

2007-2008 Alabama Autism Task Force

Recommendations for Consideration

Subcommittee Work Plan

Name of Subcommittee: Diagnosis & Early Screening

Committee Chair: Hanes Swingle, M.D.

Diagnosis & Early Screening Subcommittee

- Findings reported by the Alabama Autism Collaborative Group indicate that Alabama is behind the national average when it comes to identifying and diagnosing children with an autism spectrum disorder (ASD; i.e., autism, Asperger syndrome, pervasive developmental disorder) at an early age. They found that, in Alabama, more than 50% of survey respondents reported their children were diagnosed *after* the age of three. Further, families reported an average delay of 37 months between their first concerns and when their children received an ASD diagnosis.
- Early identification of children with ASD is the prerequisite for providing early intervention services, which have unequivocally been shown to improve the outcome for children with ASD. To improve the quality of care for children with ASD in Alabama, the Alabama Autism Task Force Diagnosis and Early Screening Sub-Committee recommends statewide changes in diagnostic services, early screening within the health care setting, screening within the early intervention service provider setting, and public awareness and education.

Diagnostic Services

Current Status: The increasing number of young children being identified as showing symptoms of ASD will tax the already limited capacities of existing diagnostic centers and service providers. Currently, health care providers and parents experience long delays in obtaining diagnostic evaluations from specialists in ASD. Delays result for a variety of reasons including limited trained professionals in the state and limited capacity of the existing diagnostic facilities in the state.

Further, families report difficulties using the results of these evaluations to obtain services for their children due to different diagnostic criteria across state agencies. Finally, as the definition of ASD has expanded to include individuals with both severe autism and Asperger's syndrome, there is a growing need for ASD-specific services that can address the diagnostic needs of individuals across the lifespan and across a wide range of intellectual ability

Research: Autism spectrum disorders affect social development, verbal and nonverbal communication skills, age-appropriate play skills, and cognitive development (American Psychiatric Association, 2000). Thus, a diagnosis of ASD requires an interdisciplinary assessment of each of these domains conducted by team of professionals with expertise in ASD (National Research Council, 2001). The American Academy of Neurology (Filipek et al., 2000) and the American Academy of Pediatrics (Johnson et al., 2007) identified very similar essential elements in the comprehensive evaluation of children suspected of having ASD. The following list is a combination of recommendations across both academies:

- ASD-specific parent interview (e.g., the Autism Diagnostic Interview-Revised)
- ASD-specific behavioral observation session (e.g., the Autism Diagnostic Observation Schedule)
- Psychological evaluation (including measures of developmental/intellectual and adaptive functioning)
- Speech, language, and communication assessment
- Medical assessment by a developmental pediatrician or neurologist, including medical history, a physical examination to detect dysmorphic features and neurologic abnormalities, and a Wood's lamp examination of the skin
- Genetic testing (i.e., high-resolution karyotype, DNA testing for fragile X syndrome, MeCP-2 testing, and a comparative genomic hybridization microarray), a lead level, and genetic counseling should be considered in all children with an ASD
- Although not considered essential, due to the sensory motor difficulties present in ASD, it is often beneficial to include an occupational and/or physical therapist in the diagnostic team
- Assessment of the parent's knowledge of ASD, coping skills, and available resources and supports

Diagnostic Services *(cont'd)*

	<u>Action Items</u>	<u>Leads</u>	<u>Timeline</u>
	<p>The Alabama Autism Task Force recommends establishment of University-Based Regional Interdisciplinary Diagnostic Evaluation Clinics that provide assessments by psychologists, speech/language specialists, education specialists, physicians (e.g., pediatric neurologists, child psychiatrists, developmental-behavioral pediatricians, geneticists), occupational therapists, and other allied healthcare providers. A regional center diagnostic clinic approach would provide greater access to services for families from all areas of the state.</p>		
	<p>Regional Autism Centers work collaboratively to develop a protocol of standardized assessments when evaluating children suspected of autism spectrum disorders. At a minimum, these evaluations should include a standardized ASD-specific behavioral observation (e.g., the Autism Diagnostic Observation Schedule), an ASD-specific caregiver interview (e.g., the Autism Diagnostic Interview), a standardized cognitive/intellectual assessment, a standardized language/communication assessment, a medical evaluation and a vision and hearing screen.</p>	Regional Center	
	<p>After a child is diagnosed with an ASD at one of the Regional Autism Centers, it is recommended that all agencies that receive state funding (e.g., public schools, mental health facilities, Early Intervention) should accept the diagnosis and provide appropriate services. Thus, the regional centers should work with each state agency to ensure that the necessary assessment information is collected to meet agency requirements.</p>	Regional Center, all public agencies	

Diagnostic Services (cont'd)

<u>Action Items</u>	<u>Leads</u>	<u>Timeline</u>
Regional Autism Centers should provide student practicum and internship training opportunities to promote the development of well-trained ASD professionals entering the workforce. These training opportunities should, at a minimum, include students in education, communicative disorders, psychology, medicine, nursing, social work, and occupational/physical therapy.	Regional Center, universities	
Regional Autism Centers should collaborate with the State Department of Education to develop guidelines for school personnel to make referrals for school-aged children suspected of autism or Asperger syndrome who have not been identified prior to school entry.	Regional Center, State Department of Education	
Third party payors should cover the costs associated with an interdisciplinary diagnostic evaluation.	Insurance companies	

