/> Individual w/ASD</p> <p><input checked="" type="checkbox"/> Family</p> <p><input type="checkbox"/> School District</p> <p><input type="checkbox"/> Other / List:</p>	<p><input checked="" type="checkbox"/> Home</p> <p><input checked="" type="checkbox"/> School</p> <p><input checked="" type="checkbox"/> Community</p>
<p>Check One: <input checked="" type="checkbox"/> Minimum Standard    <input type="checkbox"/> Best Practice Standard    <input type="checkbox"/> Gold Standard</p> <p>Citation(s) for Evidence-base:</p>			

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. *Am Fam 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 ([www.firstwords.fsu.edu/toddlerChecklist.html](http://www.firstwords.fsu.edu/toddlerChecklist.html)).

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](http://www.firstsigns.org/downloads/m-chat.PDF)).

The *ASQ: Social Emotional Questionnaires (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](http://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.

<p align="center"><b>Standard # 7 Care Coordination</b></p>	Check all that Apply		
	Service:	Recipient:	Location:
<p>Agency is able to provide evidence that demonstrates a care coordination/medical 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,</p>	<input checked="" type="checkbox"/> Direct	<input type="checkbox"/> Individual w/ASD	<input type="checkbox"/> Home
	<input type="checkbox"/> Technical Assist	<input type="checkbox"/> Family	<input type="checkbox"/> School
	<input checked="" type="checkbox"/> Consultation	<input type="checkbox"/> School District <input checked="" type="checkbox"/> Other / List: Community Providers	<input checked="" type="checkbox"/> Community

<p>behavioral/emotional, and financial needs. Agency is also able to demonstrate that care coordination efforts are fiscally efficient and outcome oriented.</p>			
<p>Check One: <input type="checkbox"/> Minimum Standard    <input checked="" type="checkbox"/> Best Practice Standard    <input type="checkbox"/> Gold Standard</p> <p>Brief Summary from Findings:</p> <p>Because ASD is a multifactorial condition, optimal care coordination and service processes should be holistic, multifaceted, family-centered and culturally sensitive. Care is patient- and family-centered, assessment-driven, and a community team-based activity. Care coordination, using a centralized medical home model, has been shown to address interrelated medical, social, developmental, behavioral, educational, and financial needs in order to achieve optimal health and wellness outcomes <u>and</u> maximize community and provider utilization and linkages.</p> <p>Care coordination for ASD should focus on the following 2 strategies:</p> <ol style="list-style-type: none"> <li>1. Linking access to a family-centered, centralized, community-based Medical Home system of primary care, integrated with necessary services and service delivery components</li> <li>2. Develop and sustain collaborative care that aligns families, Medical Homes, and various community providers</li> </ol> <p>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.</p> <p>Care Coordination efforts must serve as a bridge between service providers in order to minimize service delays and duplication. Timely referral, integration, and coordination of services lead to more streamlined and efficient service delivery.</p> <p>Care coordination efforts need to offer families both informal and formal resources, including intrafamily, peer to peer, and community supports. 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.</p> <p>Care coordinators need to meet regularly and work collaboratively with families and share information 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. Practices should also be individualized and flexible, in which resources match each family's priorities and values.</p>			

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

- Family education, training and coaching during and after appointments based on service needs/assessment
- Centralized written service care plan that includes the delivery and arrangement of clinically necessary services (i.e. Neurology, Genetics, etc) and possible transportation
- Continuous communications, linkage and monitors usage of community supports and providers through team meetings where health information is shared
- 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
- Referrals for behavior problems to Pediatric Psychology/Counseling
- Consultation regarding possible psychopharmacologic treatment and medication monitoring/compliance
- Access to services through a single point of entry, that also supports/facilitates care transitions within system

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](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 <http://www.waisman.wisc.edu/nmhai/>.
6. National Center for Medical Home Implementation. American Academy of Pediatrics. [www.medicalhomeinfo.org](http://www.medicalhomeinfo.org).

**SOP: Birth to Five Work Group**

Leader: Tonya lee, M.Ed.

<b>SOP: Birth to Five Work Group Members</b>	
Key: Autism Spectrum Expert Advisor (A.S.E.A.) / Autism Spectrum Family Advisor (A.S.F.A.) / Autism Community Advocate (A.C.A.)	
Tonya Lee, M.Ed.	Department of Children's Affairs, Technical Assistant-Special Education
Alice Widgeon, L.B.S.W., MPA	Alabama Department of Mental Health, Early Intervention
Caroline Gomez, Ph.D.	State Autism Coordinator
Brenda Beverly, Ph.D., CCC-SLP	University of South Alabama, Speech Pathology and Audiology
Melissa Bridge, M.S.	Smart Start, Alabama Partnership for Children
Kathy Flack, M.A.	Vaughn-Blumberg Services, Director of Case Management
Heather Hall, Ph.D., NNP, RNC	University of South Alabama College of Nursing, Maternal-Child Department
Kim Hill, M.S.	Assistant Alabama Early Intervention System Coordinator
Cathy Jones, M.S.	Alabama State Department of Education, Preschool Coordinator for Special Education Services
Marjorie Ann Mitchell	Student Intern- Smart Start, Alabama Partnership for Children
Gail Piggott, M.Ed.	Smart Start, Alabama Partnership for Children
Teri Pinto, B.A.	Alabama Department of Mental Health, Early Intervention
Jane Raines, Ed.S.	Director of Early Intervention Programs TriCounty Agency for Intellectual Disabilities
Connie Randall, B.S.	District Early intervention, Coordinator
June Romero, M.Ed.	Acr of Shelby Co., Early Intervention Program Director

Mary Beth Vick, M.A.	Alabama Department of Rehabilitation Services, Community Services Program
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**Meeting Dates:** April 30, 2010 / May 18, 2010 / October 4, 2010

### **State Intervention Providers Include**

#### 1. Alabama's Early Intervention System

The Alabama Department of Rehabilitation Services serves as the Lead Agency for Early Intervention, Part C of the Individuals with Disabilities Education Act (IDEA). Alabama's Early Intervention System (AEIS) serves infants/toddlers, birth to age 3, who have a diagnosed condition that may result in a developmental delay; such as, autism, cerebral palsy, blindness, etc. or who are experiencing a 25% delay or greater in one of the five developmental areas which are, physical (to include vision and hearing); cognitive, communication, social/emotional and adaptive. If a child is eligible for early intervention services then an Individualized Family Service Plan (IFSP) is developed to address the parents' priorities and concerns regarding their child's developmental needs. Services are provided in the natural environment meaning the home, childcare settings or other community locations based on the family's routines.

#### 2. Preschool Services Special Education Services

The State Department of Education, Special Education Services, meets the mandates of The *Individuals with Disabilities Education Act* (IDEA) which requires special education and related services be provided for all eligible children with disabilities, ages three through twenty-one who are in need of specially designed instruction. Preschool services are part of the total special education program offered through Local Education Agencies (LEAs) to eligible children ages three through five.

Alabama's Preschool Special Education Services are designed to meet the unique needs of young children with disabilities ages three through five. Special education and related services are available to eligible children on their third birthday. Services should be provided in the child's least restrictive environment, and include a full range of possible service delivery options available to meet the child's needs. Services may be provided in school-based early childhood programs, child care centers, home, church, Head Start, Moms Day Out, Pre-K or other programs offered through the community.

A free appropriate public education (FAPE) must be provided to all eligible children. Special education and related services are provided at no cost to the family if the child receives these services as part of his/her specially designed instruction. Preschool children are eligible to receive services on their third birthday if they meet the eligibility requirements as defined in the *Alabama Administrative Code (AAC)* for any of the thirteen areas of disability. The areas of disability include: Autism, Deaf-Blindness, Developmental Delay, Emotional Disturbance, Hearing Impairment, Mental Retardation, Multiple Disabilities, Orthopedic Impairment, Other Health Impairment, Specific Learning Disabilities, Speech and Language Impairment, Traumatic Brain Injury, and Visual Impairment.

**Assumptions:**

The process of developing SOP for children with ASD from birth to five years, will move forward based on the following tentative assumptions.

1. Alabama's Early Intervention System (AEIS) meets Part C requirements of the Individuals with Disabilities Education Act (IDEA) in serving all eligible infants and toddlers, birth to age 3; and
2. Alabama's State Department of Education (ASDE), Preschool Special Education Services, meets Part B requirements of the Individuals with Disabilities Education Act (IDEA) in serving all eligible children, ages three through five years; therefore
3. AEIS and ASDE do not require further consideration as to Standards of Practice.
4. The current requirements and practices of AEIS and ASDE should be referenced in determining Standards of Practice for private providers serving children with ASD from birth through 5 years of age.
5. Standards of Practice levels should be defined to acknowledge private providers who strive to distinguish themselves. For example,
  - Level 1: Meets Minimum Standards
  - Level 2: Meets Best Practice Standards
  - Level 3: Meets Exemplary/Gold Standards (reserved for very specific distinction [e.g., National Teacher Certification]).
6. AEIS and ASDE may decide at a later date to participate in Standards of Practice Levels based on the same or different criteria.

**Private Provider Qualifications**

Due to the nature of autism spectrum disorders, children with autism often display deficits in several areas of development. For this reason, children with autism spectrum disorders (infant/toddler to preschool age) may encounter providers from various disciplines. Providers involved in treatment of the child with autism may include the following: teachers, doctors, nurses, early interventionists, occupational therapists, speech-language pathologists, physical therapists, audiologists, behavior analysts, psychologists, and counselors. Professional qualifications vary, but families seeking services can consider the provider's credentials and information sources to determine if the provider meets expectations. Beyond exhibiting appropriate training and credentials in their disciplines, providers serving children with autism spectrum disorders need skills for treating developmental disabilities, particularly autism. Thus, children with autism and their families can benefit from access to providers who have additional training preparing them to deal with autism.

Potential Providers	Credentials	Information Sources	Types of Services Provided
Teachers	Certified Teacher Special Education II Teacher	<a href="http://www.alsde.edu">www.alsde.edu</a> Alabama Department of Education <a href="http://www.alabamapepe.com">www.alabamapepe.com</a> Alabama Professional Education Personnel Evaluation Program	Classroom-based Individualized Education in the regular classroom Small-group Instruction within or outside of the regular classroom Individualized Education in special setting – special education classroom, program, building
Doctors: Pediatricians, Neurologists, Other specialties (e.g., gastro-intestinal, geneticist, ENT, etc.)	State License as Physician	<a href="http://www.albme.org/">http://www.albme.org/</a> Alabama State Board of Medical Examiners Medical Licensure Commission <a href="http://www.masalink.org">www.masalink.org</a> Medical Association of the State of Alabama	Healthcare provision for medical concerns and developmental delay
Nurses	State Licensure as Registered Nurse or Advanced Practice Nurse	<a href="http://www.abn.state.al.us/">www.abn.state.al.us/</a> Alabama State Board of Nursing	Comprehensive and Focused Assessments Counseling and Educating Family Health Promotion of the Child and Family Consulting with and referring to other healthcare

			providers
Early Interventionists			
Occupational Therapists	Other educational or certification needed? State licensure What about OTA?	<a href="http://www.aota.org">www.aota.org</a> American Occupational Therapy Association <a href="http://www.asbot.org">www.asbot.org</a> Alabama State Board of Occupational Therapy	Fine and Gross Motor Skills Treatment Sensory Integration Treatment Self-Help Treatment Feeding/swallowing treatment
Speech-Language Pathologists	Certificate of Clinical Competence (CCC-SLP) and State licensure	<a href="http://www.asha.org">www.asha.org</a> American Speech-Language-Hearing Association <a href="http://www.abespa.org">www.abespa.org</a> Alabama Board of Examiners in Speech Pathology and Audiology	Speech-language therapy Social communication intervention Feeding/swallowing treatment
Physical Therapists	State licensure What about other certification? Degree? PTAides?	<a href="http://www.apta.org">www.apta.org</a> American Physical Therapy Association <a href="http://www.pt.alabama.gov/">http://www.pt.alabama.gov/</a> State of Alabama Board of Physical Therapy	Fine and Gross Motor skills treatment Treatment for muscle strength and coordination
Audiologists	Certificate of Clinical Competence (CCC-A) and State licensure	<a href="http://www.asha.org">www.asha.org</a> American Speech-Language-Hearing Association <a href="http://www.abespa.org">www.abespa.org</a> Alabama Board of Examiners in Speech Pathology and Audiology	Aural rehabilitation, including treatment for auditory processing disorders

