



Autism Society of Alabama

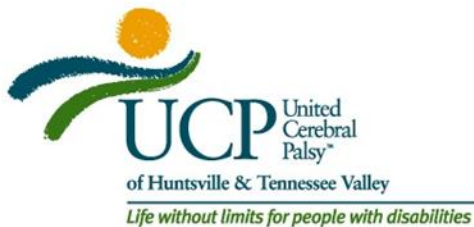
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Statewide Autism Needs Assessment

Executive Summary June 2008

Conducted by the
Alabama Autism Collaborative Group



*The Autism and Behavioral
Health Center of Alabama*



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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.

ACKNOWLEDGEMENTS

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A special thank you to all of the families and individuals who contributed to this project. Additionally, we would like to thank the facilities throughout the state that provided meeting space for our community forums and focus groups. Finally, we would like to thank the Alabama Council for Developmental Disabilities for providing the grant that made this possible.

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*