Early Screening: Health Care Settings

Current Status: Barriers to implementation of early screening include lack of familiarity of health care providers with screening instruments, time constraints in administering and discussing screening results, third party payor reimbursement, and lack of knowledge of how to proceed after a child has failed a screening instrument. The American Academy of Pediatrics (AAP) published guidelines supporting the early identification of children with ASD (Johnson & Myers, 2007) that recommended both broad development screening and ASD-specific screening at the 18 and 24 month well-child healthcare visits.

Research: This sub-committee reviewed existing screening instruments and identified two instruments that currently provide the best sensitivity and specificity values:

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).

The *Modified Checklist for Autism in Toddlers (M-CHAT)*; Robins et al., 2001) was identified as 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). 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).

Early Screening: Health Care Settings (cont'd)

	<u>Action Items</u>	<u>Leads</u>	<u>Timeline</u>
	<p>The Alabama Autism Task Force recommends that all health care practitioners who provide primary care to young children provide universal screening and surveillance for developmental delays/disabilities and for autism spectrum disorders. Health care practitioners are encouraged 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, two instruments meet these criteria: the <i>Communication and Symbolic Behavior Scales Infant Toddler Checklist</i> and the <i>Modified Checklist for Autism in Toddlers</i> with the associated caregiver interview.</p> <p>In order to fulfill this recommendation, The Alabama Autism Task Force recommends that the University Based Regional Autism Centers, in collaboration with Alabama Chapter of the American Academy of Pediatrics (AAP), the Medical Association of the State of Alabama (MASA), Alabama Department of Rehabilitation Services, and the Autism Society of Alabama (ASA), promote and conduct the following activities to overcome the barriers to screening:</p>		
	<p>Encourage third party payors to reward health care practitioners who routinely provide general developmental and ASD-specific screening (i.e., provide a greater level of reimbursement to providers who administer ASD-specific screening).</p>	Insurance companies	

Early Screening: Health Care Settings (cont'd)

	<u>Action Items</u>	<u>Leads</u>	<u>Timeline</u>
	Develop and disseminate educational materials for health care providers in Alabama that both describes the CSBS ITC and the M-CHAT and provide information about the referral process when concerns arise during screening. These “training kit” materials could be presented via a brochure, a training DVD, and online formats.	Regional Center	
	Organize and conduct regional and state training for health care professionals on early identification of ASD, administration of the CSBS ITC and the M-CHAT, and referral for follow-up services.	Regional Center	
	Provide onsite training and assistance to health care providers to facilitate screening and referral approaches for children who are identified as being at-risk for ASD.	Regional Center	

Early Screening: At-Risk Early Service Providers

Current Status: The Alabama Autism Task Force acknowledges that universal developmental and ASD-specific screening will increase the number of young children identified as being at-risk for an autism spectrum disorder. As a result, the current state Early Intervention programs will be overwhelmed by the number of health care provider referrals that they receive.

Research: Many early intervention programs measure success by IQ and language gains (Matson, 2007). However, to maximize outcomes for children with ASD in early intervention settings, it is important that the core impairments of autism be measured including social skills, nonverbal communication (gestures, eye gaze), and repetitive behaviors. Evaluations that directly measure features unique to ASD offer the best opportunities for early interventionists to observe these behaviors and to subsequently develop appropriate intervention goals. In addition to the ASD-specific screening tools discussed above (CSBS-ITC and the M-CHAT), three tools were identified that evaluate communication, behavior, and play skills that are associated with ASD:

- The Early Social-Communication Scales (ESCS, Mundy et al., 2003) is a brief play assessment appropriate for 8-30 month old children that measures joint attention, behavioral requests, and social interaction.

The Ages and Stages Questionnaire-Social Emotional Questionnaire (ASQ:SE; Squires, Bricker, & Twombly, 2002) is a parent questionnaire appropriate for 6-60 month old children that measures self-regulation, compliance, affect, adaptive behaviors, and social interaction.

Early Screening: At-Risk Early Service Providers (cont'd)

The Alabama Autism Task Force recommends that all agencies working with at-risk young children (e.g., Early Intervention, Early Head Start) conduct ASD-specific screening among the population of children they serve.

In order to fulfill this recommendation, The Alabama Autism Task Force recommends:



	<u>Action Items</u>	<u>Leads</u>	<u>Timeline</u>
	The Regional Autism Centers should consult and provide instruction on ASD-specific screening instruments to be used in at-risk intervention settings and provide prompt specialized diagnostic evaluations for children who fail these screenings	Regional Center, Early Intervention	
	Early Intervention should develop a partnership with referring physicians and provide timely feedback regarding assessments, treatments and progress of the children they serve.	Early Intervention, physicians	

Early Screening: At-Risk Early Service Providers (cont'd)

The Alabama Autism Task Force recommends that early intervention providers administer an evaluation tool that directly measures behaviors that are unique to ASD. This evaluation may be administered in addition to the evaluation measures typically administered to determine eligibility for early intervention services.