Behavior Analysts	<p><u>2 levels:</u></p> <ul style="list-style-type: none"> <li>• Board Certified Behavior Analysts (BCBA)</li> <li>• Board Certified Assistant Behavior Analyst (BCBA)</li> </ul>	<p><a href="http://www.bacb.com">www.bacb.com</a> Behavior Analyst Certification Board</p>	<p>Functional Behavior Assessment Functional Communication Training Applied Behavioral Analysis Treatment</p>
Psychologists	<p>School Psychologist Certified Psychometrist</p>	<p><a href="http://psychology.state.al.us">http://psychology.state.al.us</a> Alabama Board of Examiners in Psychology</p>	<p>Individual therapy Play, art and other creative therapies Family therapy</p>
Counselors	<p>Licensed Professional Counselor Associate Licensed Counselor School Guidance Counselor</p>	<p><a href="http://www.abec.alabama.gov">www.abec.alabama.gov</a> Alabama Board of Examiners in Counseling</p>	<p>Individual and family counseling</p>

A number of other State agencies/organizations (listed below) will be considered for the role that they may have in providing related services.

**State Agencies**

Alabama Institute For the Deaf and Blind (AIDB)  
 Early Intervention Services  
 AIDB-HEAR Center at Children's Health Center  
 Head Start  
 Pre-K Programs  
 Alabama Department of Public Health  
 Screening Services  
 Alabama Department of Rehabilitation Services  
 Children's Rehabilitation Services  
 Alabama Department of Mental Health

Regional Centers  
 Pre-Kinder (3-5 years)  
 Alabama Department of Children's Services  
 Early Head Start  
 Home Visiting Programs  
 Medicaid Care Coordinators  
 Alabama Medicaid Agency  
 Early Intervention Programs  
 Statewide Technology Access and Response (STAR) Assistive Technology  
 Office of Children's Services: Early Intervention Programs

## 310 Boards

Intellectual Disabilities: Comprehensive support service team  
 Alabama Department of Human Resources  
 University Centers for Excellence in Developmental Disabilities  
 Alabama Council on Developmental Disabilities

Office of Deaf Services

Office of Waiver Services and Case Management  
 Licensed Daycares: Exempt and Non-exempt  
 Alabama Disabilities Advocacy Program (ADAP)  
 Autism Society of Alabama

**Other Agencies:**

Alabama Parents and Teacher's Associations  
 Alabama's Parenting Assistance Line (PAL)  
 Arcs of Alabama  
 Easter Seals Rehabilitation Centers  
 Learning Disabilities Association of Alabama  
 United Cerebral Palsy Early Intervention Programs  
 HIPPPY (Home Instruction for Parents of Preschool Youngsters) □ Springboard Education Foundation □

Alabama State Board of Occupational Therapy  
 Alabama Board of Examiners in Psychology  
 Board of Physical Therapy  
 Family Voices of Alabama  
 N.A.M.I.  
 Alabama Lifespan Respite Resource Network

**Standards Directions:**

1. Assessment
2. Evidence-based intervention
3. Child-focused practices
4. Family-based practices
5. Inclusion
6. Inter-disciplinary models
7. Technology applications
8. Data Collection
9. Transition

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**SOP: Six to Twenty-one Work Group**

Leader: Abbie Felder, M.Ed

<p><b>SOP: Six to Twenty-one Work Group Members</b></p> <p>Key: Autism Spectrum Expert Advisor (A.S.E.A.) / Autism Spectrum Family Advisor (A.S.F.A.) / Autism Community Advocate (A.C.A.)</p>	
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**Meeting Dates:** May 5, 2010 / June 28, 2010 / August 16, 2010

<b>Standard # 1</b>
Thorough diagnostic, developmental and educational assessments using a comprehensive multidisciplinary approach by a multidisciplinary team familiar with the

characteristics of autism are used to identify and plan based on individual strengths and needs.

- a. Evaluations use a variety of measures and sources of information, including:
  - 1) Appropriate standardized, developmental, and observational methods.
  - 2) Autism-specific measures.
  - 3) Parent and family input.
  - 4) Review of recent progress and functional level.
- b. Speech and language evaluations use standardized measures, parental report, observation, and spontaneous language samples to assess:
  - 1) Receptive language.
  - 2) Expressive language.
  - 3) Speech production.
  - 4) Communicative intent.
  - 5) Pragmatics.
- c. Evaluations include the examination of the individual skills and strengths of students with autism, as well as their needs.
- d. Evaluation reports integrate results from all areas in ways that lead directly to programmatic recommendations for instruction.

#### **Standard # 2**

IEP/Treatment Plan addresses a broad range of developmental and educational needs, including:

- a. Communication.
- b. Social Interaction.
- c. Behavior and emotional development.
- d. Play and use of leisure time.

#### **Standard # 3**

Development of the individualized education program (IEP)/treatment program utilize evaluation results; language/communication, observation, parents and family concerns, and rating scales.

**Standard # 4**

IEP/treatment plan includes: present levels of performance (PLP), measurable goals, assessment status, nonparticipation with nondisabled students and needed services amount and frequency.

- a. Goals directly related to the PLP.
- b. Are observable and measurable.
- c. Reflect parental input and family concerns.

**Standard # 5**

IEP/Treatment plan identifies specific students needs:

- a. Modifications (instructional and environmental).
- b. Transition.
- c. Opportunities for interaction with nondisabled peers.
- d. Augmentative and alternative communication systems.

**Standard # 6**

Evidenced based Instructional practices/treatments/methodologies are used in program.

- a. Instructional programs methods have documented effectiveness and reflect empirically validated practices.
- b. Promotes maximum engagement in appropriate activities/settings.
- c. Promotes high rates of successful performance.
- d. Encourage communication and social interaction.

<b>Standard # 7</b>
<p>Practices with limited efficacy/professional judgment may be used in conjunction with evidence –based practices when:</p> <ul style="list-style-type: none"> <li>a. Information about a specific student's history is unique and specific.</li> <li>b. Need to make data-based intervention decisions.</li> <li>c. Values and preferences of family members.</li> </ul>

**SOP: Transition Services**  
 Leader: Jennifer Sellers, Ph.D.

Research has shown that a large proportion of special education students often do not receive post-school support and services (NLTS-2). As these individuals "aged out" (at age 21 students were no longer eligible for a free and appropriate education including services and support) of the educational system, families and individuals with disabilities found themselves with few options and with little guidance. While there are services, families and individuals are forced to discover services and supports on their own. They are confronted with services and resources, each with individual, services, funding sources, forms, and eligibility requirements. In order to assist families and individuals with disabilities in obtaining successful transitions, a collaborative system and or process between school systems and post-secondary life must be created.

<b>SOP: Transition Services Work Group Members</b>	
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Caroline Gomez, Ph.D.	State Autism Coordinator

Judy Barclay, A.C.A.	Full Life Ahead Foundation, President Emeritus and Founder
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**Meeting Dates:** April 22, 2010 / June 29, 2010 / August 11, 2010 / September 22, 2010

The Transition Work Group Committee has extensively researched the transitional process by reviewing literature, research and examining what other states are doing in terms of transition. There are five common elements found in the research, literature, and in programs that assists individuals with disabilities in having successful outcomes in terms of transitioning into life after high school (Kohler, 1996). The five common elements are

- Student Focused Planning
- Student Development
- Family Involvement
- Interagency Collaboration
- Program Structure

### **Status of Transition Services in Alabama**

#### **Educational Services**

Transition planning can provide a framework to assist individuals with disabilities and their families in organizing and ensuring the support necessary to work through the transition process and provide guidance about the resources and/ or support that they will need to be successful in reaching their goals. The federal government mandates that the transitional planning and educational goals addressing transitional needs begin by the age of 16.

Currently in Alabama, there are no standards to guide the transitional process in terms of a person's Individual Educational Program (IEP). However, the Alabama State Department of Education is in the process of developing these standards.

### **Vocational Services**

In terms of receiving services from the Alabama Department of Rehabilitative Services (ADRS), it must be understood that services are not mandated by the federal government. This means that a person who applies for ADRS services has to be deemed eligible for services. Rehabilitation counselors and/ or job coaches are part of the transitional process; however, there is no systematic referral procedure throughout the state. The logistics of the referral process are determined at the local level (i.e. individual school systems and counselors).

### **Post Secondary Education**

Individual Schools have specific needs in order to gain entrance. High School Case Managers, School Counselors, Families, and the Individuals' with disabilities must begin discussing college as early as 10<sup>th</sup> grade in order to meet the enrollment criterion.

### **Economic Support for Transition**

In terms of economic support for individuals with disabilities, people typically have two choices. Either they are supported by private or public (e.g. Medicaid Waiver) means. The Department of Mental Health/ Mental Illness (DMHMI) has specific guidelines in terms of when a person can apply for the Waiver. This process begins on an individual's 18<sup>th</sup> birthday. Because of DMHMI's limited funds and the growing need for support, the entire process can take 3-5 years. Therefore, it is crucial for individuals with disabilities to begin the process on or near their 18<sup>th</sup> birthday.

### **Recommendations for the Future**

Because all of the key agencies that are involved in the Transition process (i.e., Alabama Department of Education, ADRS, and DMHMI) have specific guidelines and/or standards, the committee is recommending that the creation of a time-line be introduced to all agencies; thereby not changing their individual standards but streamlining the process in order to create greater collaboration between all agencies.

Because both the Department of Education and ADRS are in the process of creating new standards the proposed time-lines are tentative suggestions contingent to change with any changes in the Departmental Standards.

**Sample of Briefs Reviewed** (National Center on Secondary Education and Transition):

1. Person-Centered Planning: A Tool for Transition (February 2004)

NCSET Parent Brief

This brief provides a concise description of person-centered planning and an explanation of the benefits of this process. The brief also provides action steps for implementing person-centered planning, references within the Individuals with Disabilities Education Act that support the process, and a list of additional resources.

2. Self-Determination: Supporting Successful Transition (April 2003)

NCSET Research to Practice Brief • Volume 2 , Issue 1

This brief outlines research on self-determination suggesting that youth with disabilities who actively direct their own lives are more likely to successfully transition into adult life. In addition, the brief addresses development of self-determination skills and student-led Individualized Education Program meetings. Also included are descriptions and contact information for several self-determination curricula and helpful Web links.

3. Quality Work-Based Learning and Postschool Employment Success (September 2003)

NCSET Issue Brief • Volume 2 , Issue 2

This brief highlights the benefits of work-based learning for youth with disabilities and outlines the elements of quality work-based learning. In addition, the brief provides selected evidence-based models of work-based learning and information on further resources.

