Autism Society of Alabama

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Statewide
Autism Needs Assessment

Final Report
June 2008

Conducted by the
Alabama Autism Collaborative Group

UCP United Cerebral Palsy of Huntsville & Tennessee Valley
Life without limits for people with disabilities

Glenwood INC.
The Autism and Behavioral Health Center of Alabama

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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

In the literature review, Education and Training is incorporated into the Screening/Diagnosis and Intervention sections. The literature review is based on current scientific research in ASD. For brevity, the citations have been removed from this summary but are available in the full literature review document (See Appendix A).

Seven community forums on autism spectrum disorders were held during the fall of 2007. There were 384 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). Low-income families and families with adolescents and adults were underrepresented across the family forums and 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 (eg., 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.

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.

III. Recommendations

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.

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.

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 across the Lifespan

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 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 young 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. Adult forum participants and their caregivers experienced similar situations as noted above (transportation, lack of awareness, social difficulties, and access to services).

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/Medical

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 that 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, Diagnosis, and Eligibility 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:

- 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 one 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*

Appendix A

CURRENT BEST PRACTICES IN ASD SCREENING, DIAGNOSIS, AND INTERVENTION: A LITERATURE REVIEW

SECTION 1: OVERVIEW OF FINDINGS

Introduction

Autism Spectrum Disorders (ASD) are a group of neurodevelopmental disorders (meaning the brains of people with ASD developed differently) including Autism, Asperger's Syndrome, and Pervasive Developmental Disorder Not Otherwise Specified. Autism Spectrum Disorders involve impairments in verbal and nonverbal communication, impaired social skills, and a restricted range of activities and interests (American Psychiatric Association, 1994). The level of impairment varies across diagnosis and person, as does the response to intervention. However, recent estimates suggest that approximately 40-60% of individuals with ASD also have mental retardation (see Fombonne, 2005, for a review; CDC, 2007). The cause is known to be genetic with likely gene-environment interactions due to early environmental insult (such as an infection in utero or maternal exposure to a toxin). However, the exact cause is, at present, unknown. Autism Spectrum Disorders occur in all racial and ethnic groups and in persons from all economic backgrounds. The gender ratio is approximately 3-4 males for every 1 female with ASD. Prevalence estimates are rising dramatically with current rates estimated to be 1 in150 (CDC, 2007). Autism Spectrum Disorders represent the fastest growing neurodevelopmental disorder of childhood, and the Center for Disease Control considers ASD to be an "urgent health problem in need of targeted public health action." This public health need is particularly evident for children with ASD and their families living in rural, impoverished environments who typically receive diagnostic and intervention services later than other children (Mandell, Novak, & Zubritsky, 2005).

Based on national CDC estimates that ASD is diagnosed in 1 out of every 150 individuals, there are approximately 30,000 people with ASD in the state of Alabama. The specific statewide data show a prevalence of ASD as being at least 1 in 250, although this is likely an underestimate because children receiving only school-based services were not included in this sample (CDC, 2007). Individuals with ASD in Alabama show the same patterns of gender distribution (3-4 males for every 1 female) and SES distribution as found in the rest of the country. In the 2007 CDC study, the median age of first diagnosis was 5.5 years, suggesting that diagnostic evaluations are significantly delayed in Alabama compared to other states. This may be associated with the high rate of rural and low income children in the state. As of December 1, 2006, the Alabama Department of Education was serving 2,373 children under the diagnostic category of ASD. These numbers are expected to rise dramatically with the increasing rates of ASD diagnoses nationwide.

The Alabama Autism Collaborative Group has identified 4 areas – 1) early screening and diagnosis, 2) intervention (early childhood, school-aged, adult, and health care/medical), 3) financial and family support, and 4) statewide systems of care – as important topics to address in both the literature review and family/community forums. The literature review examines national standards of care in each of these areas and examines the current response to these standards in other areas of the country. One of the challenges of this literature review is to summarize the large number of academic publications in an easily accessible format. The following is a brief summary of the problems and recommended

solutions for each of these areas. These "problems" and "solutions" are not specific to the state of Alabama but represent the problems and solutions noted in the larger literature. Following this brief summary, the comprehensive literature review provides a lengthier discussion of each of these areas.