In order to fulfill this recommendation, The Alabama Autism Task Force recommends:



<u>Action Items</u>	<u>Leads</u>	<u>Timeline</u>
<p>The Regional Autism Centers should provide instruction on tools such as the CSBS, ESCS, and ASQ:SE that may be incorporated into the assessment protocol administered by early interventionists.</p> <p>These assessments are not designed to diagnose ASD, but rather to identify developmental goals related to ASD-specific difficulties in social interaction and nonverbal communication.</p>	Regional Center, Early Intervention	

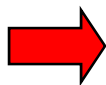
Public Awareness

Current Status: Statewide polling conducted by the University of South Alabama in collaboration with The Alabama Autism Collaborative Group revealed that autism awareness is currently high among Alabama residents. Among those polled, 80% indicated they viewed autism to be a significant problem and one in five reported that someone close to them has autism. While awareness in Alabama is high, families and pediatricians report lack of knowledge about what to do when concerns arise and about available resources.

	<u>Action Items</u>	<u>Leads</u>	<u>Timeline</u>
	Future public awareness campaigns should promote the early signs or “Red Flags” of autism spectrum disorders <i>and</i> delineate the <u>actions</u> that parents and health care providers need to follow to ensure that children with ASD are identified early. Such actions include encouraging parents to voice their concerns and to request developmental and ASD-specific screening from their child’s health care provider. The awareness campaign should provide parents and health care providers with the phone number of the Autism Regional Centers and promote referral to service providers through Child Find (1-800-543-3098).	Regional Center, ChildFind	
	The Alabama Autism Task Force recommends that the Autism Society of Alabama (or other advocacy agency) receive grant funding to collaborate with a public relations agency to direct an education campaign on ASD screening and referral for diagnostic and intervention services.	Autism Society of Alabama	

Public Awareness

The following is recommended for Continuing Medical Education:



	<u>Action Items</u>	<u>Leads</u>	<u>Timeline</u>
	The Center for Disease Control considers the high prevalence of ASDs to be an urgent public health concern. Thus, it is important for physicians and other health care providers to be educated about ASD including information on the prevalence of the disorder, identifiable causes, screening, diagnosis, co-morbidities, recurrence risks, medical treatment, complimentary and alternative therapies, educational and behavioral management, and prognosis.		
	The Alabama Autism Task Force encourages state medical licensing boards to require one hour of Continuing Medical Education on autism spectrum disorders for license renewal.		

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Subcommittee Work Plan

Name of Subcommittee: Interventions – Birth to Five

Committee Chair: Elizabeth Griffith, PhD

Birth to Five Subcommittee

- The Birth to Five Subcommittee was formed with the vision of having a system that truly served children from birth until they entered Kindergarten.
- The under-five population has unique needs and challenges. This is the age-range in which first concerns are raised for families, diagnosis will (hopefully) occur, services will first be accessed and early interventions put into place. Research indicates that the largest gains are made when children receive intensive evidence-based services prior to turning five, yet existing services and funding are minimal and there is a fundamental shift in the responsible agency in the midst of this vital period of development, and even diagnostic discovery.

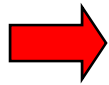
Birth to Five Subcommittee

- It is our short-term goal that better coordination exist across all of the agencies currently serving children in the years before they attend Kindergarten, including but not limited to Early Intervention, Early Head Start, Head Start, Special Education preschools and Pre-K.
- However, it is our long-term goal that there be a single agency serving children with special needs across these critical years.
- The following summarizes our four primary goals (Family Support and Training, Evidence-Based Accessible Services, Service Coordination, Inclusion in Home Communities) and the action items we believe necessary in order to reach these goals.

Family Support and Training

Current Status: Families report that services are difficult to access and that needed resources are often far from their homes.

Families will have access to the information, support (empowering families), training (specific term used for teaching skills), and resources they need in their home community.

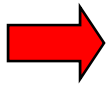


<u>Action Items</u>	<u>Suggested Leads include, but are not limited to</u>	<u>Timeline</u>
A Parent-to-Parent network will be developed or piggy-backed onto existing systems that will allow veteran parents to be well trained to then provide support to those parents whose child is newly diagnosed.	ST: ASA, Parents as Partners in Education, ADRS-CRS Parent Network, ADRS-EI, DOE, Early Start/Head Start and Pre-K, Parents/primary caregivers LT: Regional Centers	Shorter Term
Gaps in provision of information, support and training for caregivers will be identified and local agencies will be recruited to provide these services in these communities.	ST: Council, ASA, AAP, AAFP, Parents/Caregivers, DHR (foster care), Gov's Task Force on Strengthening AL Families (Family Resource Centers); PAL, 211 LT: Regional Centers	On-going
Parent training and support will be individualized	All providing agencies	On-going

Family Support and Training

Current Status: Families report that services are difficult to access and that needed resources are often far from their homes.

