



Alabama Autism Task Force

*Final Report to the Governor and Legislature
January 2009*

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INTRODUCTION

On March 20, 2007, State Representative Cam Ward and Lt. Governor Jim Folsom, Jr. announced the formation of the Alabama Autism Task Force. House Joint Resolution 23 was passed by the Alabama Legislature on March 8, 2007 and signed into law by Governor Riley shortly afterwards. The Task Force reviewed the state’s response to the increased incidence of Pervasive Developmental Disorders (PDD) commonly referred to as Autism or Autism Spectrum Disorders (ASD).

The task force was comprised of advocates, state officials, educators, physicians, and members of the academic community to recommend ways to improve the treatment of autism in Alabama. Representative Ward and Lt. Governor Folsom served as co-chairmen for the Task Force. The Task Force held its first meeting of this year on June 17, 2008, the final meeting was held on January 22, 2009.

TASK FORCE MEMBERSHIP

The Task Force was comprised of 27 appointed members and many volunteers.

<u>Appointing Authority</u>	<u>Appointee</u>
Mental Health and Mental Retardation	Alice Widgeon
Alabama Autism Society	Bama Hager
Alabama Autism Society	Keith Sellers
Alabama Autism Society	Tim Ferguson
Speaker, Co-chair	Rep. Cam Ward
Speaker of the House	Mike Curtis
Medicaid Commissioner	Debbie Flournoy
Lieutenant Governor	Lee Yount
Lieutenant Governor	Senator Myron Penn
University of Alabama Birmingham	James Meador-Woodruff, MD
State Superintendent of Education	Dr. Mabrey Whetstone
Auburn University	Dr. Robert Simpson
Alabama State University	Dr. Shirley Barnes
Alabama A & M University	Dr. Shirley King
Secretary of State	Tonya Sparks-Barnes
Speaker of the House	Dr. Jennifer Sellers
Governor	Dr. Matthew Lee Remick
Alabama Hospital Association	Mr. Dennis Griffith
Alabama Education Association	Jim Wrye
Senate President Pro Tempore	Nancy Barnes
Speaker of the House	Paula Pace
Speaker of the House	Rep. Priscilla Dunn
Insurance Commissioner	Ryan Donaldson
Lieutenant Governor	Sandra Kaye Donnelly
State Health Officer	Sandy Powell
Alabama Medical Association	Tony Fargason, MD
Dept. Rehabilitation Services	Carl Nowell

TASK FORCE COMMITTEES

The Subcommittees were restructured from last year to align with the framework provided by the Alabama Autism Collaborative Group in their Statewide Needs Assessment. Chairmen once again opened committee membership to anyone who had interest and encouraged public participation.

The Task Force was organized into the following sub-committees:

Subcommittee	Chair
Diagnosis & Early Screening	Hanes Swingle, MD
Intervention Services (0-5)	Dr. Elizabeth Griffith
Intervention Services (6-21)	Jim Wrye
Health Care	Dr. Bama Hager
Ad Hoc, Regional Center Development	Dr. Bama Hager
Systems of Care	Dr. Jennifer Sellers
Financial Impact	Commissioner John Houston

Jennifer Muller, Executive Director of the Autism Society of Alabama, served as Task Force Secretary.

A special note of thanks to Mental Health Commissioner John Houston and Rehabilitation Services Director Steve Shivers for their contributions to the work of this task force.

SUBCOMMITTEE REPORT

Diagnosis & Early Screening Subcommittee, Chairman Hanes Swingle, MD

Findings reported by the Alabama Autism Collaborative Group (AACG) 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 settings and targeted public awareness and education campaigns.

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 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

Action Items

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.

Regional Autism Centers should work collaboratively to develop a protocol of standardized assessments to use 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.

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.

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 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.

Third party payers should cover the costs associated with an interdisciplinary diagnostic evaluation.

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 payer 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).

Action Items

*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 *Communication and Symbolic Behavior Scales Infant Toddler Checklist* and the *Modified Checklist for Autism in Toddlers* with the associated caregiver interview.*

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:

1. Encourage third party payers 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).
2. Encourage third party payers 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).
3. 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.
4. 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.

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.

Action Items

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:

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.

Early Intervention should develop a partnership with referring physicians and provide timely feedback regarding assessments, treatments and progress of the children they serve.

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:

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. 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.

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.

Action Items

Future public awareness campaigns should promote the early signs or “Red Flags” of autism spectrum disorders and delineate the actions 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).

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.

The following is recommended for Continuing Medical Education:

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.

References to accompany Diagnosis and Early Screening:

American Psychiatric Association (2000). *Diagnostic and statistical manual of mental disorders* (4th ed., text revision). Washington, DC: Author.

Filipek et al., (2000). Practice parameters: Screening and diagnosis of autism: Report of the quality standards subcommittee of the American Academy of Neurology and the Child Neurological Society. *Neurology*, *55*, 468-479.

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Matson, J.L. (2007). Determining treatment outcome in early intervention programs for autism spectrum disorders: A critical analysis of measurement issues in learning based interventions. *Research in Developmental Disabilities*, *28*, 207-218.

Mundy, P., Delgado, C., Block, J., Venezia, M., Hogan, A., & Seibert, J. (2003). *A Manual for the Abridged Early Social Communication Scales (ESCS)*. Available through the University of Miami Psychology Department. Coral Gables, Florida (pmundy@miami.edu).

National Research Council, Committee on Educational Interventions for Children with Autism (2001). *Educating children with autism*. Lord, C. & McGee, J. P., Eds. Washington DC: National Academies Press.

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Squires, J., Bricker, D., & Twombly, E. (2002). *Ages and Stages Questionnaires: Social-Emotional*. Baltimore: Brookes Publishing.

Wetherby, A. M. & Prizant, B. M. (2002). *Communication and Symbolic Behavior Scales Developmental Profile*. Baltimore: Brookes Publishing.

Wetherby, A.M., Brosnan-Maddox, S., Peace, V., & Newton, L. (2008). Validation of the Infant-Toddler Checklist as a broadband screener for autism spectrum disorders from 9 to 24 months of age. *Autism*, *12*, 487-511.

SUBCOMMITTEE REPORT

Birth to Five Subcommittee, Chairman Dr. Elizabeth Griffith

The Birth to Five Subcommittee was formed with the vision of having a system that truly serves 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.

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, our long-term goal is 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.**

Action Items

A Parent-to-Parent network should 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.

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.

Parent training and support will be individualized.

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.

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.

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.

Action Items

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.

Children should 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.

There will be a mechanism to review the evidence-base on treatments at regular intervals and update providers and families on best practices.

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.

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.

Provision for ongoing consultation and coaching with treatment experts will be readily available so that providers can easily update their skills.