Early Screening/Diagnosis

The Problem: Although parents report being concerned about their child's development within the first 18 months of life, children are typically not referred for an evaluation until their third birthday. This delay has been attributed to the fact that physicians have limited knowledge about ASD symptoms and the fact that there are limited professionals with ASD-specific training who can diagnose autism. Additionally, across the lifespan there are often long delays in obtaining a diagnosis due to the limited number of professionals trained in ASD diagnoses. Even greater delays in early screening and diagnosis exist for minority children and children living in poverty or rural environments. These children are often evaluated at a later age and are more likely to receive an incorrect diagnosis (Mandell et al., 2005; Mandell, Ittenback, Levy, & Pinto-Martin, 2007). Given the strong evidence supporting early intervention, this delay between first symptoms and diagnostic evaluation is potentially harmful to long-term outcome.

The Solution: Practice parameters for the screening and diagnosis of ASD have been published by the American Academy of Neurology (Filipek et al., 1999; 2000), American Academy of Child and Adolescent Psychiatry (Volkmar, Cook, Pomeroy, Realmuto, and Tanguay, 1999), and the American Academy of Pediatrics (Johnson, Myers, and the Council on Children with Disabilities, 2007). Across these different recommendations, a consistent set of suggestions emerges, including the need for:

- Education for health care providers (pediatricians, physician's assistants, nurses) and early childhood education professionals (daycare providers) regarding normative developmental milestones and early red flags for ASD
- Routine early screening for developmental delays, including symptoms of ASD, at well-child healthcare visits
- Interdisciplinary diagnostic evaluations for children whose early screening suggests possible development delays
- ASD evaluations should be conducted by professionals with specific expertise in ASD and include psychological, speech/language, and medical evaluations

Interventions across the Lifespan

Individuals with ASD need interventions that are specifically tailored to their unique symptoms; however, few ASD-specific interventions have been studied rigorously enough to determine if they are truly effective. It is very important to use interventions that have a solid research foundation. Otherwise, time and effort is spent in training and doing programs that ultimately do not make a difference to the children and families which takes time, effort, and funding away from programs that do work. When choosing an intervention approach, families are cautioned that it is not the "brand name" of the program that should be promoted and sought, but rather the *core key elements* that have been demonstrated to be effective. Although there is limited evidence-based research to support that there is one best approach to intervention, general conclusions about the

common elements in each age range (early childhood, school-aged, and adulthood) are available in the literature.

Early Childhood Interventions (Birth to 5 years)

Caveat: Although federal funding streams and state agencies make a distinction between birth to three and three to five services, the early childhood research instead examines children from birth to age five, which is therefore reflected in the current review of that literature.

The Problem: Although it has been demonstrated that intensive early intervention with certain specific characteristics and involvement of parents makes a significant impact on the development of children with ASD, state-based early intervention programs and preschools tend to rely heavily on models of intervention designed for children with typical social motivation and with less need for the intensity of services required to impact children with ASD. This situation is compounded by the lack of training for providers (both workshops/in-services and ongoing consultations) in the symptoms of ASD and in ASD-specific techniques of intervention. Arguments over specific brand name programs have overshadowed the evidence in favor of critical elements of intervention which are subsequently rarely applied. Finally, the fact that funding streams to support services change when a child turns three years of age leads to poorly managed transitions, fragmented services, and frequently, a loss of skills.