4. Youth Employment (December 2003)

NCSET NLTS2 Data Brief • Volume 2 , Issue 2

This NLTS2 Data Brief provides a detailed description of employment trends for youth with disabilities documented within the National Longitudinal Study-2. The NLTS2 has recently gathered data on work-study employment and regular paid employment of youth with disabilities, with a focus on hourly pay, disability categories, demographic differences in employment, and individual differences such as

gender, age, race/ethnicity, and household income in relation to employment. This brief provides a concise and organized presentation of the results, including descriptive graphs.

5. National Standards & Quality Indicators: Transition Toolkit for Systems Improvement

This document, from the National Alliance for Secondary Education and Transition (NASSET), contains information and tools to provide a common and shared framework to help school systems and communities identify what youth need in order to achieve successful participation in postsecondary education and training, civic engagement, meaningful employment, and adult life.

6. IDEA 1997: Implications for Secondary Education and Transition Services

NCSET Policy Update • Volume 1 , Issue 1

This revision of the National Transition Policy Update from January 2000 presents the regulatory language and potential implications in eleven areas of the 1997 Amendments to the IDEA pertaining to the transition of students from school to adult life. This brief is a great resource for parents, teachers, administrators, and community service providers.

### Suggested Time Lines

#### Standard Diploma and pursuing Post Secondary Education

##### Age Sixteen

1. Assessments for Transitional Needs Prior to Setting Educational Transition Goals
2. Transitional Goals during IEP
3. Career Exploration (can begin at earlier ages as individuals go into the community)
4. Investigate and Plan to meet the criterion for desired school

##### Age Eighteen

Apply for Medicaid Waiver if eligible (initial contact to local mental health board should occur at approximately age 17)

#### AOD or Certificate of Attendance and pursuing Employment

#### Age Sixteen

1. Assessments for Transitional Needs Prior to Setting Educational Transition Goals,
2. Transitional Goals during IEP
3. Vocational/ Career Exploration (can begin at earlier ages as individuals go into the community)
4. Vocational Experiences and Documentation of Experiences (i.e. create a portfolio of work experiences in order for ADRS and other adult agencies to have examples of work experiences)

#### Age Eighteen

Apply for Medicaid Waiver if eligible (initial contact to local mental health board should occur at approximately age 17)

#### **Collaboration**

Collaboration between School System and ADRS (age/ grade) will be dependent on State Standards. Most adult agencies will not begin working with individuals with significant disabilities prior to their aging out of school (i.e. at age 21). Therefore, for some individuals a non-traditional method of providing educational services should be considered. A good example of this would be for students to receive employment/vocational training and/ or experiences in the community and a focus on daily living and functional skills. This type of education can be obtained for individuals who have received a Certificate of Attendance after the typical four years of secondary education and who are still under the age of 21.

#### **Suggested Trainings for Secondary Educators**

- Basic ASD training
- How to provide vocational training, exploration and how to document the experiences
- The need for collaboration to Adult agencies and the processes

#### **Suggested Training for Adult Agencies**

- Basic ASD training
- Accommodations and Modifications for the job site

#### **Suggested Assistance to Post-Secondary –School**

- Provide Basic information about ASD

- Provide self-determination skills to individuals with AS

**SOP: Adult Services**

Leader: Jade Carter, Ph.D.

The Adult Services Work Area Group considered services for all adults with ASD whether they function in the mild, moderate or severe range of disability. We considered all adults from secondary school exit to end of life. The scope of adult issues and needs encompassed so many areas that the group chose to focus on more defined strands of adult independence. Standards reflect a broad view of these areas rather than an exhaustive review of all related items, issues or concerns.

<p align="center"><b>SOP: Adult Services Work Group Members</b></p> <p align="center">Key: Autism Spectrum Expert Advisor (A.S.E.A.) / Autism Spectrum Family Advisor (A.S.F.A.) / Autism Community Advocate (A.C.A.)</p>	
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**Meeting Dates:** April 20, 2010 / May 25, 2010 / August 3, 2010 / September 20

The Adult Services Work Group reviewed and followed closely the recommendations of the AIACC Task Force Report. Members of this committee felt it was important to explore issues, services and life options for adults with ASD in our state. It quickly became evident that once an individual with ASD left the secondary school umbrella of services, the individuals, their families and service providers experienced a discontinuity of care. Services were not coordinated by any single agency, participation criteria varied significantly from agency to agency and provider to provider, eligibility required redundancy of information, paperwork and process, services were not accessible for all clients in all areas of our state, therapeutic supports were not available with any consistency, and as caretakers aged and faced personal issues, transfer to new caretakers was difficult and overwhelming.

Members believed that the surveys we completed would give us a reference from which to explore task force concerns. The committee created and completed two survey instruments to use with our consumers: adults with ASD, parents and family members of adults with ASD, service providers and others. Attached to this report are copies the summaries of these surveys. Once members had an understanding of some of the universal issues and concerns, we divided into areas of responsibility, again compatible with AIACC Task Force recommendations and developed the recommended standards. Not all areas were completed due to time constraints and the scope of the task.

**Professional Organizations** that are compatible with our work area are: CEC- DCDT, DADD, NAPSEC,- NCASES, CARF, ASDE, ASA, NASDDDDS, ACDD

**Documents Reviewed:**

- 2007-2008 Alabama Autism Task force Report,
- Council of State Governments, A survey of State Disability Policy, 2010
- Easter Seals' Living with Autism
- Life Journey through Autism: A guide to Transition for Adulthood
- Focus on Autism and Other developmental Disabilities, volume 25 number 3 September 2010
- Adolescents and Adults wit Autism- Behavior Analytic Interventions to Improve Quality of Life

- Employment Development and Support for Adolescents and Adults with Autism
- Transition to Adult Health Care for Adolescents and Young Adults with Chronic Conditions- Position Paper of the Society for Adolescent Medicine
- P.R.Ofiler: products, resources, opportunities, personal portfolio and filing system, Institute on Community Integration, UAP The College of Education and Human Development, University of Minnesota
- [www.medicalhomeportal.org/living-with-child/transition-issues](http://www.medicalhomeportal.org/living-with-child/transition-issues)
- Transition to Adult Health Care: A Training Guide in Two Parts, Waisman Center, University of Wisconsin-Madison, University Center for Excellence in Developmental Disabilities.

### **Recommendations to date**

Standards are not all included in the requested format. The next step for this area will be to complete the remaining areas for review and identify other requested information. Continued work group efforts are needed to format proposed standards, to address the remaining areas addressed in the Task Force Report: training, transportation and community inclusion. These additional areas may but do not necessarily include individual health needs. Because areas of need cross agency and service boundaries, it may be necessary to convene a professional group to address some of these issues and needs. Agency requirements as mandated by federal and state legislation drive many service opportunities for adults. Additionally, service providers are not typically required to meet any single standards of practice if the agency is outside of the structure of local, state or federal regulation. This inconsistency makes it virtually impossible for families to easily access and mobilize resources. As caretakers age, there is a pressing and necessary need to identify and form new care teams to ensure continued care and support for adults with ASD.

### **Values and Principals**

The following Values and Principals are recommended for this all adult work area standards (adapted from The Alabama Council for Developmental Disabilities' Principles Statement) -

- I. People with ASD are lifelong learners and are capable of growing in independence, productivity, integration and inclusion within the community.

- II. Individuals with ASD must have access to opportunities and the necessary supports to be included in community life; to develop and maintain interdependent relationships; to live in homes and communities; and to make contributions to their families, community, state, and nation.
- III. With education and support, communities can be responsive to the needs of individuals with ASD and their families and are enriched by the full and active participation and contributions of the individual with ASD and their families.
- IV. Individuals with ASD and their families are the primary decision makers regarding the services and supports received.
- V. Services, supports, and other assistance are provided in a manner that demonstrates respect for individual dignity, personal preference, and cultural differences.

### **Socialization Standards**

- I. Programs and services recognize the importance of the individual's social relatedness and the need for social interactions in a variety of settings.
- II. Programs and services use specialized social skills strategies to assess, teach, and promote social skills and to foster the individual's social interests and interactions.
- III. Programs and services use specialized social skills strategies to assess, teach, and promote social skills in a variety of settings including natural environments, general education and community settings.

### **Proposed Standards for Housing**

(Taken from the National Association of Residential Providers for Adults with Autism (NARPAA) Standards)

### **Funding and Services**

Funding for adult services is individualized and commensurate with the needs of the person. Service providers have specialized training and recognize that adults with autism are lifelong learners.

**Individual Rights and Responsibilities**

Adults with autism are offered choices that are meaningful and clear. Service providers teach and support creative, individualized choice-making.

**Individualized Service Planning**

Service providers facilitate a variety of opportunities and experience for the adult with autism, enabling the person to make informed choices in the development of their service/support plan.

**Community Access and Support**

Service providers teach and support community living skills in the areas of mobility and safety.

Services providers accompany the adult with autism, as needed, to assure safe access to all areas of the community.

**Residential Options**

Residential options are tailored to the individual's choices and to the unique communication, behavioral, socialization, and sensory needs of the person. The adult with autism may require a 1:1 ratio to promote safety and an opportunity for personal development.

**Employment**

Services providers will understand the unique learning style of the adult with autism and will develop individualized vocational plans.

The service provider will work with community employers to develop job accommodations for the adult with autism.

**Proposed Standards for Housing:**

(Taken from the Autism Society of America Position Paper – May 2007)

Residential services should consist of in-home support. Depending on need, services would include training or assisting individuals in self-help skills or household tasks; accompanying individuals and training during community activities; respite for families, in-home or out-of-home; and companion attendants for those who do not need intensive care but need a support person for some part of their lives.

Out-of-home placement, 24-hour care services, should be in the least restrictive settings which are feasible for normal community life. This could include group homes of four or less with adequate number of staff who are well-trained, supervised, monitored and supported; apartments, or condos, with support staff as needed, including appropriate monitoring and support of staff by well-trained, experienced supervisors; and access to home financing for individuals (or their families) who choose to live in their own home.

**Case Manager Standards**

1. The Case Manager is a supportive, qualified and motivated professional.
2. The Case Manager has minimally 30 hours training and/or documentation of experience with individuals with ASD.
3. The Case Manager identifies and assesses client: strengths; interests; dreams; communication preferences; accomplishments and target behaviors.
4. The Case Manager assesses existing and available supports necessary to accomplish client goals and dreams.
5. When necessary, the Case Manager creates and develops new resources, supports, collaborations and opportunities to accomplish client dreams.
6. The Case Manager considers family and client needs and resources in maximizing resources for each client.
7. The Case Manager reviews all relevant information related to client behavior and collaborates to identify optimal functional environments.
8. The Case Manager collaborates to develop and implement family and client life style plans.

9. Case Management is results oriented.
10. Individuals with ASD and/or family members have a clear assessment process to offer freedom of choice of a Case Manager.
11. Case Management is available for all individuals with ASD.
12. Individuals with ASD are connected to natural support networks.
13. Case Managers protect individuals with ASD from abuse and neglect.
14. Case Managers are client and family advocates.
15. Case Managers are accountable for client progress and programs and are required to collect and offer appropriate documentation to individuals with ASD and their families.
16. The Case Manager is free from conflict of interest with any independent group or agency.
17. Individuals with ASD are offered life choices consonant with their likes, dislikes, health, safety and personal needs.