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.

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.

Action Items

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.

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.

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.

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.

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.

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.

Action Items

Local community organizations (churches, daycare centers, YMCA) will receive awareness information regarding ASD.

Local community organizations will receive information regarding strategies for effective integration of children with ASD and their families.

SUBCOMMITTEE REPORT

Six to Twenty-one Subcommittee, Chairman Jim Wrye

The Alabama Autism Collaborative Group noted that “educational personnel require a clear understanding of ASD and associated interventions in order to implement successful school based interventions” (AACG, 2008). The group also cited the National Research Council’s Committee on Education Interventions for Children with Autism (2001) that suggested “Children with any autism spectrum disorder...regardless of level of severity or function should be eligible for special education services within the category of autism spectrum disorder.” Furthermore, the AACG pointed out that due to the lack of evidence-based interventions, educators are not mandated to use interventions with empirical support as long as students are making progress on their annual goals, which has consistently been upheld by case law. The American Academy of Pediatrics, however, urges that specific goals and objectives, as well as the descriptions of the needed supports be outlined in a student’s IEP. That being said, it is imperative that parents be educated about evidence-based interventions and about the law that governs special education. It is essential that parents be able to communicate effectively with teachers and administrators so that their children receive the best education possible.

Much growth and development occurs during the six to twenty one period. During this time the public school systems are the primary providers of services for individuals on the autism spectrum. Near the end of this period, students enter what is called the transition period. The successful execution of this process is vital to an individual’s long term success.

Training and Support of Education Personnel

Current Status: The move toward inclusion has brought more students with ASD into the general education classroom. Frequently, teacher prep programs do 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 necessary 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 for 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.

Specific Interventions

Current Status: There is no requirement for particular services or methods but only that students make progress toward their goals. Although research does not yet provide us with a set of evidence based practices for this age group, there are several national projects working on this. We do know that there are a number of existing interventions that have some scientific support.

Action Items

We should *continually monitor the progress of the national projects* that are working on creating a list of evidence based practices for this age group.

As a listing is available, it should be made available to the programs that currently exist in our state to train teachers. This list should also be translated into parent friendly terms and distributed to parents and other interested parties.

Consideration should be given to training teachers in the strategies identified as best practices.

Regional Center Development

Current Status: Dr. Karen Berkman from Florida's USF CARD Center presented to the Task Force Members, Interagency Council Members and key researchers and University personnel in the state last year. The Florida Code that created the CARD Centers requires the Centers to provide: 1) A staff that has expertise in Autism and autistic like behaviors and in sensory impairments. 2) Individual and direct family assistance in the home, community, and school. A center's existence should not supplant other responsibilities of state and local agencies, and each school district is responsible for providing an appropriate education program for clients of a center who are school age. 3). Technical assistance and consultation services, including specific intervention and assistance for a client of the center, the client's family, and the school district, and any other services that are appropriate. 4). Professional training programs that include developing, providing, and evaluating pre-service and in-service training in state of the art practices for personnel who work with the populations served by the centers and their families. 5). Public education programs to increase awareness of the public about Autism, autistic related disabilities of communication and behavior, dual sensory impairments, and sensory impairments with other handicapping conditions. There has been discussion about the need for Alabama's Regional Autism Centers to have an expanded scope of service given our state's lack of diagnostic services.

Action Items

Determine the scope of Alabama’s Regional Autism Centers. Careful consideration should be given to the additional services needed in regard to diagnosis and professional training. Legislation should be introduced that will allow the establishment of these centers.

Utilize the Regional Centers, and the expertise within the University Systems, to move forward research on the causes of autism spectrum disorders and the treatment practices that can be most effective.

OUTCOMES (% of Participants who Demonstrate Knowledge, Demonstrate new Skills in a Training Setting, and Use new Skills in the Classroom)			
Training Components	Knowledge	Skill Demonstration	Use in the classroom
Theory and Discussion	10%	5%	0%
...+Demonstration in Training	30%	20%	0%
...+Practice & Feedback in Training	60%	60%	5%
...+Coaching in Classroom	95%	95%	95%

*Joyce and Showers, 2002

SUBCOMMITTEE REPORT

Adult (21+) Subcommittee, Chairman Joe Carter

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.

Range of Housing and Housing Alternatives

Current Status: 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.

Action Items

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:

1. In-home Services- Assistance and training in the home for adults whose families want to continue to provide care in their home.
2. 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.
3. 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.
4. 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.

Existing providers and the housing options available for adults with autism (in-home, respite, intermittent, out of home) across the state should be identified. This can be accomplished by developing a comprehensive listing of providers and the housing options available specific to adults with autism within each region of the State.

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.

Action Items

Identify existing providers, specific to autism services, across the state. A listing of autism specific services available in each region of the state should be compiled.

Identify the number of adults being served through existing autism services and a projection of those waiting for services, by region. This can be accomplished by counting the numbers currently served by region and calculating the numbers that may be in need of services in the future.

Add an indicator for autism on the Waiver waiting list for services. The Waiver waiting list will then allow us to know the number of people with autism who are currently waiting for services.

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 should be developed.

Develop Services for Adults with Asperger Syndrome or HFA

Current Status: Currently there is no autism specific Medicaid Waiver or broad developmental disability Medicaid Waiver in Alabama. An individual must have an IQ test result of 70 or less in order to be eligible for services through the Alabama MR/DD Medicaid Waiver. We estimate that there may be approximately 40% of the individuals in need of supports who are not eligible for services through DMH/MR. There is a lack of services and support for individual with Asperger Syndrome or high functioning autism.

Action Items

Develop sources of funding for services to adults with Asperger Syndrome or HFA.

The state should *develop a Asperger Syndrome/HFA Pilot Project* to serve a designated number of individuals with ASD who are currently ineligible for existing state Waiver services, as other states have done with Legislative support.

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.

Action Items

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.

Identify/develop model programs to support young adults with ASD transitioning from school to work. Effective training and resources for young adults transitioning from school to work should be developed.

Identify/develop model programs to support adults with ASD to gain and maintain integrated community employment.

Identify the employment needs of adults with ASD. This can be done by conducting a statewide survey of employment needs of individuals with autism.

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.

Action Items

Identify the extent of existing transportation barriers to services or community involvement. This can be done by conducting a survey of the transportation barriers encountered by individuals with ASD. We must determine to what extent these have interfered with services, employment and participation in other activities of community living.

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.

Action Items

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.

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.

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.

Action Items

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.

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.

Action Items

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.*

Develop a provider directory to identify local services within each region of the State for individuals with ASD. Identify resources available to adults with ASD within each region of the State.

Develop a system to communicate local services available to adults with ASD within each region of the State. 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.