The Solution: The National Research Council Committee on the Educational Interventions for Children with Autism (2001) identified the critical elements necessary for successful early childhood intervention. They recommend treatment programs that are:

- 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)
- Based on empirically-based intervention techniques
- Include parents in treatment planning and offer parents training in empirically-based interventions

The ideal early intervention program may require an integration of approaches including techniques that have received the best empirical support thus far, including:

- Applied behavior analysis
- Developmentally based social relationships techniques
- Structured teaching

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.
For example, a preschool classroom whose teachers have training and ongoing consultation in Pivotal Response Training, the Denver Model, and University of North Carolina's TEACCH program are all likely to include the critical elements outlined above. Although these techniques are recommended specifically for children with ASD, they will have a positive impact on all children served by these programs and their providers, leading to a net gain in overall quality and outcome. It further appears that a common funding stream for children birth to five years of age should be considered at the federal level to provide this type of continuous, comprehensive program.

School-Aged Interventions (5-21 years)

The Problem: Given the current state of the literature, at this time it is not possible to identify services for school-aged children that are strongly evidence-based. However, a number of existing interventions do have some scientific evidence backing their use in the treatment of ASD. Research has clearly demonstrated that educational personnel require a clear understanding of ASD and associated interventions in order to implement successful school-based treatments. However, this type of comprehensive training is rarely available. Further, the success of school-based interventions requires an individualized treatment plan that is based on a thorough understanding of the student's personal strengths and weaknesses.

The Solution: The literature strongly recommends that school personnel receive pre-service and in-service training regarding ASD symptoms and specific intervention techniques. Further, there should be a system for monitoring and assessing both a student's response to intervention and the staff's implementation of programming. This will require ongoing consultation and supervision of school-based staff and could best be accomplished by establishing a system of highly-trained individuals who may train others within their local or regional educational system. Interventions for school-aged students with ASD should include careful consideration of the specific symptoms of ASD and a focus on ensuring that students are able to generalize behaviors learned at school to community settings (e.g., generalize math instruction in coin values to making community purchases). This may be facilitated by inclusion but it is necessary that the student with ASD and those involved in the inclusion setting (e.g., teachers and peers) receive the support needed to ensure success. Specific school-based interventions that are recommended and have some research support include:

- Social skills (e.g., Social Stories™, scripts, video modeling)
- Visual supports (e.g., schedules, structured teaching)
- Related services (e.g., speech therapy, occupational/physical therapy)
- Peer education and support

Adult Interventions (21 years and up)

The Problem: 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 (Heller, Factor, & Hanh, 1999). 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.

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. However, 40-60% of individuals with ASD do not have mental retardation. Although they still have substantial difficulties in social communication, adults with high functioning ASD do not have a funding source for long term support. Further, 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 and there is a significant lack of qualified service providers with expertise in working with this population. An individual's ability to work and live in the community is strongly influenced by the service provider's depth of knowledge about ASD.

The Solution: Because there is a wide range of outcomes for adult individuals with ASD, no one treatment approach or intervention is appropriate for all adults, nor is there sufficient empirical evidence to demonstrate that a single approach is most effective. However, the following recommendations are most supported by the literature:

- A coordinated system of intervention and support that addresses academic transition, job training and coaching, college support daily living skills, communication, and social skills
- An autism specific waiver for individuals without MR that would enable individuals to access residential and support services
- Training for adults service providers on empirically validated supports (education, job, living, etc) and behavioral strategies
- Collaborative approach among the individual, parent, mentor, and support agencies with an emphasis on developing maximum independence as appropriate to each individuals' developmental and cognitive level
- Emphasis on self-advocacy

Medical Interventions

The Problem: 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), including dental preventive care, problematic for individuals with ASD and their families. As in other areas of intervention, there is a lack of research into the effects of psychopharmacologic agents on individuals with ASD. In addition, there is a proliferation of alternative medicine treatments, on which scientifically-validated studies are almost non-existent, raising concerns regarding their safety. Finally, families often express concerns about the lack of access to medical services due to the failure of their insurance companies to cover some or all of their child's therapy services.