Families will have access to the information, support (empowering families), training (specific term used for teaching skills), and resources they need in their home community.

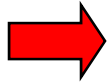


<u>Action Items</u>	<u>Suggested Leads include, but are not limited to</u>	<u>Timeline</u>
Web Directory of services in local communities will be enhanced, revised, and updated with additional information from local communities. A statewide calendar of ASD related events will be maintained.	ASA, Autism State Coordinator	Shorter Term
Existing community supports (ex. Churches and other local supports that people are already comfortable with) will be made aware of the needs of children with ASD and their families in order to better support them.	ST: ASA LT: Regional Centers, ASA	Shorter Term

Evidence-Based Accessible Services

Current Status: Children most often receive services based on the availability of funding and service providers and on the training of the available service providers, rather than having services that match their individual needs and that utilize techniques that are evidence-based and best practice. Children in many areas across the state have no service providers with ASD training or training in evidence-based treatments demonstrated to work for children with ASD in their home communities.

Children will receive individualized evidence-based and best practice treatments which are readily available in their home communities



	<u>Action Items</u>	<u>Suggested Leads include, but are not limited to</u>	<u>Timeline</u>
	There will be a mechanism to review the evidence-base on evaluation, assessment, and diagnostic criteria at regular intervals and update providers and families on best practices	ST: UCEDD & University Collaborators LT: Regional Centers	Medium Term
	Children will be allowed to access services under more flexible eligibility criteria (i.e. those that take into account social-emotional, adaptive, and functional deficits as well as communication, academic, and cognitive) that are consistent across all publicly funded service systems	AEIS, SDE, Early Start/Head Start, Pre-K, AAP	Medium Term
	There will be a mechanism to review the evidence-base on treatments at regular intervals and update providers and families on best practices	ST: UCEDD & University Collaborators, AAP, AAFB LT: Regional Centers	Medium Term

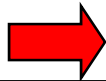
Evidence-Based Accessible Services (cont'd)

	<u>Action Items</u>	<u>Suggested Leads include, but are not limited to</u>	<u>Timeline</u>
	National recommendations and recommendations from updated reviews of the evidence-base will be given to all providers and parents (e.g. given at diagnosis and with the Parent Rights statement at IFSP/IEP) in an easily digestible format	ST: UCEDD & University Collaborators LT: Regional Centers	Medium Term
	Providers in local communities will be trained to provide a variety of specific, targeted, developmentally appropriate, and intensive evidence-based treatments to fidelity using didactic presentations, experiential learning (onsite and hands-on), and ongoing consultation and coaching	ST: AEIS, SDE, UCEDD, Teacher training programs LT: Regional Centers	Medium Term
	Provision for ongoing consultation and coaching with treatment experts will be readily available so that providers can easily update their skills.	ST: AEIS, SDE, UCEDD, Teacher training programs LT: Regional Centers	Longer Term
	Data based decision making (e.g. data on measurable, observable behaviors and skills will be taken at baseline and following brief periods of intervention) about treatment strategies and efficacy for each child will be used. Strategies will be changed if progress is not being observed.	ST: AEIS, SDE	On-going

Service Coordination

Current Status: Children transition at age 3 years from AEIS which is family-centered and provides parent training in the natural environment to SDE where eligibility requirements differ, service coordination ceases, and which may be in the natural environment or a classroom setting dependent on location rather than individualized needs. Although there is some preparation for this shift, it occurs at a bad time in the developmental course of ASD, around the time of first diagnosis.

Children and families will experience a seamless transition between interventions/agencies through service coordination that is maintained from birth to five years of age



	<u>Action Items</u>	<u>Leads</u>	<u>Timeline</u>
	Service Coordination (Case Management) will be provided by all agencies providing services to this population to ensure a seamless transition from time of screening to diagnosis to intervention, and across the age range	ST: Gov's ICC for EI, Pre-KLT: 0-5 Agency?	Shorter Term
	Service Coordinators will be trained to provide support to families and to track children and their services from screening to diagnosis and through the transition to Kindergarten	ST: Gov's ICC for EI, Pre-K, Medicaid: 0-5 Agency?	Shorter Term
	Service Coordination will also ensure that families have knowledge about their rights, the process involved in obtaining services from local agencies, and their choices of service providers	ST: Gov's ICC for EI, Pre-KLT: 0-5 Agency?	Shorter Term
	Service Coordination will also ensure a seamless transition from AEIS (or other agency providing early intervention services) to SDE (or other referral source chosen by the family) at three years of age by ensuring that transition meetings are held, a plan is in place, and there is no lapse in services when a child turns three years of age - EI provides services up until the last eligible day and SDE begins services on the first eligible day	ST: Gov's ICC for EI, Pre-KLT: 0-5 Agency?	Shorter Term
	Alteration to the funding streams will be advocated and considered to ensure seamless services and to allow positive effects of early investments to be experienced by the same funding agency	Gov's ICC for EI, Pre-K, MHMR, Health Agency, Children's Affairs	Longer Term

Inclusion in Home Communities

Current Status: Families report being unable to function in their home communities in the manner that other families do due to a lack of understanding by local organizations.