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.

Action Items

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:

- 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

Identify recommended training for emergency response personnel. 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.

SUBCOMMITTEE REPORT

Ad Hoc Subcommittee, Chairman Bama Hager

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:

1. Interdisciplinary diagnostic services
2. Model intervention programs using evidence based practices
3. Case management and family support
4. Professional training for educators, therapists, and medical professionals. These would include certification programs for professionals and training programs for students.
5. Ongoing consultation to ensure quality service provisions by professionals.
6. 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. 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.

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

Action Items

This subcommittee agrees that the *proposed regional resource center should be a source for assessment and intervention services information for autism, Asperger's Syndrome and PDD-NOS disorders*. Furthermore, the center should serve the entire autism spectrum regardless of the affected child's or adult's IQ or family resources.

As was highlighted in the Systems of Care section of the Needs Assessment report, this subcommittee concurs that the *center should be a training site for many professionals*—early intervention therapists, physicians, psychologists, speech-language pathologists, teachers, occupational therapists, nurses, therapists and other providers. In particular, the committee discussed the need for pediatrician training and family practice physician training for the screening and diagnosis of ASD

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 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.

The Needs Assessment report discussed the need for family support. This subcommittee recommends *that the resource center should establish a parent to parent support network to assist families in the transitions from early intervention to preschool to school and to adulthood.* In addition, the subcommittee states that the regional resource center for autism should have a working relationship with the Autism Society of Alabama. The Autism Society of Alabama is the leading autism advocacy group in the state and can assist with parent networking and family support.

Related to the fifth recommendation, a *public awareness/education campaign should be in place in conjunction with the development of the center.* This campaign will support families affected by ASD by raising awareness of ASD in the general population and nurturing understanding of those affected.

The Systems of Care subheading of the Needs Assessment report discusses the need for trained professionals throughout the state. The subcommittee recommends that the regional resource center be a remote consultation site for providers 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 IEP training, insurance coverage information, respite care services information and crisis management information and referrals. The center should assist families with young children in these areas.

*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 REPORT

Systems of Care Subcommittee, Chairman Dr. Jennifer Sellers

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.

Action Items

State Autism Coordinator should possess the following knowledge, skills and abilities.

Knowledge:

ASD through the lifespan

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

Skills and Abilities:

Collaboration, negotiation, diplomacy, conflict resolution

Working with the consumers and families

Computer/technology

Grant Writing

Communication-written and oral

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

Duties:

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 a Legislative Plan

Continuity of Ideas

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.

Action Items

The committee recommends that the Interagency Council develop a set of bylaws that clearly define its goals, responsibilities, representation of council, length of term and how the Coordinator will report to the Council, etc.

The committee recommends that the Alabama Autism subcommittees 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.

CONCLUSIONS

In a random sample of Alabama households over 80% indicated that they had some knowledge of autism and felt it was a societal concern. Respondents indicated that Alabama needed to develop a Coordinated System of Care for persons living with autism. There are several critical elements involved in a comprehensive system of care.

We are fortunate that the legislature overwhelmingly supported the establishment of an Interagency Autism Council last year. This Interagency Council is comprised of self advocates, parents and grandparents, state agency representatives, professionals in the field and individuals from other organizations. Having the recommendations that have been established over the course of two years, the Council along with the State Legislature and our Governor will be able to reform policies within state agencies and enact new legislation that will ensure the residents of Alabama who are affected by Autism Spectrum Disorders have access to coordinated services that are of affordable and utilize best practices.

It is essential that individuals with autism be identified early so that they may enter intensive treatment programs as soon as possible. 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 at an early age. Early screening within the healthcare setting is necessary. In order to improve the quality of care for children with ASD in Alabama, there must increase the number of providers who are able to reliably diagnose autism spectrum disorders. There is also a need to screen children for autism spectrum disorders within our existing Early Intervention program and provide intervention aimed at their core deficits.

The under-five population has unique needs and challenges which have already been clearly laid out in this report. 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 pivotal period of development. Coordination amongst the agencies who are involved with children during this critical period of develop is essential. It is during this time that families realize the need for support and training. A comprehensive system for children and their families would allow parents access to all of the information that is essential for their child's long term success. An essential element in this is that services and training be made available in an individual's community. The systems to navigate are complex and cumbersome even to those that work within them; case management is a vital piece to creating a system that works for families.

Children, regardless of their abilities, spend an enormous amount of time in the education system. There is level of specialization that is needed by teachers who interact with students on the autism spectrum. This specialty training is not uniformly available to teachers going through pre-service training in our state. More and more we see that our students with autism are in general education classrooms and the teachers are often not equipped to handle the students who are on the spectrum. It is essential that we provide

the training necessary to our teachers who will be responsible for these students. This training must be ongoing and provide teachers with the opportunity to receive technical assistance in their classrooms. Transition to adulthood starts when students are in high school; it is very important that the Education System and the Vocational Rehabilitation System work together to prepare our students for life after high school.

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. Alabama is severely lacking in adult services and very few providers have services for those over age 21. The issues of adulthood involve college, employment, housing, transportation and medical care. We must remember that not everyone with autism is the same. There are varying degrees and therefore not everyone with autism needs the same level of support. The nature of the disability, however, requires that support personnel be accessible to these individuals as they are needed. Funding mechanisms must be examined to allow for the variability to the individual and his/her needs. Over 62% of the respondents polled by USA indicated that with the right training individuals with autism could be productive citizens.

Alabama is in a position to make significant changes to how we serve individuals with Autism Spectrum Disorders. Throughout the recommendations one will see that there is a strong feeling that we should look at utilizing a regional service delivery model. Given our need to increase the number of personnel in various fields who are trained to work with this population, a system affiliated with our State Universities seems to make sense.

While there seems to be general awareness of this set of disorders by the community, the Task Force agrees that there is a continued need for increased awareness. Community awareness of early warning signs is vital to ensuring that children are identified early and placed into the appropriate treatment programs. The long term success of these individuals rests in our ability to recognize them and to have the services they need available within their communities.

Someone's child, grandchild, niece or nephew will be the one in 150. Autism can steal a child's voice and force him/her into a world of isolation. Every child should have the opportunity to access high quality, affordable services no matter where they live in Alabama.

We look forward to the changes that are on the horizon and appreciate the opportunity we have had to work on this report for you.

Appendix A

Statewide Autism Needs Assessment
Executive Summary
2008



Statewide
Autism Needs Assessment

Executive Summary
June 2008

Conducted by the
Alabama Autism Collaborative Group



*The Autism and Behavioral
Health Center of Alabama*



The contents of this product were developed under a grant from the Alabama Council for Developmental Disabilities (ACDD). However, these contents do not necessarily represent the views or policies of the Council.