**Standards for adult day programs for adults with autism.**

1. Staff has adequate training specific for people with ASD. (Characteristics, behavior management, etc)
2. Ongoing staff development. Required to attend at least one continuing education program per year. This could take place at the center.
3. Everyone working with clients required to have background check
4. Competitive pay for staff to insure quality applicants
5. Clients are involved in realistic job training; on or off site
6. Clients have clearly defined structure daily with written or picture schedules
7. Each client (or family member) has entry meeting with day hab personel to establish clearly defined goals for progress that are realistically measurable (not like IEP goals). These should be placed in client's record with a plan for meeting goals. Meetings should take place at set times during the year to evaluate, update or change these goals.
8. Some form of communication with client and/or caregiver at least weekly to report progress, problems or just an assessment of how the week has been.
9. Clients have regular (at least weekly) access to community outings; restaurants, entertainment, shopping, parks, ballgames.
10. Random observation checks for staff to insure clients are being treated kindly
11. Center has clearly written guidelines for client or family member to address concerns
12. Client's individual preferences/needs are respected when planning his program. (Not a one size fits all approach)

- 13. Centralized resource information access for families so they will know what programs are available in their area
- 14. Above would also include funding sources and how to apply for them (in EASY TO UNDERSTAND LANGUAGE)
- 15. Adequate transportation to site of day program

**Employment Standards**

<b>Standard # 1</b>
<p>Transition services should begin early in middle school, for all young adults with Autism Spectrum Disorders (ASD) and should include unpaid school-based experiences for younger students or paid community-based experiences for older students. Ultimately, goals in the transition plan would include:</p> <ul style="list-style-type: none"> <li>• Taking part in "real life" vocational activities in the community through "job sampling" at actual places of employment. (i.e., volunteering, trying out a job for several hours or days, and summer jobs.)</li> <li>• Having the opportunity to express what his or her work preferences might be.</li> <li>• Providing sufficient opportunities to develop basic competencies in independent life skills, self-monitoring, and travel training outside the classroom.</li> <li>• Developing effective disclosure strategies relative to the person's abilities and needs.</li> <li>• Identifying critical skill deficits that may impede the transition to postsecondary education or work; and provide individualized instruction to minimize the deficits.</li> <li>• If appropriate, learn the basics of the interview process and practice being interviewed.</li> <li>• Learning more about school-to-work programs in the community, which offer opportunities for training and employment through job sampling, youth apprenticeships, cooperative education, tech-prep, and internships.</li> </ul>
<p>Check One: <input type="checkbox"/> Minimum Standard <input type="checkbox"/> Best Practice Standard <input checked="" type="checkbox"/> Gold Standard</p> <p>Citation(s): See Employment Standard Resource Appendix</p>
<b>Standard # 2</b>
<p>Beginning in the 10<sup>th</sup> grade of high school, each individual with autism will undergo a complete vocational evaluation/career planning assessment that will be a part of the IEP goals. One of three post- secondary pathways will be chosen by the individual and transition team by linking the students' courses, academic abilities, and postsecondary education plans with their career goals.</p> <p>The three pathways are:</p>

1. Employment Development/Community Employment -career opportunities that typically require on-the-job training or completion of a specialized course.
2. Vocational/Technical Training-career opportunities that typically require completion of a two-year or under community college associate degree, completion of a certification program, or an apprenticeship.
3. Professional -career opportunities that typically require completion of a four-year university bachelor's degree or graduate degree program.

Check One:  Minimum Standard  Best Practice Standard  Gold Standard

Citation(s): See Employment Standard Resource Appendix

### Standard # 3

A training module to increase the proficiency in, but not limited to, the following social and communication competences will be designed and implemented by the lead agency in collaboration with other state agencies and education organizations for young adult's with autism leaving high school or college and adults in the community seeking employment in a competitive work place.

Social Skills:

- Age- and job-appropriate clothing and footwear
- General cleanliness and good hygiene
- Grooming of hair, teeth, and nails
- Interpersonal greetings ranging from someone saying "Hello" to shaking hands and initiating an introduction
- Issues related to sexual orientation
- Table manners, particularly if one wants to be socially included with colleagues during lunch
- Awareness of others' personal space across all work environments
- Understanding private behavior as being different from public behavior
- Tolerance of unusual sounds, actions, behavior of others, and changes in schedule of activities
- Social rules regarding the appropriate touching of others
- What to do on your break
- What to talk about and what not to talk about at work
- Awareness of time requirements/constraints for task completions

<p>Communication Skills</p> <ul style="list-style-type: none"> <li>_ Expressing preferences or likes</li> <li>_ Ordering their own lunch within budgetary requirements</li> <li>_ Excusing oneself to use the restroom and time awareness of restroom break</li> <li>_ When, and with whom, it might be appropriate to start a conversation</li> <li>_ Listening skills</li> <li>_ Level of response to others</li> <li>_ Eye contact during regular interaction</li> <li>_ Voice volume, tone, and tempo</li> <li>_ General manners, including responding to greetings, not interrupting others, etc.</li> <li>_ Recognizing when assistance is needed and appropriately obtaining same</li> <li>_ Understanding abstract thought. (not being overly literal)</li> </ul>
<p>Check One: <input type="checkbox"/> Minimum Standard <input checked="" type="checkbox"/> Best Practice Standard <input type="checkbox"/> Gold Standard</p> <p>Citation(s): See Employment Standard Resource Appendix</p>

<p><b>Standard # 4</b></p>
<p>Individuals with Autism Spectrum Disorders will be able to procure competitive full-time or part-time employment in a fully integrated work force with natural supports and natural consequences, market wages, benefits and responsibilities without the assistance of a job coach.</p>
<p>Check One: <input type="checkbox"/> Minimum Standard <input type="checkbox"/> Best Practice Standard <input checked="" type="checkbox"/> Gold Standard</p> <p>Citation(s): See Employment Standard Resource Appendix</p>
<p><b>Standard # 5</b></p>
<p>Individuals with Autism Spectrum Disorders work in competitive jobs or competitive "carved out" jobs alongside a job coach/developer and receive ongoing support services as long as the person holds the job. Job carving is defined as the process of recognizing the complexity of jobs and "carving" out tasks by removing or avoiding tasks a person cannot do well and creating supports and environments where an individual with Autism Spectrum Disorders (ASDs) can maximize their performance thereby, making employment a reality.</p>

The amount of job coach/developer supervision may be faded over time as the person becomes able to do the job more independently. The work setting must provide frequent social integration with non-disabled co-workers who are not paid caregivers.

Supported employment may be offered in the following models:

- Supported individual jobs: Adults with autism are matched and begin jobs with no prior training alongside of a job coach who starts and fades as needed.
- Enclave/Work Stations in Industry-rehabilitation agency offers support and supervision to a group placed together.
- "Entrepreneurial supports"- defined as typed of supported employment business that is created around the skills and interests of a very limited number of individuals. For example, adults who like to destroy things could go to different offices and shred documents. Contracts with a number of offices could constitute full time or part time employment.
- Mobile Work Crews focuses on grounds and maintenance contracts. Usually small crews with one supervisor.
- Entrepreneurial ventures: establishes a business employing both disabled & non-disabled workers.

Check One:  Minimum Standard  Best Practice Standard  Gold Standard

Citation(s): See Employment Standard Resource Appendix

**Standard # 6**

Establish regional pre-vocational employment development training programs for autistic individuals who are severely impaired. When an individual reaches job readiness the individual's case manager will make recommendations for college mentoring or supported/community employment. "Work" in such programs should promote the development of an individual's personal, social, educational, and prevocational functioning to the fullest extent of their abilities and should use reinforcements that are of special interest to the person. At a minimum, the staff-to-worker ratio will be 1:15 to maximize learning of basic daily living skills and behavioral controls. This type of community-based program is generally supported by a combination of Federal and/or state funds.

Check One:  Minimum Standard  Best Practice Standard  Gold Standard

Citation(s): See Employment Standard Resource Appendix

**Standard # 7**

State agencies, autism organizations and families will advocate strongly that most individuals with ASDs can work in an integrated setting if the proper support, training, and attention are given to matching job characteristics to the individual's talents and interests.

Check One:  Minimum Standard  Best Practice Standard  Gold Standard

Citation(s): See Employment Standard Resource Appendix

**Standard # 8**

Persons with Autism Spectrum Disorders will actively participate in decisions about quality of life, services and supports as it relates to employment.

Check One:  Minimum Standard  Best Practice Standard  Gold Standard

Citation(s): See Employment Standard Resource Appendix

**Standard # 9**

Work opportunities will be provided to individuals with autism in the community of their choice-- including rural community settings-- in order to nurture family and community ties.

Check One:  Minimum Standard  Best Practice Standard  Gold Standard

Citation(s): See Employment Standard Resource Appendix

**Standard # 10**

Any job offered to an individual with autism will meet all aspects of that person's needs in terms of motivation, challenge, interest, comfort, camaraderie, status, hours, pay, and benefits.

Check One:  Minimum Standard  Best Practice Standard  Gold Standard

Citation(s): See Employment Standard Resource Appendix

**Standard # 11**

All autism specialists (case managers, rehabilitation counselors, behavior therapists or job coach/job developers) will provide opportunities for young adults and adults with Autism Spectrum Disorders to express their interest in potential jobs/careers. At a minimum, each individual with autism will participate in an interest survey to help in developing a customized individualized job plan based on their interests, needs, strengths and barriers to successful job placement and maintenance.

Check One:  Minimum Standard  Best Practice Standard  Gold Standard  
 Citation(s): See Employment Standard Resource Appendix

**Standard # 12**

Ongoing group meetings will be offered to individuals with autism who are seeking employment. Topics include, but are not limited to, the following concepts: filling out applications, understanding body language, developing appropriate work relationships, navigating the workplace, preparing for an interview, basic budgeting and money management, utilizing public transportation to and from the workplace, becoming involved in the community, maintaining proper hygiene, and dressing appropriately for work.

**Standard # 13**

The lead agency with collaboration from other local and state agencies will establish the criteria for allowable diagnostic situational work assessments and testing and will ensure that the assessments will only be performed by qualified individuals with experience or training in autism.

Check One:  Minimum Standard  Best Practice Standard  Gold Standard  
 Citation(s): See Employment Standard Resource Appendix

**Standard # 14**

Behavioral supports and reward systems provided by behavioral interventionists with training in autism and will be utilized in coordination with a job developer/coach, rehabilitation counselor or case manager to increase participation in the work place.