	<u>Action Items</u>	<u>Suggested Leads include, but are not limited to:</u>	<u>Timeline</u>
	Local community organizations (churches, daycare centers, YMCA) will receive awareness information regarding ASD	ASA, Gov's Task Force on Strengthening AL Families (Family Resource Centers)	Shorter Term
	Local community organizations will receive information regarding strategies for effective integration of children with ASD and their families	ASA, UCEDD, Gov's Task Force on Strengthening AL Families (Family Resource Centers)	Shorter Term

Subcommittee Work Plan

**Name of Subcommittee: Interventions –
Six to Twenty-One**

Committee Chair: Jim Wrye

Subcommittee Work Plan

Name of Subcommittee: Interventions – Adult

Committee Chair: Joe Carter

Adult Subcommittee

- Autism Spectrum Disorder (ASD) is a lifelong condition. Three quarters of a person's life, including those living with ASD, will be spent in adulthood. Yet currently, services specific to adults with autism are almost non-existent in the state of Alabama. The only advocates for adults with ASD are the parents (worn out after twenty years of advocating) and the few service providers willing to take on this population. Reaching the age of adulthood does not lessen the needs of vulnerable adults with ASD, nor our responsibility to help them.

Adult Subcommittee

RANGE OF HOUSING OPTIONS AND ALTERNATIVES:

- Forcing adults with autism to assume the role of “forever children”, living at home with their parents without services or supports is not an acceptable option for Alabama. Placing the aging, exhausted parents of an adult with autism in the position of providing 24-hour care to their adult family member, often until a “crisis” occurs, is equally unacceptable.
- The needs of individuals with autism are often intense and require a highly specialized program. Reimbursement rates are typically low, so providers typically gravitate toward serving clients with less intensive needs than those with autism.
- Recommendation: The Adult Intervention Subcommittee recommends the establishment of a continuum of residential options specific to individuals with ASD, accessible in each region of the state. Services for adults with autism should include:
 - In-home Services- Assistance and training in the home for adults whose families want to continue to provide care in their home.
 - Respite Care – Respite to families, both in-home and out-of-home, to allow families the time to devote to other family activities and for a break from the responsibilities of 24-hour care.
 - Intermittent Services- As needed, intermittent services for those adults who do not need 24-hour care but who do need assistance in particular areas of their daily living.
 - Out-Of-Home Residential Placements- Small, 3 to 4 bed, group homes or apartments in each region of the State with programming and supports specific to the needs of individuals with autism.

Adult Housing Options & Alternatives *(cont'd)*

RANGE OF
HOUSING
OPTIONS AND
ALTERNATIVES



<u>Interagency Strategy</u>	<u>Short-term deliverables</u>	<u>Leads</u>	<u>Timeline</u>
Identify existing providers and the housing options available for adults with autism (in-home, respite, intermittent, out of home) across the state.	Develop a listing of providers and the housing options available specific to adults with autism within each region of the State.	Interagency Council Autism Provider Group	

Develop a System to Identify the Number of Adults with Autism in Alabama

Current Status: There is no statewide system in place to identify the number of adults with autism in need of services.

Information on the number in need of services and the type of services needed is critical in order to develop plans and determine the resources needed in the State. Currently, the state of Alabama has a long waiting list for services through the Alabama Department of Mental Health and Mental Retardation. We do not have an accurate number on how many of these individuals have autism. We estimate that there may be approximately 40% of the individuals in need of supports who are not eligible for services through DMH/MR, and they are not included in the waiting list for services.

<u>Interagency Strategy</u>	<u>Short-term deliverables</u>	<u>Leads</u>	<u>Timeline</u>
Identify existing providers specific to autism services across the state.	A listing of autism specific services available in each region of the state.	Interagency Council with the Autism Provider Group.	
Identify the number of adults being served through existing autism services and a projection of those waiting for services, by region.	A listing of the number served by region, with a projection of those on waiting lists for services.	Interagency Council with the Autism Provider Group.	
Add an indicator for autism on the Waiver waiting list for services	The Waiver waiting list will indicate the number of people with autism waiting for services.	DMH/MR	
Identify those young adults transitioning from school.	A listing of the number of young adults transitioning from school who will be in need of services or supports within the next 3 years.	SDE – Child Find and Child Count Systems	

Promote Employment Opportunities for Adults with ASD

Current Status: Lack of knowledge in Autism Spectrum Disorders and the supports needed to address the range and types of challenges individuals may face in the workplace, in combination with large case loads by professionals, contribute to decreased success rate with employment of individuals with ASD. In addition, Vocational Rehabilitation is set up as a time limited program, and the needs of someone with ASD are not commonly seen as time limited.