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I. Overview, Purpose, and Methods of Needs Assessment

Autism Spectrum Disorders (ASD) include Autism, Asperger Syndrome, and Pervasive Developmental Disorder Not Otherwise Specified. These disorders involve impairments in communication and social skills and a restricted range of activities and interests. The level of impairment varies across diagnosis and person, as does the response to intervention. The Centers for Disease Control and Prevention (CDC) considers ASD to be an “urgent health problem in need of targeted public health action.” National CDC estimates are that ASD will be diagnosed in 1 out of every 150 individuals. Based on these estimates, there may be approximately 30,000 people with ASD in the state of Alabama.

The Alabama Autism Task Force was created by House Joint Resolution 23 sponsored by State Representative Cam Ward and Lt. Governor Jim Folsom, Jr. The Task Force is charged with recommending ways to improve the condition of individuals with Autism Spectrum Disorders (ASD) in Alabama. Task Force members quickly realized the need for a source of statewide data. Thus, the Alabama Council for Developmental Disabilities (ACDD) issued a call for proposals to conduct an assessment of the needs of individuals with ASD and their families in Alabama. The Alabama Autism Collaborative Group (AACG) was formed in response to the call, consisting of individuals concerned about ASD, those with expertise in ASD and in conducting needs assessments. The AACG was awarded the grant to begin the Alabama Autism Needs Assessment in September 2007.

The Needs Assessment consisted of two phases. First phase (September 2007 – January 2008) activities included reviewing published literature and other documents to determine current best practices in ASD screening, diagnosis, intervention, and family support; conducting seven community and family forums; conducting in-person and on-line surveys of parents and providers; and conducting key informant interviews. Activities conducted during the second phase (January –May 2008) included examining data bases, conducting focus groups, and completing key informant interviews to provide missing or in-depth information. This approach is intended to inform the assessment of the needs and resources available for individuals with ASD and their families in Alabama. The information gathered from this project will be used to assist the Alabama Autism Task Force to meet its stated goals:

1. To improve lives of persons with Autism Spectrum Disorders and allow them to be productive, self-sustaining members of society;
2. To make recommendations to the Alabama Legislature and state agencies that will achieve Goal 1, that are accompanied by background and rationale; and
3. To make recommendations that will address research, access, and implementation of services across the lifespan.

The original charge from ACDD was to provide an assessment of the needs and resources for individuals with ASD and their families in Alabama to guide the recommendations of the Task Force. However, this document offers information to all individuals with an interest in ASD, including parents, professionals, and legislators. Researchers have highlighted best practices in ASD and gaps in meeting these best practices in Alabama.

II. Data Used in the Assessment

Eight community forums on autism spectrum disorders were held during the fall of 2007 and spring of 2008. There were 416 attendees, including parents, caregivers, family members, service providers, self-advocates, and other concerned individuals. Responses were received in oral and written form.

Additionally, written and online questionnaire data were available from 270 individuals (128 respondents had also attended the forums). Families with low-incomes and families with adolescents and adults were underrepresented across survey data. For example, only 26% of survey respondents reported incomes of \$40,000 or less and respondents reported the average age of the individual with ASD in their family was 10.4 years. However, survey respondents represented 141 different zip codes in 102 different cities and towns across the state and about one-third of respondents identified themselves as being a member of an ethnic minority group.

Eighteen individuals selected as key informants (e.g., directors of public and private agencies and clinics) for this process responded to eight questions regarding services as perceived by a system and service provider. Focus group members were asked a series of 10 questions designed to trigger directed discussion of availability, accessibility, and effectiveness of existing services and systems in Alabama. Additionally, provider comments were solicited through 171 online and written surveys. Complete data for each of these sources are available in Appendix B that follows this Executive Summary.

For this summary, **priority needs** were identified in each category when the needs were noted across data sources. Verbatim quotations are also included to illustrate the nature of respondents' written comments.

Please see Appendix A of the full report to view the literature review that incorporates Education and Training into the Screening/Diagnosis and Intervention sections. The literature review is based on current scientific research in ASD and is omitted from the summary for brevity.

III. Recommendations

This summary should be relevant for each of the 2008 Task Force Subcommittees: Systems of Care, Diagnosis and Screening, Interventions-Birth to Five, Interventions-Six to Twenty-one, Interventions-Adults, Healthcare/Medical Services, and Financial Impact.

This section begins with recommendations on systems of care, considered to be the central component through which to administer all other recommendations. Building functional systems of care will require careful planning, partnership, and sustained effort across statewide entities including public and private agencies and universities.

Informants in forums, focus groups, surveys, and interviews praised specific providers and agencies they felt had been helpful to Alabamians with ASD. However, the findings in the Alabama Autism Needs Assessment indicate significant unmet needs. Highlights from the needs assessment are presented below, together with specific recommendations for consideration by the Alabama Autism Task Force.

Systems of Care

The Alabama Autism Collaborative Group identified weaknesses in both the quality and quantity of services that are delivered to individuals with ASD in Alabama. Results of the statewide needs assessment indicated great variation in available service providers, type and intensity of services, and reimbursement mechanisms according to geographic region, age of the individual, and specific diagnosis. Many families are unclear how to navigate the maze of service delivery systems that currently exist in our state. Appendix A includes a description of model statewide programs.

Recommendations

Create a statewide network of University affiliated regional centers in partnership with public and private agencies. The most effective programs provide:

- Interdisciplinary diagnostic services
- Model intervention programs utilizing evidence-based practices.
- Case management and other family support services.
- Professional training for educators, therapists, and medical professionals
 - Provide certification programs for professionals interested in specializing in ASD
 - Combine student practicum placements with service delivery to ensure ongoing quality of service
- Ongoing consultation with other agencies to ensure quality service provision following professional training
- Support basic and intervention research to increase our understanding of these enigmatic disorders.

Building this strong system of care to support individuals with ASD and their families is critical. This concept underlies all the recommendations emerging from the Needs Assessment. To move this system forward:

- The Alabama Autism Task Force is encouraged to examine the strengths and weaknesses of the regional systems of care established in neighboring states such as North Carolina and Florida.
- The regional networks of support should integrate the public service systems across funding streams through the Interagency Coordinating Council utilizing expertise found within the local Universities.

Strengthen the existing statewide advocacy organization, The Autism Society of Alabama, to undergird many of the activities that are critical to the future of individuals with ASD and their families. As more and more children and adults are diagnosed with ASD, there is an enormous need for ongoing advocacy on their behalf. Families need access to training so that they know how to work with their children at home and a system of scholarship support to facilitate training opportunities is recommended.