Check One:  Minimum Standard  Best Practice Standard  Gold Standard  
 Citation(s): See Employment Standard Resource Appendix

<b>Standard 15</b>
<p>Job coaches/developers should not be time locked and will provide continuous support for each person with autism based on the need of the individual. Duties include: continuous situational skill assessment, ensuring that reasonable accommodation at worksite are made, job development and coaching for each enrolled individual, modification recommendations of the custom job plan, monitoring of each individual's progress toward being fully integrated into the workforce, and providing targeted support and training in different areas of need throughout the duration of employment.</p>
<p>Check One: <input type="checkbox"/> Minimum Standard <input checked="" type="checkbox"/> Best Practice Standard <input type="checkbox"/> Gold Standard</p> <p>Citation(s): See Employment Standard Resource Appendix</p>
<b>Standard # 16</b>
<p>A job developer/coach must be proficient at "job carving" to meet the specific needs of the individual with autism. Effective job carving requires sharp observational and negotiating skills, along with direct knowledge of a potential workplace, community resources and of the potential employee's abilities, interests, and limitations. (See Standard 5- definition of job carving)</p>
<p>Check One: <input type="checkbox"/> Minimum Standard <input checked="" type="checkbox"/> Best Practice Standard <input type="checkbox"/> Gold Standard</p> <p>Citation(s): See Employment Standard Resource Appendix</p>
<b>Standard # 17</b>
<p>An interagency team will develop a training module for job coaches/developers. A minimum of 30 hours of training will be required regarding the process of customizing employment for adults with autism by creating, carving or negotiating the work needed by the employer that fits the potential employee's needs, strengths and interests. Emphasis of the training should give examples of types of jobs that would fit different strengths and abilities; as well as show, how this approach enhances the employment relationship between the employee and employer in ways that meet the needs of both. The job coach will also receive on- the -job training by a job development specialist before he or she is allowed to work solo. (Discussed in <i>Life Journey Through Autism: A guide for Transition to Adulthood</i>- See Appendix I)</p>
<p>Check One: <input checked="" type="checkbox"/> Minimum Standard <input type="checkbox"/> Best Practice Standard <input type="checkbox"/> Gold Standard</p> <p>Citation(s): See Employment Standard Resource Appendix</p>
<b>Standard # 18</b>

During job development for an individual with Autism Spectrum Disorders, the following components should be taken into consideration by the job coach/developer to best match the job to individual's personal preferences:

- Hours of employment
- Acceptable noise levels at the job site
- Pay, leave, and other benefits
- Acceptable activity levels
- Physical requirements of the job (e.g., lifting)
- Acceptable margin of error (quality control)
- Production requirements
- Acceptable level of interaction with coworkers and supervisors
- Clear communication about job expectations (written/ picture postings and/or verbal)
- Grooming and hygiene requirements
- Demands on communication skills
- Personal space available
- Use phone or vending machine and navigate in cafeteria lines.
- Coworker training and support
- Travel distance and time to and from residence.
- Accessible transportation.
- Individual's response to free time (such as break, task completion or lunch)

Check One:  Minimum Standard  Best Practice Standard  Gold Standard

Citation(s): See Employment Standard Resource Appendix

**Standard # 19**

ADA guarantees that people with disabilities may request certain accommodations in the workplace. Depending on the individual's needs and where he or she is working, the job developer/coach will ensure that reasonable accommodations are made for the individual with autism. These may include, but are not limited to:

- Pictures or drawings of the task
- Templates of forms or documents
- A note taker
- A voice recorder
- Written instructions
- Daily checklists
- Written or verbal reminders
- Written or picture instructions next to machines, such as postage machine, copier, printer
- Minimal clutter in the work environment
- Minimal noise in the work environment (such as no radios or music)
- Large tasks broken down into small steps
- A "Where to" guide for resources or coworkers
- A timer or alarm as a reminder
- Additional hands-on training
- Headset for telephone or a speaker phone
- Multiple breaks
- Performance feedback presented visually (charts, diagrams)
- Mentor or job coach
- Information for coworkers about ASD
- His own desk or workspace
- Checklist for completing task
- Timelines for completion of task
- Assignment of one task at a time
- Training on appropriate workplace behaviors (e.g., interacting with customers)
- Notice before changes (such as rearranging supply closet or change in job related work)
- Consistent supervision by one person
- Prioritization of tasks
- Regular feedback on performance (positive and constructive)

Check One:  Minimum Standard  Best Practice Standard  Gold Standard

Citation(s) for Evidence-base: See Employment Standard Resource Appendix

**Standard # 20**

Regional Centers, along with the job developer/coaches, rehabilitation counselor or case manager will educate employers and coworkers about autism and how to best work with individuals with Autism Spectrum Disorders so that they can offer support when necessary. As part of the process of integrating into a work environment, an individual's support team will establish what information will be useful to future employers and coworkers about autism, and the specific individual seeking employment. Emphasis should be placed on areas where the individual will need help, along with their particular strengths.

Check One:  Minimum Standard  Best Practice Standard  Gold Standard  
Citation(s): See Employment Standard Resource Appendix

**Standard # 21**

The regional centers will promote at least four opportunities a year to attend informational or training seminars about autism to the community at large in order to enable the community to support the full and active participation of individuals with autism in their pursuit of higher education and meaningful employment in the most normal and least restrictive social and physical environments.

Check One:  Minimum Standard  Best Practice Standard  Gold Standard  
Citation(s): See Employment Standard Resource Appendix

**Standard # 22**

Through the regional center's, the state lead agency will establish a bi-annual accreditation process that will assist the individual with autism and/or their family in judging the quality of the service or program they choose or are attending.

Check One:  Minimum Standard  Best Practice Standard  Gold Standard  
Citation(s): See Employment Standard Resource Appendix

**Standard # 23**

The lead agency, along with other state agencies will work with local universities, colleges and Jr. colleges to establish professional and paraprofessional adult autism specialist/rehabilitation degrees.
Check One: <input type="checkbox"/> Minimum Standard <input checked="" type="checkbox"/> Best Practice Standard <input type="checkbox"/> Gold Standard
Citation(s): See Employment Standard Resource Appendix

<b>Standard # 24</b>
At a minimum, the lead agency in collaboration with other agencies will develop and provide 40 hours of autism-specific pre-service education with appropriate additional training/certification for professionals and paraprofessionals in regards to adult services for individuals with autism. Target groups will include, but are not limited to those working in case management, employment development, speech therapy, occupational therapy, behavioral intervention and medical specialties.
Check One: <input checked="" type="checkbox"/> Minimum Standard <input type="checkbox"/> Best Practice Standard <input type="checkbox"/> Gold Standard
Citation(s): See Employment Standard Resource Appendix

<b>Standard # 25</b>
The lead agency in collaboration with other agencies will provide professional development conference/training opportunities for autism professionals and paraprofessional. Each professional and paraprofessional will obtain 20 hours of in-service training a year related to adult autism issues/strategies.
Check One: <input type="checkbox"/> Minimum Standard <input checked="" type="checkbox"/> Best Practice Standard <input type="checkbox"/> Gold Standard
Citation(s): See Employment Standard Resource Appendix

<b>Standard # 26</b>
Professionals will obtain a Master's degree or better in autism and paraprofessionals will obtain a bachelor's degree in a related social service/rehabilitation field with a concentration in autism.
Check One: <input type="checkbox"/> Minimum Standard <input type="checkbox"/> Best Practice Standard <input checked="" type="checkbox"/> Gold Standard
Citation(s): See Employment Standard Resource Appendix

**Standard # 27**

The lead agency in collaboration with the state legislature will establish adequate funding for adult support systems so that all adults with autism have the opportunity to live and work in the most normal and least restrictive setting possible.

Check One:  Minimum Standard  Best Practice Standard  Gold Standard

Citation(s): See Employment Standard Resource Appendix

**Standard # 28**

An interagency council along with the state legislature will create innovative state incentives and policies to achieve integrated employment with livable wages, potential career advancement, and benefits for all citizens with disorders along the Autism Spectrum.

Check One:  Minimum Standard  Best Practice Standard  Gold Standard

Citation(s): See Employment Standard Resource Appendix

**Standard # 29**

The lead agency will contract with Vocational Rehabilitation and other specialized autism organizations to provide job development/coaching services as vendors.

Check One:  Minimum Standard  Best Practice Standard  Gold Standard

Citation(s): See Employment Standard Resource Appendix

**Standard # 30**

The lead agency will ensure that case management or service coordination provides accountability and continuity of services which promote meaningful choices to adults with autism within an integrated community environment. This service is crucial in linking, referring and assisting individuals with autism and/or their families to accessible life-long services and needed supports.

A. Major responsibilities of the case manager include:

1. Assessment
2. Life Planning
3. Linkage and Referral
4. Advocacy
5. Monitoring quality of life, health and safety issues
6. Crisis response planning
7. Providing clients, their families and/or their legal representatives with information about their rights and responsibilities

B. Responsibilities of the Case Management Agency

1. Provide a reasonable case load (1:25) so case managers can do their jobs adequately.
2. Remain autonomous from any other type of agency that provides a service to individuals with autism.

Check One:  Minimum Standard  Best Practice Standard  Gold Standard

Citation(s): See Employment Standard Resource Appendix

#### EMPLOYMENT STANDARDS RESOURCE APPENDIX

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Contributors:

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- Organization for Autism Research, [www.researchautism.org](http://www.researchautism.org)
- Southwest Autism Research and Resource Center, [www.autismcenter.org](http://www.autismcenter.org)

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## CONSUMER SURVEY

### Results

#### Consumer Information:

Name of Person Completing Form (optional): 10 Adult Participants

Relation to Person Completing Form: 6 individual or self 0 parent/guardian 4 service provider other\_\_\_\_ (the 4 completed by provider have limited verbal communication)

Email (optional): none

**Are you employed?** 0 full time 6 part time - averaging 2 hours/week

What jobs have you had since leaving high school? 7 have worked at Glenwood; out of these 7, 3 have also had community jobs:

1 at a bakery

1 at Bruno's and The Sheraton and Protective Life

1 at the Sheraton and Food Fair

Where do you work now? 6 with jobs at Glenwood, 4 not working at this time

What is/are your job(s)? 6 Housekeeping/Mail

Do you have a job coach? 6 YES 4 NO

Did someone help you find this job? 6 YES

Who? Job Coach

Are you satisfied with your current job(s)? 6 YES

What would you change about your current job? 1 would like to earn more money and 1 said they like to work in the kitchen

Do you receive benefits with your job?	YES	10 NO
Health benefits?	YES	10 NO
Vacation/sick days?	YES	10 NO
Retirement plan?	YES	10 NO
Other? _____		
Do you receive SSI	10YES	NO
SSDI?	YES	10 NO
Medicare?	1 YES	9 NO
Medicaid?	10YES	NO
Other?	9 MRDD HCBS Waiver	

**Are you in a training program?** See Adult Day Program for all 10 participants

full time part time \_\_\_\_\_hours/week

*[You may need a short definition or example to differentiate these activities/programs—for example, I'm not real sure where I would put Horizons School.]*

Please describe your current training:

What would you change about your training so that it meets your plans for your future?

**Are you in school?** 10 No

Where are you enrolled?

What are you studying?

Will you receive a degree?

What help do you get with school (classes, instructors, schedule, other)?

What would better help you with school? 10 No answer

**Are you participating in a structured adult program?**

10 full time part time 30 hours/week

Name of program: Glenwood Adult Day Program

Are you satisfied with your program? 10 YES 0 NO

What would make this program better for you? 2 people said go out more; 2 people said more long-term stable staffing; 1 person said more community work opportunities; 1 person said more swimming.

**Do you do volunteer work?** 4 YES 6 NO

What do you do as a volunteer? 2 volunteer 2 x's a wk at an animal clinic; 1 volunteers at the animal clinic and a community food kitchen 1x a week; 1 volunteers at the YMCA and the food kitchen

**What is your current transportation?** Staff members drive participants

Is it working well for you? 10 YES NO

Do you have any problems? 1 YES 9 NO

Describe: 1 person said it is hard to share transportation with others

What would help you meet your transportation needs? 1 person said a dedicated car for his group

**Do you receive in home services?** 10 YES NO

Describe: All receive residential services – 4 live in community residential homes; 2 live in a community apartment program; and 4 live in one of the campus residential homes.

What would you change about those services? 1 person said he would like to live with just 1 roommate rather than 2.