The Solution: Implementing continuing medical education requirements to increase the knowledge of medical and dental practitioners regarding medical and behavioral management issues of individuals with ASD. A postgraduate training curriculum should be developed to address the specific problems faced by patients with developmental disabilities and ASD to educate residents in pediatric dentistry, child psychiatry, pediatrics, and family practice. In addition, consultation teams should be available at regional ASD centers to assist medical personnel regarding management of patients with ASD on both an outpatient and inpatient basis. These consultation teams could be involved from the initial evaluation to the formulation of cognitive and behavioral plans. Finally, healthcare providers need more information regarding evidence-based interventions (including alternative treatments) so that they can best guide the families who turn to them for advice.

Systems of Care

The Problem: On May 16, 2005, the Interagency Autism Coordinating Committee reported an urgent need to coordinate care across agencies. ASD is lifelong disorder, yet services for children and young adults with ASD are often fragmented. In Alabama, at least three different state agencies provide services to children and young adults with ASD from birth to age 21. Further, it is often necessary for individuals with ASD to access psychological and medical care from multiple professionals, such as ASD diagnosticians and interventionists, speech-language pathologists, psychiatrists and other medical doctors, physical therapists, and school psychologists, in order to receive the highest standards of care. Because these professionals and agencies usually work independent of one another rather than working collaboratively, the healthcare system can be costly and confusing for individuals and families, resulting delays in screening, diagnosis, and intervention.

The Solution: The National Research Council's Committee on Educational Interventions for Children with Autism (2001) 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. A network of regional centers could work with the various federal, state, county, and city agencies in order to accomplish that task. States that have successfully implemented a regional center system include North Carolina, Florida, and California. Different states have focused on various service delivery

programs, with some regional centers focused on providing diagnostic services, some focused on consultation services, and some focused on intervention services. Regional centers have typically relied on state funding mechanisms to support their mandate, as costs cannot be reasonably shouldered primarily by families or local school systems, nor can they continue to be written off by providers. The most effective programs appear to establish university affiliated regional centers in partnership with public and private agencies and provide the following programs:

- Interdisciplinary, regional 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.

University-based regional centers in the Southeastern United States (Florida and North Carolina) are recommended as model programs. In addition to providing diagnostic, treatment, and consultation services, university-based regional centers are able to provide both continuing education for current providers and provide degree and certificate training to grow the work force specializing in ASD. Further, university-based programs will provide continued research on the development and effectiveness of new treatment approaches.

SECTION 2: LITERATURE REVIEW OF SCREENING AND DIAGNOSIS

The Problem: Although parents report being concerned about their child's development within the first 18 months of life, children are typically not referred for an evaluation until their third birthday. This delay has been attributed to the fact that physicians have limited knowledge about ASD symptoms and the fact that there are limited professionals with ASD-specific training who can diagnose autism. Additionally, across the lifespan there are often long delays in obtaining a diagnosis due to the limited number of professionals trained in ASD diagnoses. Even greater delays in early screening and diagnosis exist for minority children and children living in poverty or rural environments. These children are often evaluated at a later age and are more likely to receive an incorrect diagnosis (Mandell et al., 2005; Mandell et al., 2007). Given the strong evidence supporting early intervention, this delay between first symptoms and diagnostic evaluation is potentially harmful to long-term outcome.

Early Screening

By definition, the age of onset of autism is prior to three years of age (APA, 2000). In a nation-wide CDC study in the United States, parents in most states (including Alabama), reported that they were concerned about their child's development before their child's second birthday. Similarly, in a large epidemiological study in the United Kingdom, parents reported concerns about their child's development around 18 months of age (Chakrabarti & Fombonne, 2005). However, there is often a significant delay between parents' first concerns and the child's first referral for an evaluation. In Chakrabarti and Fombonne's (2005) study, children were typically not referred for an evaluation until 32-37 months.