Ideas on the types of services coordinated through these recommended systems of care include: screening and diagnosis, intervention across the lifespan, healthcare and medical services, and financial support. Each of these is addressed below.

Screening and Diagnosis

Early diagnosis of ASD is critical. Nationally children receive a diagnosis by age three; however, in Alabama, families report the average age of diagnosis to be six years. Needs assessment respondents strongly supported national recommendations for early and continuous screening for developmental concerns. Parents seeking diagnostic evaluations often experience long waits. National recommendations stress the need for comprehensive interdisciplinary evaluations.

Recommendations

Use a broad based developmental screener that includes early social and communication symptoms associated with autism and other developmental disabilities (e.g., Ages and Stages Questionnaire, Communication and Symbolic Behavior Scales).

Create a brochure/document to be distributed through pediatrician offices that outlines next steps and local referral sources when developmental concerns arise.

Develop a system of regional interdisciplinary diagnostic evaluation clinics including psychology, speech/language, occupational therapy, medical assessments, and other allied health providers. A regional center approach would ensure that diagnostic evaluations are being conducted by professionals with expertise in ASD, would provide greater access to services and reduce frustration with long wait lists.

Interventions and Education

There is no “one size fits all” intervention approach; however, there are empirically validated core key elements that increase the efficacy of programs. It is essential that programs be tailored to each person’s developmental (age and cognitive ability) needs throughout the lifespan. Access to evidence-based interventions is limited due to the lack of trained providers and to distance from existing services.

Interventions in Early Childhood and for School-Aged Children

The National Research Council recommends 100 hours per month for early childhood services. These may include one-on-one delivery by professionals, one-on-one interactions with family, and small group educational or peer interactions, as long as the child is actively engaged. Over half of survey respondents reported that their young children (birth to three) receive 4 or less hours of intervention per month, and that their preschool aged children receive 29 or less hours per month. Interventions are often not individualized to the specific needs of children with ASD and do not contain the key elements recommended by the National Research Council.

Recommendations

Training, supervision, and on-going consultation on empirically validated intervention techniques for Autism Spectrum Disorders is imperative for those who intervene with children with ASD at any level (teachers, paraprofessionals, allied service providers) and parents of children with ASD. Funding for a number of trainings in evidence-based techniques (Applied behavior analysis, to promote skill development and to reduce problem behaviors; developmentally based social relationships techniques; structured teaching and visual supports; peer and community education and awareness) across the state is predicted to reap exponential benefits.

With the growing incidence rate of ASD, there is a parallel need for well-trained ASD professionals entering the workforce. As a result, increased university-based degree and certificate programs that provide ASD specific training are needed.

Increase the number of hours of intervention available to children with ASD in order to meet national standards.

Interventions in Adulthood

With a growing number of individuals being diagnosed with ASD, there is a dire need for affordable transition and support services that span all possible outcomes for individuals with ASD ranging from supported employment to college programs. In 1999, it was estimated that there were more than 525,000 individuals with autism and other developmental disabilities over the age of 60 and the number of elderly individuals with developmental disabilities was expected to double by the year 2030. Due to their social difficulties, adults with ASD can be perceived as harassing, insensitive, or even dangerous, making it difficult for them to sustain employment or complete post-secondary degrees. Many adults with ASD will require continued treatment to build social and communication skills and to troubleshoot misunderstandings that occur in their environments. Interventions need to be tailored to the specific and different needs of adults with ASD.

The primary source of funding for adult services is available through Alabama's Departments of Rehabilitation Services and Mental Health/Mental Retardation. A lack of qualified available service providers makes individual/family choice virtually non-existent. An individual's ability to work and live in the community is strongly influenced by the service provider's depth of knowledge about ASD.

Recommendations

Create coordinated system of intervention and support that addresses academic transition, job training and coaching, college support daily living skills, communication, and social skills

Develop a collaborative approach with the individual, parent, mentor, and support agencies that allows for maximum independence and increasing self-advocacy

Fund an autism specific waiver to include individuals without MR that would enable individuals to access residential and support services.

Train individuals providing adult support services on empirically validated supports (education, job, living, etc) and behavioral strategies.

Healthcare

Families look to their medical providers for guidance. A large proportion of medical professionals have little training in working with people with ASD. This makes obtaining adequate health care (primary and specialty care) problematic for individuals with ASD and their families. In addition, there is little research into the effects of psychopharmacologic agents and alternative medicine treatments for individuals with ASD. Among the survey respondents, the average age of the family member with ASD was 10.4 years, but the majority was reported to be taking at least one prescription medication. Many of the medications were used to treat behavioral symptoms of autism.

Recommendation

Train physicians to recognize the early warning signs of autism and make appropriate referrals and appropriate use of various medications and other therapies. Dissemination of ASD specific basic information to all care providers is an urgent need.

Train physicians in the use of various medications specifically for ASD and to assist families in evaluating treatments, including alternative practices.

Educate parents to understand the effects and consequences of various medications.

Support research into most effective medications to treat ASD specific symptoms.

Family Support

Families in Alabama are accessing support through community support groups but have a desire for more training related to ASD. It was noted that families need an array of services to support themselves while supporting the family member with ASD. Families who have loved ones with ASD are under extreme stress. There needs to be more family support available to parents, siblings, and other family members. Support should also include appropriate education regarding their family member's treatment as well as available services to enhance their skills as advocates for their family member when necessary.

Recommendations

Respite care, summer camps and recreational opportunities should be made available to family members.

Case management is not widely available to this group. Case management services would be helpful to families who are struggling with the wide-ranging effects of ASD.

Consolidate available information in a family-friendly format. Immediately after diagnosis, families should be given information on local support networks and the recommended therapies. If monies were made available to synthesize the final report of the Alabama Autism Collaborative Groups' Needs Assessment findings with information regarding local agencies, parents receiving their diagnosis could immediately have access to information about best practices in ASD intervention. The Needs Assessment document could also be available on provider's websites.

Financial

The financial implications of ASD Alabama are enormous. Monies are needed for training and service delivery to affected individuals. Research indicates monies invested in the early years of life will decrease the dollars needed later in life. Early intervention programs for ASD are estimated to save the U.S. government and Social Services more than \$200,000 per child by the time that the child reaches early adulthood. The financial impact of ASD is also a significant burden to families as they seek to obtain the best services and supports for their family member.

Recent estimates suggest that approximately 40-60% of individuals with ASD also have mental retardation. Individuals with autism, who are also diagnosed as having Mental Retardation, may have access to an array of services via a Medicaid Waiver, if available. Because the reimbursement for adults may be as high as 2/3 less than these individuals received as children, there are very few residential providers for even the neediest of adults with autism. Because of the economic challenge, there are insufficient services available for adults with autism. Further, individuals diagnosed with ASD who have average and above average intelligence but still have substantial difficulties in social communication do not currently have a funding source for long term living supports.