**In what community activities do you regularly participate?**

Church	0daily	10 weekly/0monthly	0 occasionally
Exercise center/program	2daily	3weekly0monthly	5 occasionally
Social/recreation center	1daily	weekly1monthly	8 occasionally
Movies	daily	weekly6monthly	4 occasionally
Out-to-eat	daily	6weekly/4monthly	0 occasionally

Other: 1 Special Equestrian

What keeps you from participating? 1 Limited communication, 2 said behaviors, 1 said income and 1 was uncomfortable with some settings

What would help you participate more? 1 person said more long-term, dedicated staff familiar with regular scheduled activities; 1 said there was no family available to help; and 1 said more practice

Specifically, how could a regional resource center help you? *[This is going to need more explanation as this is a totally new concept for Alabama. You might look at the various roles that have been suggested for the regional centers/networks, categorize them, and let the consumers prioritize the roles that they would see as most helpful.]*

They did not understand the concept of the question being asked.

### **SOP: Personnel Preparation and Training**

Leader: Doris Hill, Ph.D.

As stated in the Alabama Autism Task Force Final Report to the Governor and Legislature (January, 2009, p. 13):

Current Status: The move toward inclusion has brought more students with ASD into the general education classroom. Frequently, teacher prep programs do not provide teachers with the knowledge necessary to teach these students in their classroom. Teachers training in special education are generally trained in the methodologies but may not have the administrative and financial support to prepare their students for success.

Action Items: Teachers (and all school personnel) should receive pre-service and in-service training regarding ASD and specific intervention techniques. There should be a system to monitor and track this training, and the training should include the rationale why particular methods are of use to the students. Teachers should have ongoing access to model sites and individuals who have worked successfully with students on the spectrum for technical assistance and training.

<b>SOP: Personnel Preparation and Training Work Group Members</b>	
Key: Autism Spectrum Expert Advisor (A.S.E.A.) / Autism Spectrum Family Advisor (A.S.F.A.) / Autism Community Advocate (A.C.A.)	
Doris Hill, Ph.D.	Auburn University
Alice Widgeon, L.B.S.W., MPA	Alabama Department of Mental Health, Early Intervention
Caroline Gomez, Ph.D.	State Autism Coordinator
Shirley Barnes, Ph.D.	Alabama State University, College of Education
Larry Beard, Ed.D.	Jacksonville State University, Department of Curriculum and Instruction
Joe Carter, M.A.	Glenwood Inc., Executive Director
David Ellis, Ph.D.	University of South Alabama, College of Education
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**Meeting Dates:** May 6, 2010 / June 14 / July 26 / August 23 / October 4

## Progress

This work group made it their first priority to examine current professional preparation programs for teachers (general and special education) and rehabilitation counselors serving individuals with ASD. Results as of this report are outlined in paragraph 3. The group is also working to develop a directory of existing teacher education programs offering behavior management or ASD specific classes and points of contact.

### Existing Programs (state of the state)

**General education-** Teacher preparation programs, at a minimum, include one undergraduate survey course on exceptionality. ASD and Behavior Management are generally included as part of the curriculum of the survey course and ASD/behavior management is covered for one or two class periods each (approximately 2.5 hours of class time). Most courses do not have a field component in exceptionality.

**Undergraduate-** Special education teacher preparation programs are collaborative degrees. Graduates of these programs are generalists in special education and coverage of ASD and more severe disabilities depends on who is providing the classroom or practicum training.

**Master's Programs-** Currently there are several masters' programs that focus on low incidence, developmental disabilities and/or autism. These programs are offered at the University of Alabama and Auburn University. An Ed.S. degree in collaborative special education with a concentration in autism has recently been approved and will be offered at the University of Alabama in Birmingham.

**Rehabilitation counseling programs-** These programs incorporated autism, as a general rule, into the curriculum to the same degree as other disabilities.

### Existing Standards

#### Minimum Standards

- Alabama Quality Teaching Standards
- Council for Exceptional Children teaching standards,

- Interstate New Teacher Assessment and Support Consortium (INTASC)
- National Council for Accreditation of Teacher Education (NCATE)

**Best practices/Model Standards**

- Council for Exceptional Children standards for DD/autism
- National Autism Center's National Standards Report
- Behavior Analyst Certification Board Task List for ASD
- ASD competencies as developed by other states
- Commission on Accreditation of Rehabilitation Facilities (CARF)

**Recommendation (to date) for Standards of Professional Service**

Minimum Standards for special educators pursuing a Class B, A or AA certification are geared toward the collaborative degree. There are several routes to pursuing this certification. 16 universities offer some form of collaborative degree at the bachelor's level (Early Childhood or Collaborative Special Education (K-6, 6-12), and 10 at the master's level. The standards for collaborative teacher are outlined under paragraph 4 above (minimum standards).

Of concern to some members of this group is the "collapsing" of the collaborative programs into inclusive programs for Pre-K -6. The University of West Alabama, Jacksonville State University, and the University of South Alabama are examples. The "collapsed" degree rolls Early Childhood, Special Education (K-12) and Elementary Education together. The teacher then graduates with a certification in all three areas or dual certification in elementary/special education. It is the opinion of several members of this work group that collapsing programs waters the curriculum even further and results in a lack of much needed content coverage. Others feel it is a positive trend. The group agrees, however, that training for pre-service teachers of students with autism require more specialized training than the collaborative degree gives them at the current time. While dual certification may help the inclusion teacher, which is a positive outcome, it has the potential to minimize the specialized knowledge required of teachers working with students with more severe developmental disabilities/autism.

For individuals in a dual certification program, it must be ensured that best practices/model standards (see paragraph 4) are followed in the teacher certification program. As an alternative, it is suggested that a DD/autism certification (endorsement) be required for those teaching this unique population.

### **Best Practices/Model Standards**

Best practices for all educators serving students with Developmental Disabilities/Autism are those outlined by the Council for Exceptional Children standards for teaching students with developmental disabilities/autism (2010). These should be the standard for special educators working with students with ASD/developmental disabilities. This group recommends that pre-service teachers meet these CEC standards for DD/autism and should have an undergraduate class in behavior management as well as practicum experience with students with developmental disabilities to include autism. Courses in transition and the Alabama Alternate Assessment (AAA) are also recommended.

Best practices for preparing the pre-service teacher to serve students with developmental disabilities/autism include mentoring, observation, practicum and internship opportunities in model classrooms where highly qualified special education teachers already teach students with ASD. Unfortunately, since there is no requirement in the state of Alabama to ensure that teachers who serve this population understand the disorder as well as the evidence based practices required to teach them, many teachers may not have been trained in methods that work. Teachers of students with ASD need to use evidence-based practices as outlined by the National Research Council (2001) and the National Autism Center's National Standards Project (2009), which were designed to benefit parents, caregivers, educators, and service providers since these individuals make the complicated decisions regarding the education and interventions used for our students with ASD.

Evidence shows these best practices include early and intense instruction specifically tailored to the individual student and include antecedent and behavior packages, joint attention intervention, modeling, naturalistic teaching strategies, peer training, schedules, self-management, and story-based interventions. Programs using existing minimum standards are not likely to cover these best practices. Teachers also need to be aware of treatments that lack empirical evidence (such as facilitated communication, gluten and casein free diet, and sensory integration) (National Standards Project, 2009). (CEC Standards for Advanced Knowledge, 2010; National Research Council, 2001).

Other best practices include collaboration among stakeholders (and between departments), strategies that promote successful transitions, facilitate maintenance and generalization of skills learned, and integration into various settings with levels of support that change to meet individual need.

The use of proactive strategies and positive behavioral supports, specialized instruction to foster communication, maintaining a safe environment, social skills training, and promoting autonomy for individuals as well as involvement in the transition process are also very important.

Best practices for training teachers (in and out of college) include modeling the promotion of FAPE and LRE, setting high expectations for self, staff, and exceptional learners. Mentoring teacher candidates, newly certified teachers and colleagues, as well as providing structure, on-going training and support to families, professionals and paraprofessionals should be incorporated into programs with a focus on service to students with significant disabilities (National Standards Report, 2009; National Research Council, 2001).

### **Opportunity for Change and Vision of this Work Group:**

#### **Where we need to go and how we get there...**

**Current Direction:** The group is currently examining the "state of the state" regarding in-service and paraprofessional training programs in Alabama. In addition, a directory of classes/degree programs existing in university psychology programs (autism/behavior management and behavior analyst certification) is being developed.

**Finally:** Members of this work group see this as an opportunity to develop standards of professional service, a vision for the future, and to build a consortium of educators, through the Alabama Autism Regional and In-Service Centers, and service providers to meet the pre-service and in-service needs of professional educators who serve students with developmental disabilities/autism.

#### **Selected References:**

Alabama Autism Task Force (2009). *Final Report to the Governor and Legislature*. Montgomery: Alabama Task Force.

Alabama Department of Human Resources (2009). *Alabama pathways to quality care and education*. Montgomery: Child Care Development Fund.

Joint Report (2008). *Autism Awareness: Recommendations for Teacher Preparation and Professional Development*. Washington: State of Washington Educator Standards Board and the Office of Superintendent of Public Instruction.

Competency Committee of the Statewide Autism Council (2004). *Competencies for professionals and paraprofessionals supporting individuals with autism across the lifespan in Virginia*. Virginia Department of Education.

National Autism Center (2009). *National Standards Report*. Randolph: National Autism Center.

National Research Council (2001). *Educating children with autism*. Washington, DC: National Academy Press.

**Special Projects Committee**

Chair: Melanie Jones, B.S.

The purpose for the special projects committee is to address current needs among the ASD community.

**Special Projects: Autism Awareness Work Group**

Leader: Tuwanna McGee, M.Ed.

The Awareness Work Group is focused on developing resources to help families navigate the system of services available in Alabama. The first focus has been on developing an Alabama Autism Spectrum Lifespan Resource Tree and Directory with direct links to and contact information for services/providers throughout the State.

<p><b>Special Projects: Autism Awareness Work Group Members</b></p> <p>Key: Autism Spectrum Expert Advisor (A.S.E.A.) / Autism Spectrum Family Advisor (A.S.F.A.) / Autism Community Advocate (A.C.A.)</p>	
Tuwanna McGee, M.Ed., A.S.F.A.	Alabama Disabilities Advocacy Program
Melanie Jones, B.S., B.A	Autism Society of Alabama, Executive Director

Caroline Gomez, Ph.D.	State Autism Coordinator
Anna Bloom, M.P.H., L.G.S.W.	Autism Society of Alabama, Program Manager
Tracy Camp, A.S.F.A.	Autism Parent Networking, Tuscaloosa Group Leader; Autism Society of Alabama, Board of Directors
Amy Cox, M.Ed., BCBA	Supervisor of ABA services at Mitchell's Place
Jill Jones, A.S.F.A.	Advocate
Ginger Henry, R.N., FACHE	Advocate
Daphne Reardon, A.S.F.A.	Advocate
Jennifer Robertson, A.C.A.	Autism Society of Alabama, Fundraising Manager
Tracy Robinson, A.S.F.A.	Calhoun County Networking Group, Leader

### ***Alabama Autism Lifespan Resource Tree and Directory***

*Alabama's state-wide services and supports for children and adults with autism spectrum disorders and their families.*

- Autism Lifespan Resource Tree: This information graphic is organized by need from birth through adulthood. Under each category, statewide providers/resources are listed with links to the Directory.
- Autism Lifespan Resource Directory: This section provides detailed contact information and direct links (where available) for each of the resources on the Tree. Entries are listed in alphabetical order.

Surveys were sent to individuals who have shown an interest in Alabama's autism spectrum disorder (ASD) community personally and/or professionally. Those responding were asked to share all of the Alabama Resources that they were aware of in a number of areas that provide services to individuals with disabilities, complete and return the Survey, and then forward the Survey on to others who may have been interested in providing information (Survey submission is to be ongoing). The original Survey responses informed the design of the follow-up Survey (see below) that will be sent to all who indicated an interest. The original Survey also informed the draft Lifespan Resource Tree (2 pages). The draft below includes some *sample* items, but is not intended to be representative. The shaded areas indicate links.