In addition to the lag between parents' first concerns and the child's referral for an evaluation, there may be an additional lag between referral and ASD diagnosis. These additional delays may be related to professionals being cautious about giving an ASD diagnosis to young children or may be related to a limited number of professionals who have ASD-specific training. Indeed, parents often report long waitlist to receive an ASD evaluation. In the United Kingdom study, the average age of diagnosis was 38-42 months (Chakrabarti & Fombonne, 2005). However, in the United States, diagnoses are often later. The CDC (2007) reported that most children were diagnosed when they were 4 years of age. The average age of diagnosis in Alabama was 5 years, 6 months in their study. Even within states, there tends to be wide disparities in the age of first diagnosis. For example, African-American children receive a diagnosis approximately 1 ½ years later than white children (Mandell, Listerud, Levy, & Pinto-Martin, 2002).

The age of first diagnosis is often related to the ASD subtype and level of developmental delays that the child displays. Children who have average or better intelligence or fewer symptoms of ASD tend to be diagnosed later than children with more severe symptoms and more developmental delays. For example, in a statewide survey conducted in Pennsylvania, children with autism received a diagnosis at an average age of 3.1 years, children with PDD-NOS received a diagnosis at an average age of 3.9 years, and children

with Asperger syndrome received a diagnosis at an average age of 7.2 years (Mandell et al., 2005).

This delay between parent's first concerns, referral for an evaluation, and an accurate diagnosis of ASD is concerning as researchers have suggested that earlier age of intervention leads to better long-term outcome. Children with ASD who participated in intensive early intervention services before 3 ½ years of age were reported to have significantly better outcomes than children with ASD who did not receive services until 5 years of age (Fenske, Zalenski, Krantz, & McClannahan, 1985; Harris & Handleman, 2000).

Early screening studies have been shown to decrease the lag between parental concerns and early intervention services. For example, Hix-Small, Marks, & Squires (2007) used the Ages and Stages Questionnaire to screen for ASD at 12 and 24 month well child visits. They reported that sixty-seven percent of children identified with delays on the ASQ were not identified by their pediatricians. These findings highlight the impact early screening could have on children receiving the early intervention services they need. The American Academy of Pediatrics (Johnson et al., 2007) recommends that, in addition to regular developmental screening, all children receive early screening for an ASD during routine well-child pediatrician visits at 18-24 months.

The American Academy of Neurology (Filipek et al., 1999, 2000) made similar recommendations including developing a list of practice parameters to help determine when an ASD specific screening is necessary. They recommended the following three step process:

Step 1: Routine Developmental Surveillance

Immediate further developmental evaluation including ASD screening if the following concerns are noted:

- No babbling, pointing, gestures at 12 months
- No single words at 16 months
- No spontaneous, non-echoed 2-word phrases by 24 months
- Any loss of language or social skills at any age

Step 2: Screening Specifically for ASD

If concerns arise during the routine developmental screening, the following recommendations are made for screening specifically for ASD.

- Recommend the use of an ASD-specific screening measure
- Medical evaluation to rule out hearing loss, visual impairment, and/or other physiological problems

Step 3: Diagnostic Evaluation

If concerns arise during the screening for ASD symptoms, a referral for a comprehensive diagnostic evaluation is recommended.

While there is a growing consensus about the need for developmental and ASD-specific screening within the primary care office, there is a lack of consensus regarding the most

appropriate screening instrument, particularly whether screening should occur at a more general developmental level, should be specific for an ASD, or should assess for both ASD and other related communication delays. Instruments are available for each of these purposes. Several of the most popular screening instruments are described below. This is not a comprehensive list but provides a guide to the types of instruments that are currently available. For a more comprehensive list of screening instruments, see Johnson et al., 2007.

Ages and Stages Questionnaire (ASQ)
The ASQ (Bricker, Squires, & Mounts, 1995; Squires, Bricker, & Twombley, 2002) is a broad-based measure of developmental milestones in infants and young children from 4-48 months of age. It is a 30 item primary caregiver questionnaire that takes approximately 10-15 minutes and screens for communication, gross motor, fine motor, problem-solving, and personal-social skills. It is a fast, reliable method of screening for a wide variety of developmental disorders.