Recommendations

Financial resources need to be permanently allocated to these efforts. Line items within the state budgetary process are advisable.

Increasing the providers' reimbursement for services would increase the number of services that are available to individuals with ASD.

Increased state support of services would lessen the significant financial burden associated with ASD for families.

Working with insurance companies to expand coverage types and amounts for the range of services recommended and required for individuals with ASD.

IV. Assessment Results

Screening and Diagnosis across the lifespan

Literature Review

In the literature, parents demonstrate concerns about their child's development within the first 18 months of life. However, children are not typically diagnosed with ASD until their third birthday. This delay between first symptoms and diagnostic evaluation is considered potentially harmful to long-term outcome. Consistent practice parameters for the screening and diagnosis of ASD have emerged from the American Academy of Neurology, American Academy of Child and Adolescent Psychiatry, and the American Academy of Pediatrics:

- Provider education for health care and early childhood education professionals regarding typical development and early warning signs for ASD
- Routine early screening for developmental delays at well-child healthcare visits
- Interdisciplinary diagnostic evaluations by professionals with specific expertise in ASD
- Training for early childhood providers in warning signs of ASD to enable early identification and referral

Current State of the State

In the surveys, caregivers reported that the average length of time between first concern and when they received a diagnosis for their child was three years. On average, children in Alabama were six years of age before they received a diagnosis of ASD. Twenty-three percent of respondents received their diagnosis outside of the state of Alabama. Providers reported that while many medical professionals use the DSM-IV and ICD-9 definitions of ASD, the interpretation of these definitions and other eligibility criteria varies greatly among systems, including education and rehabilitation. It was suggested that a diagnosis should be supported by appropriate measurement tools as well as clinical judgment. Key informants were in agreement that a lack of access to trained providers is a limiting factor. For example, provider key informants indicated they often have anywhere from two to six times as many requests for diagnostic services per month than they can fulfill.

Priority Needs

The following were identified as priority needs related to diagnostic services across the lifespan:

- More training for primary care providers that includes early warning signs, treatment options (i.e., evidence-based and alternative medicine), and follow up strategies after diagnosis
- Increase the number of ASD-specific diagnosticians & providers statewide to reduce waiting time and increase availability of services

Selected quotations:

- *(We need to improve) We have applied everywhere starting in October '07 and we still do not have a date for a diagnosis. We have applied to all the places talked about here and only have vague commitments for a diagnosis sometime mid-to-late NEXT year!" (2008)*
- *(It was) "very hard to get an accurate diagnosis for our daughter with Asperger's. One (provider) said she could not have it because she 'could count backwards.' She still 'falls through the cracks' at 18 years. More awareness and training by providers is needed and we parents need to be able to find the knowledgeable ones."*
- *It should be a "requirement of first-line practitioners (MD, nurses, day care workers, preschool workers, etc.) to have training in first signs. (We need) more qualified diagnosticians."*

Interventions and Education

Literature Review

Individuals with ASD need interventions that are specifically tailored to their unique symptoms. There is limited evidence-based research to support the notion of a single best approach to intervention. However, key elements of effective interventions have been identified for each age range (early years, school-aged, and adulthood). Health care and social service professionals should include family members as part of the treatment team and provide ongoing support. The National Research Council Committee on the Educational Interventions for Children with Autism identified the critical elements necessary for successful intervention programs.

- Intensive (25 hours a week or more)
- Targeted toward specific goals
- Developmentally appropriate
- Targeted to the core symptoms of ASD (verbal and nonverbal language, social interactions, and imitation, as well as attention and motivation)
- Specific training in empirically-based intervention techniques for providers
- Parents need to be included in both treatment planning and given training in empirically-based interventions

Although the precise implementation of these techniques will vary depending on the age and developmental level of the individual with ASD, research review suggests that the intervention techniques with the best empirical evidence across the lifespan (from birth to death) are:

- Applied behavior analysis (to promote skill development and to reduce problem behaviors)
- Developmentally-based social relationship techniques
- Structured teaching and visual supports
- Peer and community education and awareness

Current State of the State

Key informants listed community providers, state agencies, universities, public and private providers, and non-profit organizations when asked about overall strengths in regard to serving individuals with Autism Spectrum Disorders in Alabama.

Interventions in Early Childhood (Birth to Five)

Sixty-eight percent of survey respondents reported that their child received early intervention services. Despite the finding that respondents reported relatively high household incomes, over half the families surveyed received only four hours or less of intervention each month prior to their child turning three. Over half of the families reported receiving 29 hours or less of intervention each month during the preschool years (i.e., 3-5 years of age).

Focus group participants reported a need to:

- Increase ASD-specific education and training for service providers, communities, and families.
- Address disparities by area of residence by using regional centers to provide services (i.e. diagnostics, respite, parent education, service coordination, parent mentorship, technical assistance)
- Improve collaboration among systems (Rehabilitation Services (Early Intervention and Vocational Rehabilitation) & State Department of Education (Special Education Services)) for transition and planning purposes
- Address differences in determination of service eligibility within each system.
- Increase funding.
- Increase emphasis on long-term functionality.

Key informants indicated concerns regarding a lack of reimbursement for therapeutic services; the limited number of service providers; the limited amount of funding, training, and resources available; and geographic disparities.

Priority Needs

These themes emerged as priority needs regarding interventions in the early childhood years (birth to age five) for individuals with ASD:

- Increase number of hours of intervention
- Train parents to intervene with their children
- Increase numbers of ASD-specific intervention providers and generalists
- Train early childhood providers in evidence-based interventions for ASD

Selected quotations:

- *“Once a child with Autism ages out of EI, there are no preschool services provided by the public school system other than speech, and sometimes OT and PT. These services are minimal. What is the (autism) task force doing to address the lack of preschool services in the majority of school systems?”*
- *“Got speech and OT one time per month; not enough therapy. There were no services during the summer during transition. Neurologist who saw my other child told me about EI. I would have wanted more behavioral and communication support.”*
- *“Having moved to the area when my son was eighteen months and not knowing what services were available, we did not know about EI. Our pediatrician did not refer us. Eventually at age 3, we went to our local school system. We missed out on EI services!”*

Interventions for School-Aged Children and Youth (Six to Twenty-one)

Seventy-five percent of survey respondents reported that their family member with ASD received services through the public school system. Forty percent of families felt that their school system could provide the resources necessary to support their child with ASD, but only 35 % felt that the school was very effective (9%) or somewhat effective (26%) in providing the social skills support their children required. Of the 49 families with children 16 years of age and older, only one-third (33%) stated that transition was discussed.