<u>Interagency Strategy</u>	<u>Short-term deliverables</u>	<u>Leads</u>	<u>Timeline</u>
Vocational services must be defined and offered in a manner appropriate to adults with ASD. The eligibility for services and length of time supports are in place should be redefined for people with ASD.			
Develop effective training and resources for young adults transitioning from school to work.	Identify/develop model programs to support young adults with ASD transitioning from school to work. Identify/develop model programs to support adults with ASD to gain and maintain integrated community employment.	SDE and VRS VRS and Providers	
Identify the employment needs of adults with ASD	Conduct a statewide survey of employment needs of individuals with autism.	VRS	

Remove Transportation Barriers

Current Status: Lack of transportation was noted by some individuals as a barrier to services and a barrier to participation in activities promoting an integrated community life for individuals with ASD.

<u>Interagency Strategy</u>	<u>Short-term deliverables</u>	<u>Leads</u>	<u>Timeline</u>
Identify the extent of existing transportation barriers to services or community involvement.	Conduct a survey of the transportation barriers encountered by individuals with ASD and the extent these have interfered with services, employment and participation in other activities of community living.	Interagency Council	

Adequate Funding for Services

Current Status: Services specific to adults with autism are almost non-existent in the state of Alabama. The only advocates for adults with ASD are the parents (worn out after twenty years of advocating) and the few service providers willing to take on this population. The needs of individuals with autism are often intense and require a highly specialized program. Reimbursement rates are typically low, so providers typically gravitate toward serving clients with less intensive needs than those with autism. In addition, the reimbursement rates for adults with autism are less than the reimbursement rates for children, because Education funding is no longer available. Therefore, there is little incentive to provide services to adults with autism.

<u>Interagency Strategy</u>	<u>Short-term deliverables</u>	<u>Leads</u>	<u>Timeline</u>
We recommend that services to individuals with autism be life-long rather than time sensitive. To terminate support to individuals because they have reached 21 years of age is not appropriate. The Subcommittee understands the limitation of resources within the state of Alabama. However, the quality and quantity of services for adults with autism is dependent upon an adequate amount of funding to support programs specific to autism. We recommend that funding for adults with autism should be maintained at current levels or ideally be increased.			

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<u>Interagency Strategy</u>	<u>Short-term deliverables</u>	<u>Leads</u>	<u>Timeline</u>
Increase incentives for program development specific to adults with autism within each region of the State.	Evaluate the difference in reimbursement rates between programs for children with autism versus the reimbursement for programs specific to adults with autism. Evaluate the difference in reimbursement rates between programs for adults in the DMH/MR system and the reimbursement rates for programs specific to adults with autism.	SMH/MR SMH/ M	

Community Awareness of Adults' Needs

Current Status: Adults with ASD need access to people who understand autism. Many live isolated lives and have little to no access to the typical community-church, exercise center, a friend with whom to go to the movies. Sometimes, this social unawareness results in severe personal problems and even problems with law enforcement. The community more naturally understands the needs of children. Reaching the age of adulthood does not lessen the needs of vulnerable adults with ASD.

<u>Interagency Strategy</u>	<u>Short-term deliverables</u>	<u>Leads</u>	<u>Timeline</u>
The Subcommittee recommends an ASD awareness campaign to include the needs of adults with ASD, specifically to assist adults with integration into community.			
Coordinate public awareness efforts to bring attention to the needs of individuals with ASD, specifically adults.	Opportunities to link public awareness activities through DMH/MR, SDE, ASA, ACDD and providers.	Interagency Council	Sept. 2009

Case Management Services

Current Status: With adults with ASD, needs are often intense and require highly specialized and individualized programming to help adults become successful or maintain gains. Too often, because of the lack of services specific to adults with autism, families are referred from one contact person to the next. A knowledgeable and accessible case manager is critical to helping individuals and their families with appropriate service provision.

<u>Interagency Strategy</u>	<u>Short-term deliverables</u>	<u>Leads</u>	<u>Timeline</u>
<p>The Subcommittee recommends the system for access to case management and case coordination should be easy for families and individuals and recommends the development of regional service coordination for Autism Spectrum Disorders.</p>			
<p>Develop a provider directory to identify local services within each region of the State for individuals with ASD.</p>	<p>Identify resources available to adults with ASD within each region of the State.</p>	<p>Interagency Council Autism Provider Group DMH/MR ASA VRS</p>	
<p>Develop a system to communicate local services available to adults with ASD within each region of the State.</p>	<p>Disseminate the provider directory to each regional community services office, VRS office and ASA chapters/websites. Identify a central contact within each region of the State.</p>	<p>Interagency Council Autism Provider Group DMH/MR ASA VRS</p>	

Training for Emergency Response Personnel

Current Status: Children with ASD grow up to be adults with ASD. Sometimes, individuals with ASD still have behavior concerns as adults, and might run into the law enforcement or emergency response personnel. Emergency responders may not have an awareness of ASD or an understanding of the methods to use to best maintain the safety of the individual.