Modified Checklist for Autism in Toddlers (M-CHAT)
The M-CHAT (Dumont-Mathieu & Fein, 2005; Robins, Fein, Barton, & Green, 2001) is a 23-item primary caregiver questionnaire designed for use in a primary care setting as a screener for autism–specific symptoms. It is appropriate for children between 16 and 48 months of age and takes approximately 10 minutes to complete. The M-CHAT specifically assesses symptoms associated with early signs of autism including a failure to respond to name, poor eye contact, and failure to following another person's nonverbal cues. The data suggest that children identified as having as having a possible ASD on the M-CHAT were likely to indeed have that diagnosis (sensitivity of .85). Further, children who were identified as having limited risk for a possible ASD were not likely to have an ASD (specificity of .93). Thus, this is a fast, reliable way to screen for an ASD in order to determine whether a referral for a more comprehensive evaluation is needed. This instrument can be downloaded through www.firstsigns.org/downloads/m-chat.pdf

Communication and Symbolic Behavior Scales – Infant Toddler Checklist (CSBS)
The CSBS Infant Toddler Checklist (Wetherby & Prizant, 2002; Wetherby, Woods, Allen, Cleary, Dickinson, & Lord, 2004) is a measure of early social and communication behaviors in infants and toddlers. It is a one page primary caregiver questionnaire designed for use in pediatrician's offices during well-child check-up. The CSBS is appropriate for use at both the 12 and 24 month primary care visits and takes approximately 5 to 10 minutes to complete. The CSBS was designed to screen seven language predictors: emotion and use of eye gaze, use of communication, use of gestures, use of sounds, use of words, understanding of words, and use of objects. Although it is designed to screen for ASD and other communication disorders, it is fairly accurate at detecting autism. Children identified as having as having a possible ASD on the CSBS were likely to indeed have that diagnosis (sensitivity of .89). Further, children who were identified as having limited risk for a possible ASD were not likely to have an ASD (specificity of .89). This instrument is available free of charge through the publisher (Paul H. Brookes Publishing) or through http://firstwords.fsu.edu/pdf/checklist.pdf

Diagnostic Evaluations

Autism spectrum disorders are considered to be pervasive developmental disorders, which means that all areas of development are affected, including 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 assessment of each of these domains and typically requires an interdisciplinary team approach including a psychological evaluation and a speech/language evaluation (Klin, Saulnier, & Tsatsanis, 2005; National Research Council, 2001; Ozonoff et al., 2007).

The actual diagnosis of autism spectrum disorders is based on a detailed history and behavioral observations and requires an interdisciplinary evaluation that considers multiple aspects of a child's life. The diagnostic evaluation should include assessment of functioning across multiple domains and the evaluation of behaviors that may interfere with daily functioning and learning. It is crucial that the multidisciplinary evaluation be conducted by team of professionals with expertise in ASD (National Research Council, 2001). The American Academy of Neurology Filipek et al. (1999; 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 Autism Spectrum Disorders. 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 and a possible neurological evaluation
- 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.

Although professionals and parents both express concerns about whether an accurate diagnosis can be made at an early age, the research suggests that an accurate diagnosis can be made by an experienced clinician as early as 2 years of age (Stone, Coonrod, & Ousley, 2000; Wetherby et al., 2004). Of children diagnosed with ASD at 2 years of age, over 85% retained this diagnosis at four years of age (Lord, Risi, DiLavore, Shulman, Thurm, & Pickles, 2006; Turner, Stone, Pozdol, & Coonrod, 2006). Thus, this type of comprehensive evaluation is accurate and effective in the early diagnosis of an ASD.