Focus group participants reported:

- Regional disparities exist.
- Extended School Year (ESY) is not uniformly available or accessible. It is difficult to prove regression; however, if structure is not provided throughout the year, social, academic, and safety issues may arise.
- Transition services are poor statewide. Transition services are required to start at age 16 or ‘earlier if necessary.’
- It is difficult to prove eligibility for services. The time for the Individualized Education Program (IEP) process and the Building Based Student Support Team (BBSST) assessment is too lengthy. State regulations focus on required skills that some individuals with ASD may not have yet acquired. Functional language and adaptive skills should be part of the IEP and education, not pushed out by state regulations.
- Education and training is necessary for administrators, general educators, special educators, and other professionals and paraprofessionals. The current collaborative degrees at the university level do not address special education—specifically autism—in much detail. Training is also needed concerning behavior modification techniques.

Key informants cited needs regarding training for all school personnel and for offices of disability assistance, knowledge of education rights, and more behavior management training.

Priority Needs

The following priority needs were noted regarding interventions for school-aged children:

- Access to services needs to be broadened, schools need to accept diagnoses from elsewhere
- Regional centers would be helpful in providing resources, training, and advocacy information for parents and professionals.
- Training for teachers (regular education and special education), paraprofessionals, administrators, peers in the areas of:
 - Understanding symptom presentation of individuals with ASD from birth to young adulthood
 - Evidence-based interventions to include behavioral and classroom management, social skills, and increasing adaptive behaviors
- Parent education related to IEP and evidence-based interventions

- Increased support for children who require it
- Greater intensity and duration of services to include extended school year
- Attention and support through the transition out of the school system with planning occurring earlier in a child's life

Interventions for Adults (Post High School)

A total of 29 survey respondents were caregivers of individuals 21 years of age or older. Seventy-three percent of the adult family members with ASD were male and ranged in age from 21 to 60 years with the median age being 27 years. Caregivers of the adults with ASD reported that about 50% of their family members with ASD were lacking in appropriate communication skills and most had some difficulties with one or more daily living skill, such as bathing (21%), cooking (62%), managing money (86%) and driving or riding a bus (70%). For nearly 60% of these adults with ASD their caregivers reported that they need frequent (23.1%) or continuous (30.8%) supervision. Only 28% of the caregivers reported having support networks for ASD in their community. Sixty-four percent said they did not have long-term care plans and 13% said they were on a waiting list for residential services for their family member with ASD.

With regard to services for adults with ASD, focus group participants suggested:

- Regional centers that offered skilled case management, community integration, and advocacy may help address the issue of disparities by geographic area. Some families seek residential placements because they cannot support their child/adult child using existing community resources.
- Services and structure end for most individuals with ASD upon high school graduation. Services that are available are private-pay, or are based on a mental retardation diagnosis, which many individuals with ASD do not have. Existing services are also offered inconsistently. Some adults with ASD will require long-term supports for successful employment, independent living, and social health.
- Increased funding for adult service providers may increase the number and quality of services provided in Alabama. Insurance reimbursement should also be reviewed. A state line item for autism is part of other states' budgets and may work in Alabama.
- Education and training is needed for adult service providers—this includes Vocational Rehabilitation, medical providers, and emergency personnel.
- The range of symptoms for those with ASD varies widely; however, all individuals on the spectrum are at-risk for social isolation without the needed supports.

Key informants cited needs regarding vocational support and employment options, transportation, living options, a need for more trained mental health providers to provide ongoing services, and more financial resources.

Facilitators of the original seven forums noted that there were few caregivers of adult family members with ASD represented at the forums. Thus, a family forum for

individuals with Asperger's Syndrome or high-functioning autism was held to gather more input regarding adult issues and concerns. Thirty-two individuals affected by ASD were present at this forum. Several key findings emerged in this group of high functioning adults with ASD. Forty-seven percent have a job, 50% graduated with a regular high school diploma, and 52% attended or are attending college. Thirty-eight percent rely on public transportation and 38% reported that they were originally given an incorrect diagnosis.

Priority Needs

Priority needs in regard to adult services included:

- Education and training for providers, such as employers and agency professionals (public and private)
- Access to services based on ASD diagnosis (rather than also requiring MR)
- Increased attention to transition and future planning (work, transportation, residential, and social)
- Increased number of ASD-specific trained specialists to assist individuals with ASD
- Interventions that are tailored to the specific and different needs of adults with ASD
- Adult support groups to deal with specific problems and issues related to ASD (social interactions, stuttering, rocking, etc)

Selected quotations:

- *"We need better social skills training on the job front, better employment opportunities, and better and more reliable transportation"* (adult with ASD)
- *"...I have a desire for friends and significant others and I am very depressed. How do I do this now? There are not opportunities like in high school. It is hard to meet people."* (adult with ASD)
- *"I wish for my adult family member with ASD to become a productive member of society; to be happy and have valuable relationships with peers; to feel important, valuable and successful in our world; (we) need job training, mentor(ing) program, and help with living arrangements."*(caregiver of individual with ASD)
- *"Will there be something in place for parents with kids that are not adults yet? To help (make the) transition easier to adulthood."*(caregiver of individual with ASD)

Healthcare/Medical Services

Literature Review

Traditionally, clinical professionals have little training in working with people with ASD. It can be difficult for those with ASD to obtain quality health care including physical examination, specialized treatment and oral health care. There is limited research into the effects of psychiatric (and other) medication on people with ASD. Alternative and unproven treatments have proliferated without systematic scientific studies of efficacy.

Current State of the State

Eighty-four percent of respondents to the survey reported that their children were on one or more medications. In fact, 29% had tried three or more medications. Fifty-three percent of respondents reported trying an alternative medical treatment such as diet, vitamins, or chelation. Most families reported having some form of public or private

insurance. However, 91% of families reported that their insurance did not cover all needed services for their family member with ASD. Sixty percent reported that insurance covered some of their ASD-related service needs. For the adults, caregivers reported that 88% had insurance (56% were receiving Medicaid). However, 19% said *no services* were covered, 58% said *some services* were covered, and only 12% reported that *all services* needed by their adult family member with ASD were covered by health insurance.

Focus group participants reported:

- Regional disparities are present. A statewide coordinated and comprehensive system of care is needed to bring uniformity to services provided. This system may be provided through a state agency or department and should be state funded.
- More service providers (child psychiatrists, medical professionals, case managers) are needed to avoid individuals being placed on lengthy waiting lists for limited services.
- Increased emphasis should be placed on education and training requirements of service providers of adult services (Vocational Rehabilitation, medical professionals, mental health professionals, etc.).
- Limitation of eligibility criteria of current waiver system. Individuals with Asperger's or High Functioning Autism do not qualify for services but need support. Mental health centers do not treat ASD as a diagnosis. If an individual does qualify for the MR waiver, the waiting list may be lengthy.
- Increased funding to support providers who treat individuals with autism.
- Increased public and private insurance coverage of services is also needed.
- Increase the number of providers who accept clients with ASD. Loan and reimbursement programs at the university level and continuing professional education may increase service capacity.