**Alabama Interagency Autism Coordinating Council (AIACC)**  
**An Invitation**

**Dear Service Provider:** Your name/organization was submitted to the AIACC as a potential listing on the *Alabama Autism Lifespan Resource Tree and Directory* (details p.2). The resource is being compiled by the AIACC and will be available in print and on-line. If you (a) provide services to Alabama's children and/or adults with autism spectrum disorders and/or their families and (b) would like to be included, please complete the information below and submit. In addition, please forward this to others who may also be interested in being included. Thank you.

<b>Alabama Autism Lifespan Resource Tree and Directory: Follow up</b>			
I am the provider or represent the organization below (name):			
Provider / Organization Name:			
Address:			
Phone:		Fax:	
E-mail:		Web-site:	
Description of Services (1-2 sentences):			
<b>Check categories that apply</b> (limit 3 without written documentation of rationale).			
√	<b>Category</b>	√	<b>Category</b>
	Early Identification/Screening		Diagnostic Services
	Public Education : Early Intervention (Birth to 3 years)		Public Education: Preschool (3 to 5 years)
	Private Education : Early Intervention (Birth to 3 years)		Private Education: Preschool (3 to 5 years)
	Public Education: School-aged (6 to 21 years)		Private Consultant
	Private Education: School-aged (6 to 21 years)		Private Tutoring
	Transition to Adulthood: Higher Education		Family Supports: Organization
	Transition to Adulthood: Employment		Family Supports: Respite-care

	Transition to Adulthood: Community Services		Family Supports: Recreation / Camps
	Advocacy /Legal Support		Funding Sources
	Medical / Specialty / Therapy Providers		Mental Health Providers / Psychologists
	Independent Living: Housing & Assisted Living		Independent Living: Assistive Technology
	Education & Training: Professional		Safety
	Education & Training: Family / Caregivers		ASD Friendly Service Providers (e.g., barber)

**Please return to Caroline Gomez**

[caroline.gomez@mh.alabama.gov](mailto:caroline.gomez@mh.alabama.gov) / Fax: (334)353-7062

RSA Union Building / 100 North Union St. / Montgomery, Alabama 36130-1410

**Draft Alabama Autism Spectrum Lifespan Resource Tree follows:**

Does my child have autism spectrum disorder?  
Learn the Signs. Act Early Page 1

Need Help?  
Search

Early Identification/  
Screening

Child Find  
American Academy of Pediatrics Referral Service  
Developmental Pediatricians  
Glenwood

Diagnostic Services

USA  
UAB Sparks  
EA Easter Seals  
AU  
Glenwood

Public Education  
Early Intervention Birth to 3 years of age      Preschool 3-5 years of age      School-aged 6-21 years of age

Early Intervention System  
Children's Rehabilitation Services

Department of Special Education- Special Education Services

Department of Special Education- Special Education Services  
Special Education Coordinators  
Transition Services

Transition to Adulthood  
Higher Education      Employment      Community Services

Career and technical Education

Department of Vocational Rehabilitation  
ASPE Network on Employment

Family Supports  
Organizations      Respite-care      Sports / Camps

Autism Society of Alabama  
Autism Parent Support Groups  
Asperger's Support Groups  
Asperger's Young Adults of North Alabama  
Family Guidance Center

Lifespan Network  
Church Ministries  
UCP  
Easter Seals  
Private Centers

Special Olympics  
Hypotherapy  
Soccer  
Cheer Leading/Dance  
Music  
Art  
Martial Arts  
Camps

Does my child have autism spectrum disorder?  
Learn the Signs. Act Early Page 2

Need Help?  
Search

Advocacy / Legal Support

ADAP  
Wright's Law  
Governor's Office on Disability

Private Education / Consultants

Tutoring Services  
Preschool  
Little Tree  
Mitchell's Place  
Glenwood  
Riley  
School-aged  
Learning Tree  
Glenwood

Medical / Mental Health  
Medical Mental Health Funding

Pediatric Neurologists  
Pediatric Psychiatrists  
Geneticists  
Pediatric  
Dentists  
Speech and Hearing  
Occupational Therapy

State Regional Centers  
Psychologists  
Glenwood

Medicaid  
SSI  
CHIP Healthcare for Low income  
Autism Resource Foundation

Independent Living  
Housing Assisted Living Assistive Technology

STAR Technology  
Access & Response

Education / Training  
Professional Family / Caregiver

Glenwood

APAC Parent Education Center  
ACDD Consumer Involvement Fund  
Partners in Policymaking

ASD Friendly Service Providers

Haircuts  
Specialty Food Retailers  
Safety

### Special Projects: Community Services Work Group

Leader: Anna Bloom, M.P.H., LGSW

The Community Services Workgroup of the Special Projects Committee for the Alabama Interagency Autism Coordinating Council focuses on meeting the immediate needs of individuals on the spectrum and their families by improving existing community resources. The group is guided by input from Alabama citizens – particularly addressing the safety concerns regarding individuals with Autism Spectrum Disorders. The group has participated in providing professional training for first responders and is in the process of working on a safety awareness campaign.

<b>Special Projects: Community Services Work Group Members</b>	
Key: Autism Spectrum Expert Advisor (A.S.E.A.) / Autism Spectrum Family Advisor (A.S.F.A.) / Autism Community Advocate (A.C.A.)	
Anna Bloom, M.P.H., L.G.S.W.	Autism Society of Alabama, Program Manager
Melanie Jones, B.S., B.A	Autism Society of Alabama, Executive Director
Caroline Gomez, Ph.D.	State Autism Coordinator
Cliff Andrews, A.C.A.	The Learning Tree, Inc.
Erin Brunson, M.Ed.	Educational Consultant, Autism Integrated Services, LLC
Joe Johnson, A.S.F.A.	Advocate
Monica Johnson, A.S.F.A	Advocate
Jennifer Robertson, A.C.A.	Autism Society of Alabama, Fundraising Manager
Susan Shirley, A.S.F.A.	Advocate
Lisa Ann Spurling, A.C.A	The Learning Tree, Inc., Services and Supports
Becca Wood, M.S., OTR/L	Mitchell's Place, Outreach Director

**Meeting Dates:** May 17, 2010 / June 16-18, 2010 / September 27, 2010

#### Activities:

1. Assisted in coordination and notification of the First Responders Training.
2. Held discussions with Red Cross regarding first aid training opportunities – possibly to be held in conjunction with safety campaign.
3. Researched police academy training requirements and made contact with local consultants.
4. Researched safety campaigns already in existence (AWAARE, EmFinders, etc.)

**Future Activities:**

1. Safety campaign involving ASA's Networking Group Leaders (including identification options, community involvement with first responders, etc.)
2. Law enforcement academy training support.

**Collaborators:**

Alabama Department of Mental Health

Alabama Department of Public Health

Alabama Council for Developmental Disabilities

**Special Projects: Developmental Surveillance & Early Screening Work Group**

Leader: Sarah O'Kelley, Ph.D.

The Developmental Surveillance and Early Screening Workgroup met approximately every other month to plan the implementation of a statewide awareness campaign utilizing the *Learn the Signs. Act Early.* materials available from the Centers for Disease Control and Prevention (CDC). The efforts of this group were initially driven by the discussions and goals set by a team of lead agencies, service providers, and other consumers that attended an Act Early Summit in October 2009. The Work Group has developed a long-term plan of disseminating information regarding early identification of developmental delays and appropriate referrals for children with known or suspected delays, with a target audience including parents/caregivers, service providers (e.g., physicians), and early childcare providers (e.g., daycare centers, early education training programs).

<b>Special Projects: Developmental Surveillance &amp; Early Screening Work Group Members</b>	
Key: Autism Spectrum Expert Advisor (A.S.E.A.) / Autism Spectrum Family Advisor (A.S.F.A.) / Autism Community Advocate (A.C.A.)	
Sarah O'Kelley, Ph.D.	University of Alabama at Birmingham, Civitan-Sparks Clinics
Melanie Jones, B.S., B.A	Autism Society of Alabama, Executive Director
Caroline Gomez, Ph.D.	State Autism Coordinator
Angela Barber, Ph.D., CCC-SLP	University of Alabama, Department of Communication Disorders
Sue Berry, LCSW	Alabama Department of Human Resources, Program Supervisor
Anna Bloom, M.P.H., L.G.S.W.	Autism Society of Alabama, Program Manager
Karen Dahle, Ed.D., NCSP, A.S.F.A.	University of Alabama at Birmingham, School of Education
Jane Duer, M.Ed., ECSE	Children's Health System, Early Intervention Program Manager
Gary Edwards, Ph.D.	United Cerebral Palsy of Greater Birmingham, Executive Director
Lisa Highfield, M.A.	Muscle Shoals City Schools, Student Services Supervisor
Beth Johns, OTR/L, MPH	Success by Six, Assistant Vice-President of Early Childhood Initiatives and Education
Jonathan Nelson, B.A.	Birmingham Barons, General Manager; Autism Society of Alabama Board of Directors
Teri Pinto, B.A.	Department of Mental Health, Early Intervention
Myriam Peralta, MD, FAAP	University of Alabama at Birmingham, Children's Hospital
Alice Sette, MPA, Au.D.CCC-A/ABA	Alabama Department of Rehabilitation Services, Children's Rehabilitation Service
Katie Todd, B.S.	Walker County Schools, Collaborative teacher

**Meeting Dates:** February 9, 2010 / March 8, 2010 / May 17, 2010 / July 19, 2010 / September 27, 2010

This Work Group represents a number of collaborations among state universities (i.e., University of Alabama at Birmingham, The University of Alabama, University of South Alabama), state agencies and programs (i.e., Department of Mental Health, Early Intervention), existing early

intervention/screening initiatives (e.g., ABCD project, Success by 6), private organizations (i.e., UCP of Greater Birmingham, Children's Health System, Autism Society of Alabama), and additional consumers and service providers (e.g., parents of children with ASD and other DD, special education teachers). Technical assistance has been provided by the CDC and Association of University Centers on Disabilities (AUCD).

The Work Group was awarded a grant from AUCD in March to support awareness efforts, and an application for additional funding through the CDC and Association of Maternal and Child Health Programs (AMCHP) is in preparation. The Work Group team has started obtaining Public Service Announcements and print materials to tag with state-specific information and will begin distributing these materials at local, state, and regional conferences with an audience of parents/caregivers and early childcare professionals and service providers. Statewide information dissemination will also be achieved through a coordinated media campaign in the coming year. The Work Group hopes to develop and provide trainings to individuals and groups across the state regarding developmental screening and referral in Alabama and how to utilize existing resources for achieving the goal of early recognition and intervention for children at risk for developmental disabilities, including autism spectrum disorders.

**Special Projects: Family Supports Work Group**

Leader: Jennifer Robertson, A.C.A.

The Family Supports work groups main focus is to reach out to those services that would help families affected by Autism Spectrum Disorders. The group identified several areas of support that was needed but narrowed the focus to respite care. The group identified and contacted current respite providers in the state and is creating a Respite Resource Tree for families to be able to easily access information about how to obtain respite services.