Until recently, the diagnosis of ASD has been based on clinician observation and intuition rather than a score on a standardized instrument. However, more objective

diagnostic measures are now available. The "gold-standard" diagnostic instruments are the Autism Diagnostic Interview-Revised (ADI-R; Lord, Rutter, & LeCouteur, 1994) and the Autism Diagnostic Observation Schedule (ADOS; Lord et al., 2000). These instruments have significantly increased our ability to reliably diagnose children with ASD. The ADI-R is a semi-structured caregiver interview appropriate for children between the ages of 18 months of age through adulthood. The interview focuses on each child's social skills, communication skills, and the presence of any restricted and repetitive behaviors. Because diagnostic symptoms change across the lifespan, an ADI-R diagnosis is based on caregiver report of symptoms during the preschool years when symptoms tend to be the most severe. However, current behaviors are also assessed in order to get a picture of each individual's current skills. This is a lengthy interview; the short version takes approximately 1 ½ hours to administer. Because it is so lengthy, many practitioners find the ADI-R difficult to administer in their daily practice.
The ADOS is a semi-structured play session (or conversation for adults) that assesses social skills, communication skills, and the presence of restricted or repetitive behaviors. It takes approximately 30-45 minutes to administer and is appropriate for individuals from two years of age through adulthood. There are 4 different ADOS modules based on the individual's developmental level. Module 1 is appropriate for nonverbal children, Module 2 is appropriate for individual's using phrase speech, Module 3 is appropriate for children and adolescents with fluent language, and Module 4 is designed for adults with fluent language. The materials in the first two modules are more appropriate for young children and assess (e.g., bubbles, balloons, a set of family dolls), the third module is appropriate for school aged children and young adolescents (e.g., book, markers, action figures), and the fourth module does not use toys. The ADOS is widely used to diagnose an ASD. However, the ADOS diagnosis is based on social and communication skills only because repetitive behaviors and restricted interests may not occur during the short observation session. If these behaviors are observed, the examiner can feel confident that they are present. However, if they are not observed, a caregiver interview is necessary to assess these behaviors. Thus, a parent interview is an important component of making an accurate diagnosis.

Both the ADI-R and the ADOS must be administered by a professional who has had extensive training in their use and scoring. There are a variety of less intensive instruments, mostly caregiver questionnaires, which are available although, thus far, none of the other instruments are as accurate as the ADI-R and the ADOS. It is beyond the scope of this review to describe each of these instruments. A recent review by Ozonoff et al. (2007) is a good resource for further information.

There are differences in opinion regarding the capacity of professionals to differentiate reliably among different diagnoses within the autism spectrum. Indeed, our gold standard diagnostic instruments do not differentiate between the ASD subtypes. The ADOS diagnosis is either "autism" or "autism spectrum" and the ADI-R diagnosis is "autism spectrum." The difficulty differentiating between ASD subtypes is particularly true when differentiating between children with high functioning autism and Asperger syndrome. According to our current diagnostic system (DSM-IV; APA, 2000), Asperger syndrome is defined by the presence of impaired reciprocal social skills and the presence of

restricted behaviors and interests in individuals who have average intelligence and who did not have a history of language delay (i.e., single words by 2 years and phrases by 3 years). Individuals with a history of language delay, regardless of their current level of language skills, cannot be given a diagnosis of Asperger syndrome. Research comparing the Asperger syndrome and high functioning autism provides mixed evidence about whether these are indeed separate disorders as the long-term outcome data are similar for both groups (Ozonoff, South, & Miller, 2000). Given this debate about how to differentiate between ASD subtypes and whether these subtypes represent different diagnoses, some argue that it is less important to know which diagnosis within the autism spectrum is applicable, and more important to know about the skills, strengths, and weaknesses of the individual.

In contrast to the debate about our ability to differentiate between ASD subtypes, individual differences in language development, verbal and nonverbal communication, sensory or motor skills, adaptive behavior, and cognitive abilities have significant effects on behavioral presentation and outcome, and consequently, have specific implications for educational goals and strategies" (NRC, 2001, p. 220). However, the Individuals with Disabilities Education Act (IDEA, 2006) requires that an individual have a diagnosis, such as an ASD, that may "adversely affect educational performance" in order to qualify that individual for educational services.