Key informants cited needs regarding insurance reimbursement for services and service providers' knowledge of diagnostic tools, EPSDT, and referral sources as significant issues.

Priority Needs

These themes emerged as priority needs in regard to medical services:

- More training for primary care providers, including treatment options (i.e., evidence-based and alternative medicine), associated features (e.g., seizures), and behavioral techniques for interacting with patients with ASD.
- Increased public and private coverage for treatment/therapy (e.g., speech, OT, PT, & ABA)
- Expand reimbursement mechanism beyond mental health coverage for ASD, thereby increasing coverage for providers who typically are trained in evidence-based interventions (e.g., psychologists)
- Training for first-responders, emergency personnel, physician assistants, nurse practitioners, etc.

Selected quotations:

- “We haven't found any successful treatments to-date. Insurance companies will only pay 50% of psychological medications. It will not pay for occupational therapy.”
- (We need) “dental and other services that will work with autistic children. ABA -- I could only get once a month because it was in Birmingham and I can't afford to go to Birmingham more than once a month. (We) need to help low-income family.”
- “My problem is our insurance says autism is psychological and pays at 60%; speech therapy is the only covered portion. It is neurobiological and psychological! We also have numerous allergies. Most effective therapy is ABA, especially expressive programs. Nothing is paid for by others (anti-yeast medication, gluten-free and casein-free diet, auditory integration therapy, hyperbaric O2 treatment). Our savings are gone.”

Systems of Care

Literature Review

It is difficult for families to navigate the complex and often confusing system of services provided. Families of individuals with ASD exhibit significantly greater levels of stress than families of individuals with other disabilities. The National Research Committee on Educational Interventions for Children with Autism recommends that states develop regional centers in order to provide supports for diagnosis, care across the lifespan, and the training and support of families and providers. In addition, the National Institute of Health Interagency Autism Coordinating Committee reported an urgent need to coordinate care across agencies. A review of well-established statewide programs indicates the need for:

- Regional diagnostic services
- Regional professional training services for educators, therapists, and medical professionals
- Ongoing school consultation services to insure quality service provision following professional training
- Model intervention programs utilizing sound scientific practices

Current State of the State

Providers and parents reported that, for all practical purposes, there is no statewide system of care for all individuals with ASD and their families. Individual providers and specific organizations or groups were frequently cited as being very helpful; however, there appears to be a scarcity of resources and insufficient numbers of diagnosticians and interventionists who can assist citizens with ASD across the lifespan. The lack of a centralized service system responsive to all families of children and adults with ASD creates frustration and delay in locating the services and resources that do exist. Families experience significant emotional and financial stress as they attempt to care for their relative with ASD. As a result of these stressors, parents and siblings are more likely to experience depression and marital discord. In this sample 67% of those who had groups in their communities indicated they participated in community support groups. Members of focus groups emphasized the need for regional resources accessible to all citizens. Providers also reported gaps in the system of care at the local level. Key informants indicated a pressing need for improved access to ASD services in rural and urban areas (including respite and support services).

Priority Needs

These themes emerged as priority needs in regard to systems of care:

- Centers across areas of the state offering diagnostic services, model intervention programs, professional training, school consultation, and case management
- Strengthen local support networks for parents, siblings, and caregivers to include parent education and respite care
- Increase community and recreational opportunities for individuals with ASD and provide programming after school and during summer months

Selected quotations:

- *We didn't receive any services until he was in kindergarten, and only through school, and (these were) very limited. When I called the mental health facility covered by my insurance, I had to beg them to see him, because he was so young. I called the local school system, and they told me they could not help him until he was in kindergarten. I had to initiate the diagnosis process myself, pay for it myself, and still the school system refused to recognize the diagnosis. Behavioral therapy would have been helpful, as well as occupational therapy for sensory issues and fine motor skills.*
- *(We need) better services for community (residents) that need help with some funding and day care for kids like these. Day and night care so parents can keep their jobs.*
- *I need respite care or my mind and marriage are going to implode!*
- *Has ASD influenced family relationships? Yes! Mostly negatively -- even our family doesn't understand what our lives are like. It's hard on a marriage. Has ASD been a strain? Duh, "Yes!" We make too much \$ to get help but not enough to support our family. This is wrong!*
- *There is a need for after-school care and summer programs for children with autism. I cannot find a dependable place for my child to stay while I work. No one is trained to assist children with autism!*

Financial

Literature Review

Quality early intervention is predicted to save a million dollars in lifetime care for individuals with ASD. Families experience a significant financial strain that adds to their levels of stress.

Current State of the State

Providers and parents reported that current sources of funding, including health insurance coverage is inadequate to meet the lifelong needs of individuals with ASD. Key informants cited the lack of insurance reimbursement for a variety of needed services (medical, psychological and other therapies) as being problematic. Focus group participants also cited a number of financial barriers commonly encountered among persons with ASD. Recommendations:

- Increase funding to reimburse service providers who treat individuals with autism.
- Increased public and private coverage for treatment/therapy (e.g., speech, OT, PT, & ABA)
- Expand reimbursement mechanism beyond mental health coverage for ASD, thereby increasing coverage for providers who typically are trained in evidence-based interventions (e.g., psychologists)

Selected Quotations

- *We desperately need to get autism/ Asperger's/ ASD out of the mental health category and into the medical category. This is a neurological abnormality, not a mental illness. This has been proven with PET/ MRI/ CT scans that show a physical abnormality in the amygdala in the brain. This could help parents with extreme medical costs and related services, as well as the educational system that is maxed out with the services they have to offer to our children.*
- *ABA nor OT are covered under my state employee insurance plan. This financial burden is too much to take and my family will not be able to provide the needed treatment for my son.*
- *BCBS insurance coverage of essential therapy sessions is not available throughout AL. There needs to be a state mandated change to insurance coverage for ASD or parents need access to state funding to cover the costs associated therapy sessions.*
- *It would be helpful to have more coverage for therapies, including alternatives ones, from our insurance plans. We have a really good insurance plan from Blue Cross Blue Shield, but we're practically going broke paying for things for our son.*
- *My husband and I have to seek out private services for my son so that he can get the help he needs in a timely manner. This is very expensive and has caused us to go into significant debt in order to care for our son. However, the services we have obtained have helped him greatly. Our state's services for a child diagnosed with ASD are extremely outdated and poor compared to other states*