<u>Interagency Strategy</u>	<u>Short-term deliverables</u>	<u>Leads</u>	<u>Timeline</u>
<p>We recommend developing a requirement for ongoing training for law enforcement and other emergency responders in Alabama. Training to include Autism and Law Enforcement training and videos by Dennis Debbaudt. Training needs to include emphasis on entire autism spectrum, including autism and Asperger's Syndrome. Training should assist in:</p> <ul style="list-style-type: none"> -Becoming Americans with Disabilities Act (ADA) compliant -Increasing responder and citizen safety -Enhancing response skills -Avoiding litigation -Building community partnerships -Increasing awareness of Autism Spectrum Disorders 			
<p>Identify recommended training for emergency response personnel.</p>	<p>Review training and videos by Dennis Debbaudt and other sources. Recommend/provide information on training to emergency responders within each region of the State. Survey emergency responders for training currently received on autism or developmental disabilities.</p>	<p>Inter-agency Council ASA chapters</p>	

Subcommittee Work Plan

Name of Subcommittee: Healthcare/Medical/Ad Hoc

Committee Chair: Bama Folsom Hager, PhD

Ad Hoc Subcommittee

- The Statewide Autism Needs Assessment conducted by the Alabama Autism Collaborative Group identified key features of the most effective regional resource centers for autism in the U.S.
- The features include:
 - Interdisciplinary diagnostic services
 - Model intervention programs using evidence based practices
 - Case management and family support
 - Professional training for educators, therapists, and medical professionals. These would include certification programs for professionals and training programs for students.
 - Ongoing consultation to ensure quality service provisions by professionals.
 - Support for basic and intervention research

Regional Center Development

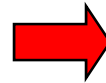
Current Status: The Autism Needs Assessment report described a fractionalized service system for families affected by Autism Spectrum Disorder (ASD). Under the Systems of Care findings of the Needs Assessment report, a disjointed provision of services is described for toddlers, preschoolers, school age children and adults with ASD.

Action Items	Leads	Timeline
The regional resource center development subcommittee identified the coordination of services for ASD throughout the lifespan as a primary responsibility of the regional center.		

Regional Center Development

Current Status: The Statewide Needs Assessment report indicated that many Alabamians affected by ASD are diagnosed on average a year later than the national average age of diagnosis. Many respondents reported difficulty procuring an assessment appointment. As stated at the beginning of this report, the Needs Assessment Committee identified diagnostic services as a desirable goal for a resource center.

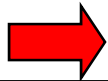
Components
of a
Regional
Center



<u>Action Items</u>	<u>Leads</u>	<u>Timeline</u>
<p>This subcommittee agrees that the proposed <u>regional resource center should be a source for assessment and intervention services information for autism, Asperger's Syndrome and PDD-NOS disorders. Furthermore, <u>the center should serve the entire autism spectrum</u> regardless of the affected child's or adult's IQ or family resources.</u></p>		
<p>As was highlighted in the Systems of Care section of the Needs Assessment report, this subcommittee concurs that <u>the center should be a training site for many professionals</u>—early intervention therapists, physicians, psychologists, speech-language pathologists, teachers, occupational therapists, nurses, therapists and other providers. In particular, the committee discussed the <u>need for pediatrician training and family practice physician training</u> for the screening and diagnosis of ASD.</p>		
<p>The screening and diagnosis subheading of the Needs Assessment report described the difficulties Alabamians reported in finding a qualified professional in their area to diagnose their child or adult family member. In addition, families described difficulties in finding treatment after diagnosis. The regional resource subcommittee recommends that <u>the center should identify a best practices statewide multidisciplinary battery for the assessment of ASD and an agreed upon best practices treatment of ASD. These assessment instruments and treatment recommendations should be research based.</u></p>		

Regional Center Development

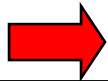
Components
of a Regional
Center *(cont'd)*



<u>Action Items</u>	<u>Leads</u>	<u>Timeline</u>
<p>The Needs Assessment report discussed the need for family support. This subcommittee recommends that <u>the resource center should establish a parent to parent support network</u> to assist families in the transitions from early intervention to preschool to school and to adulthood. In addition, the subcommittee states that <u>the regional resource center for autism should have a working relationship with the Autism Society of Alabama</u>. The Autism Society of Alabama is the leading autism advocacy group in the state and can assist with parent networking and family support.</p>		
<p>Related to the fifth recommendation, <u>a public awareness/education campaign should be in place in conjunction with the development of the center</u>. This campaign will support families affected by ASD by raising awareness of ASD in the general population and nurturing understanding of those affected.</p>		

Regional Center Development

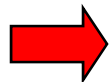
Components
of a Regional
Center *(cont'd)*



<u>Action Items</u>	<u>Leads</u>	<u>Timeline</u>
The interventions for adults subheading of the Needs Assessment report highlighted the many needs of adults affected with ASD in Alabama. Respondents indicated that living arrangements and employment opportunities were the biggest needs for this group. Based on this information, <u>the center should be a resource for information regarding residential placement of an ASD child or adult.</u> In addition, <u>job opportunity information</u> should be incorporated into the resource center mission.		
The Needs Assessment report indicated there are disparities amongst the regions of Alabama in regard to availability of ASD services. The proposed <u>center should assess and identify regions of the state that have deficiencies in ASD services and assist in provision of training to rectify deficiencies.</u>		

Regional Center Development

Components
of a Regional
Center *(cont'd)*



<u>Action Items</u>	<u>Leads</u>	<u>Timeline</u>
The Systems of Care subheading of the Needs Assessment report discusses the need for trained professionals throughout the state. The subcommittee recommends that <u>the regional resource center be a remote consultation site for providers</u> who are working with ASD clients/patients.		
The interventions in early childhood subheading of the Needs Assessment report indicated that families in Alabama are looking for a range of services for their ASD child. The regional resource center subcommittee identified the most frequent requested needs to be <u>IEP training, insurance coverage information, respite care services information and crisis management information and referrals.</u> The center should assist families with <u>young children in these areas.</u>		

*The committee discussed development in the following areas, but postponed discussion of future development until the achievement of the current goals are underway. These future areas of interest include interstate communication, trust planning, grant funding information and remote conferencing capabilities.