<p align="center"><b>Special Projects: Family Supports Work Group Members</b></p> <p align="center">Key: Autism Spectrum Expert Advisor (A.S.E.A.) / Autism Spectrum Family Advisor (A.S.F.A.) / Autism Community Advocate (A.C.A.)</p>	
Jennifer Robertson, A.C.A.	Autism Society of Alabama, Fundraising Manger
Melanie Jones, B.S., B.A	Autism Society of Alabama, Executive Director

Caroline Gomez, Ph.D.	State Autism Coordinator
Java Bennett, LBSW, B.S. Sp Ed	Alabama Lifespan Respite Resource Network, Director
Anna Bloom, M.P.H., L.G.S.W.	Autism Society of Alabama, Program Manager
Susan Colburn, B.S.	CRS State Parent Consultant; Family Voices of AL, Co-director.
Genia Harrison, M.Ed., A.S.F.A	Alabama Family Ties graduate
Sandra Hazzard, A.C.A	Children's Rehabilitation Services, Parent Consultant
Linda Lamberth, A.C.A.	Alabama Lifespan Respite Resource Network, Project Manager
Sandy Naramore, M.A. Admin. Cert.	Mitchell's Place, Executive Director
Mary Thweatt, A.S.F.A	Center for Autism & Asperger's Resources, Inc., Director

**Meeting Dates:** May 4, 2010 / July 14 / September 10

#### **Coordinator's Glimpse Ahead**

Caroline Gomez, Ph.D.

The information below was included in an unfunded grant. It is included in this Progress Report to provide a glimpse of the activities involved in beginning a Regional Network of Care. The timelines were based on grant proposal information and not intended to be final. Again, this is not an approved plan, but can give you a glimpse of what is ahead.

#### **Alabama Autism Regional Networks of Care**

The purpose of Alabama Autism Regional Networks of Care is to improve access to a comprehensive and coordinated system of care for Alabama's children and youth with Autism Spectrum Disorder (ASD) and related disabilities. Activities will build on the existing *State Autism Plan: A Work in Progress* (as informed by the Alabama Autism Task Force Report).

**Year One:**

Objective 1: Initiate State efforts to improve infrastructure that results in community and state systems that are integrated across service sectors and are collectively responsible for achieving individual, family, and community outcomes.

Objective 2: Determine elements for Individualized Interagency Intervention Plan (IIP) to facilitate meeting needed services and funding arrangements for the individual and family across a variety of programs, agencies, and services.

<b>Activity</b> All activities will be informed by youth/family participation and specialist consultants. The Project Director is ultimately responsible for all activities.	<b>Responsible Staff</b>	<b>Date Complete</b>
1.1. Identify goals and guiding principles.	Project Director, AIACC	10/01/10
1.2 Maintain web-site to communicate Project development.	Project Director, ADMH	10/01/10
1.3 Develop and follow protocols and mechanisms for ensuring the full participation of families, youth, and advocacy organizations in decision-making, governance, and evaluations.	Project Director, AIACC	10/01/10
1.4 Hire research assistant.	Project Director, AIACC, DMH	10/15/10
1.5 Hire care coordinator.	Project Director, AIACC, DMH	11/01/10
1.6 Hire formal evaluator and draft evaluation plan.	Project Director, AIACC, DMH	11/01/10 2/01/11
1.7 Hire consultants and develop and implement plans for Continuous Quality Improvement, Systems of Care Development, Family-centered Care/Cultural and Linguistic Competence, and Family/Youth Involvement.	Project Director, AIACC, DMH, Consultants	12/01/10 3/01/11

<p>1.8 Identify and organize formal and informal supports to facilitate development of IIP.</p>	<p>Project Director, Care Coordinator</p>	<p>12/01/10</p>
<p>1.9 Complete and disseminate Service Provider Standards of Practice for Regional Networks of Care.</p>	<p>Project Director, Care Coordinator, AIACC</p>	<p>2/01/11</p>
<p>1.10 Review and analyze policies and procedures (legislative, organizational, multi-agency) and identify those that hinder or support the network of care development and implementation.</p>	<p>Project Director, Research Assist, Evaluator</p>	<p>2/01/11</p>
<p>1.11 Generate inventory of</p> <ul style="list-style-type: none"> <li>- required data elements from statutes, rules, and laws for service plans</li> <li>- common elements among existing service plans,</li> <li>- additional required elements for some, and</li> <li>- additional information required to meet federal and state laws or rules.</li> </ul>	<p>Project Director, Research Assist, Care Coordinator</p>	<p>2/01/11</p>
<p>1.12 Review collaborating agency organizational structure to inform building of collaborative governance structure.</p>	<p>Project Director, Care Coordinator, AIACC, DMH</p>	<p>4/01/11</p>
<p>1.13 Draft principles and values for inclusion in IIP Draft Guide.</p>	<p>Project Director, Care Coordinator, AIACC</p>	<p>4/01/11</p>
<p>1.14 Develop certification application package for Regional Networks of Care service providers (e.g., guide with measurement criteria, process, and application).</p>	<p>Project Director, Care Coordinator, AIACC, ADMH</p>	<p>5/01/11</p>
<p>1.15 Define State Infrastructure for interagency organization.</p> <ul style="list-style-type: none"> <li>- Structure of governing body</li> <li>- Decision-making process and oversight</li> <li>- Identification and roles of participants</li> <li>- Define services to be provided</li> <li>- Establish formal links between lead agency and other agencies</li> <li>- Define referral and intake mechanisms</li> </ul>	<p>Project Director, AIACC, DMH</p>	<p>6/01/11</p>

1.16 Determine plans to be coordinated through the IIP.	Project Director, AIACC, DMH	6/01/11
1.17 Define communications protocol that outlines protocols between participants, State and local governments, the public, elected officials, current and potential funders, families, and other audiences identified by stakeholders.	Project Director, Care Coordinator, AIACC, DMH	7/01/11
1.18 Identify pilot site for first Regional Network of Care.	Project Director, AIACC, DMH	7/01/11
1.19 Generate <i>Pilot Guide: Starting a Regional Network of Care</i>	Project Director, Care Coordinator, AIACC	8/01/11
1.20 Identify and make available documents, materials, and resources other than English that have been useful in systems of care.	Project Director, Care Coordinator	8/30/11
1.21 Identify and utilize pool of cultural brokers who will assist families in increasing access and decreasing disparities.	Project Director, Care Coordinator	8/30/11
1.22 Put into place memoranda of understanding to detail roles, responsibilities, and relationships among stakeholders.	Project Director, AIACC, ADMH	8/30/11

**Year Two:**

Objective 3: Create foundation for pilot site Regional Network of Care as informed by the State infrastructure planning.

Objective 4: *Generate Care Coordination Guidelines/Training Modules and Individualized Interagency Intervention Plan (IIP) and Guide.*

2.1. Provide on-going Consultant training in identified areas including Continuous Quality Improvement, Systems of Care Development, Family-centered Care/Cultural and Linguistic Competence, and Family/Youth Involvement.	Project Director, Consultants, Care Coordinator	9/10/11

2.2. Continue identifying and utilizing (a) pool of cultural brokers and (b) non-English SOC information.	Project Director, Consultants, Care Coordinator	9/10/11
2.3. Detail care coordinator responsibilities and requirements.	Project Director, Care Coordinator, AIACC	10/01/11
2.4 Identify IIP data tracking system, data elements, and arrangement of data elements.	Project Director, Care Coordinator, Research Assist, Evaluator	10/01/11
2.5 Survey families to assess access to services and supports.	Project Director, Care Coordinator, Research Assist, Evaluator	11/01/11
2.6 Survey service providers to identify available services.	Project Director, Care Coordinator, Research Assist, Evaluator	11/01/11
2.7 Analyze regional environmental strengths, weaknesses, opportunities, and threats.	Project Director, Care Coordinator, AIACC	12/01/11
2.8 Map resources, partnerships, and assets.	Project Director, Care Coordinator, AIACC	1/01/12
2.9 Schedule and hold public forum to gather information on what different stakeholders want in a Regional Network of Care.	Project Director, Care Coordinator, AIACC	2/01/12
2.10 Create regional advisory board of stakeholders and agency representatives.	Project Director, Care Coordinator, AIACC	3/01/12
2.11 Increase provider and consumer awareness of importance of early screening of children for ASD and related disorders through a state-wide <i>Learn the Signs. Act Early.</i> campaign.	Project Director, Care Coordinator, AIACC	3/01/12
2.12 Evaluate current fiscal utilization.	Project Director, Care Coordinator,	3/01/12

	Evaluator, AIACC, DMH	
2.13 Develop process for case coordination, case review, and continuous quality assurance.	Project Director, Care Coordinator, AIACC, DMH	4/01/12
2.14 Identify strengths of stakeholders and agencies for collaboration.	Project Director, Care Coordinator, AIACC	4/01/12
2.15 Complete a cost analysis for the pilot regional network.	Project Director, AIACC, DMH	5/01/12
2.16 Generate Draft (a) Care Coordination Guidelines and (b) IIP and Guide.	Project Director, Care Coordinator, AIACC	5/01/12
2.17 Create IIP crisis plan format and procedures.	Project Director, Care Coordinator, AIACC, DMH	5/01/12
2.18 Disseminate Draft (a) Care Coordination Guidelines and (b) IIP and Guide, request feedback, and make needed revisions.	Project Director, Care Coordinator, Research Assist	6/01/12
2.19 Detail services to be provided at pilot site Regional Network of Care.	Project Director, Care Coordinator, AIACC, DMH	6/01/12
2.20 Secure approvals for IIP to replace pre-determined existing service plans.	Project Director, AIACC, DMH	7/01/11
2.21 Develop and implement social marketing plan, regional evaluation plan, and sustainability plan.	Project Director, Care Coordinator, AIACC, Consultants	7/01/11
2.22 Design Care Coordination training plan and modules.	Project Director, Care Coordinator, AIACC	8/01/12
2.23 Finalize Regional Network Evaluation Plan.	Project Director, AIACC, DMH,	8/30/12

	Evaluator	
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**Year Three:**

Objective 5. Implement pilot site Regional Network of Care.

3.1 Begin pilot site care coordination services.	Project Director, Care Coordinator, AIACC, DMH	9/01/12
3.2 Provide on-going training and technical assistance to pilot site.	Project Director, Care Coordinator, AIACC, Consultants	9/01/12
3.3 Provide on-going Consultant training in identified areas including Continuous Quality Improvement, Systems of Care Development, Family-centered Care/Cultural and Linguistic Competence, and Family/Youth Involvement.	Project Director, Care Coordinator, Consultants	9/01/12
3.4 Continue identifying and utilizing (a) pool of cultural brokers and (b) non-English SOC information.	Project Director, Care Coordinator, Consultants	9/01/12
3.5 Organize and distribute an Alabama Lifespan Resource Tree and Directory.	Project Director, Research Assist, AIACC	2/01/13
3.6 Create and distribute an Alabama Family Navigation Guide to Services for ASD and related disorders.	Project Director, Care Coordinator, Research Assist, AIACC	5/01/13
3.7 Elicit feedback from all stakeholders to inform revision of process as needed.	Project Director, Care Coordinator, Research Assist, AIACC, DHM, Evaluator	6/01/13
3.8 Evaluate pilot site effectiveness of services, training, technical assistance, and revise as needed.	Project Director, Care Coordinator, Research Assist, AIACC, DMH,	7/01/13

	Evaluator	
3.9 Evaluate effectiveness of <i>Pilot Guide: Starting a Regional Network of Care</i> and revise as needed.	Project Director, Care Coordinator, Research Assist	7/01/13
3.10 Identify pilot replication sites throughout the state.	Project Director, Care Coordinator, AIACC, DMH	7/01/13
3.11 Disseminate Project initiatives and results to audiences at events, conferences, state and national events.	Project Director, Care Coordinator AIACC, DMH,	8/30/13