Subcommittee Work Plan

Name of Subcommittee: Systems of Care

Committee Chair: Jennifer Sellers, PhD

Systems of Care Subcommittee

- Recommendations for the 2007 Task Force were based on data from informants in forums, focus groups, surveys, and interviews of providers and agencies believed to have been helpful to Alabamians with Autism Spectrum Disorder (ASD).
- The findings from the Alabama Autism Needs Assessment indicated several significant needs. From these needs, the *Task Force recommended that a State Autism Coordinator position be created*. The following contains the job description for the position and a brief explanation of desired areas, skills, and abilities believed to be needed for success of the position.

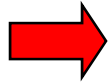
Job Description for State Autism Coordinator

Current Status: An Interagency Council was formed as a result of the 2007 Alabama Autism Task Force recommendations. In addition, it was recommended that a position for Autism Coordinator be created for the state.

The sub-committee reviewed different job descriptions from various states that have similar positions. From the various job descriptions and considering the needs of the state of Alabama as defined in the Statewide Needs Assessment, the subcommittee created a job description below.

State
Autism
Coordinator
Position job
description:

Knowledge

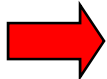


Action Items	Leads	Timeline
ASD through the lifespan	DMH/MR	
Best practices in the field of ASD (e.g. instructional strategies)		
Funding avenues		
Home, educational, and community based services		
Child development		
State Government and Non-governmental agencies		
State and Federal rules and regulations regarding ASD and related subject matter		

Job Description for State Autism Coordinator

State
Autism
Coordinator
Position job
description:

Skills

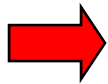


	<u>Action Items</u>	<u>Leads</u>	<u>Timeline</u>
	Collaboration, negotiation, diplomacy, conflict resolution		
	Working with the consumers and families		
	Computer/technology		
	Grant Writing		
	Communication-written and oral		

Job Description for State Autism Coordinator

State Autism
Coordinator
Position job
description:

Abilities



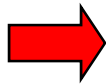
	<u>Action Items</u>	<u>Leads</u>	<u>Timeline</u>
	Financial matters (e.g. budgets, funding sources, grants)		
	Communicate effectively and work with primary and secondary groups (e.g. consumers, interest groups both private and public)		
	Represent the needs and wants of individuals with ASD and their families		
	Professionalism		

Job Description for State Autism Coordinator

Current Status: The last section of recommendations for the position is a list of duties. These duties consist of what the committee believes to be the day-to-day functions of the Coordinator. The committee emphasized the importance of understanding the needs of individuals with ASD, their families, and the roles and services of all service providers. This understanding is key in order to facilitate communication with agencies, interest groups, and stakeholders. The committee also recommends that the coordinator be an advocate for individuals with ASD and their families to public and private service providers and in the political arena. The following are the list of duties:

State Autism
Coordinator
Position job
description:

Duties

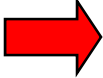


	<u>Action Items</u>	<u>Leads</u>	<u>Timeline</u>
	Bring needs/wants of consumers to the attention of stakeholders		
	Represent consumers and/or families		
	Bring key agencies together		
	Assist in locating and obtaining funding		
	Advocate interests of consumers to key agencies, interest groups, and stakeholders		
	Travel—may involve extensive travel		
	Facilitating key agencies, interest groups, and stakeholders		
	Developing Legislative Plan		

Interagency Council

Current Status: In addition to the creation of a State Autism Coordinator position, the 2007 Alabama Autism Task Force recommended that an Interagency Council be created. A council was appointed in fall 2008. The 2008 Systems of Care committee recommends that the council create a set of bylaws which would appoint subcommittee chairpersons be appointed to the council. Lastly, the Systems of Care committee recommends that the subcommittees continue to exist to help support both the council and the state coordinator. The following is a brief description of the recommendations.

Operations



	<u>Action Items</u>	<u>Leads</u>	<u>Timeline</u>
	The committee recommends that the Interagency Council develop a set of bylaws that clearly defines goals, responsibilities, representation of council, length of term, how coordinator will report to council, etc.		
	The committee recommends that the subcommittee continue to exist. The subcommittees could provide feedback and allow for greater involvement from providers and individuals with ASD and their families.		
	The committee recommends that the chairpersons of each committee be council members. This will allow for both the council and subcommittees to know what is occurring in each group, provide feedback, and allow for greater knowledge and input from all significant parties.		