The Solution: Practice parameters for the screening and diagnosis of ASD have been published by the American Academy of Neurology (Filipek et al., 1999; 2000), American Academy of Child and Adolescent Psychiatry (Volkmar, Cook, Pomeroy, Realmuto, and Tanguay, 1999), and the American Academy of Pediatrics (Johnson et al., 2007). Across these different recommendations, a consistent set of suggestions emerges, including the need for:

- Education for health care providers (pediatricians, physician's assistants, nurses) and early childhood education professionals (daycare providers) regarding normative developmental milestones and early red flags for ASD
- Routine early screening for developmental delays, including symptoms of ASD, at well-child healthcare visits
- Interdisciplinary diagnostic evaluations for children whose early screening suggests possible development delays
- ASD evaluations should be conducted by professionals with specific expertise in ASD and include psychological, speech/language, and medical evaluations

SECTION 3: LITERATURE REVIEW OF INTERVENTION/TREATMENT APPROACHES

"Children with autism spend much less time in focused and socially directed activity when in unstructured situations than do other children" (National Research Council's Committee on Educational Interventions for Children with Autism, 2001, p. 220), which means that they are learning less on a minute-by-minute basis from the adults in their environments than their peers with typical development. The autism spectrum presents a unique cluster of symptoms and behaviors that are not well addressed by programs that are implemented to address other developmental disorders. This occurs in part because of the reliance on social relatedness and typical patterns of motivation by standard interventions and in part because of the generally low intensity level of standard treatments (Howlin, 1998). Therefore, individuals with ASD need interventions that are specifically tailored to their unique symptoms; however, few ASD-specific methodologies and interventions have received strong research support. It is very important to use treatments that have a solid research foundation, that is, those that have evidence that they actually work. Otherwise, we spend time and effort in training and doing programs that do not ultimately make a difference to the children and families and that take time, effort, and funding away from programs that do work.

Cautions on Interpreting the Literature

Pseudoscience (that which pretends to be scientific) is abundant in the area of ASD (Green, 2001; Herbert and Sharp, 2001). The opportunity to take advantage of families is very high, with families typically trying between seven and nine different therapies (Goin-Kochel & Mackintosh, 2007). There is also a large "placebo effect" (meaning that it is not the treatment itself that is driving changes in behavior, but rather the fact that a treatment was introduced, so that *any* treatment would have gotten the same effects) especially if the treatment is expensive (Herbert, Sharp, & Gaudiano, 2003). Although there is a large literature addressing intervention techniques for individuals with ASD, few intervention programs have "evidence-based" data. However, various treatment components or interventions within these programs have shown some promising and emerging scientific strength. The precise definition of evidence-based treatments varies slightly between groups of professionals. However, the bottom line is that, in order to be considered a true scientifically backed treatment, it must have been 1) studied by multiple researchers in multiple locations, and 2) have been demonstrated to be associated with significantly better outcome than other common treatments when the participants are randomly assigned to either study-treatment or nonstudy-treatment groups. For example, a treatment that has one or even several studies that associate it with improvements in symptoms would not count unless multiple researchers had compared it to the effects of another treatment and had randomly assigned participants to receive the two different treatments. Although there is scientific evidence that interventions *do* cause change and that without intervention there will continue to be significant ASD symptoms, more rigorous scientific studies of interventions in ASD are needed, particularly cross-program comparisons (the type of study that would indicate if one program is better than another; Goldstein, 2002; Lord, et al, 2005; McConnell, 2002; Smith, et al, 2006). Indeed, this educational interventions based on this type of rigorous scientific study is mandated by

IDEA (2006) and NCLB (2001). It will continue to be important for policy makers, educators, parents, and providers to support the scientific evaluation of interventions so that resources may be channeled into the most effective methods (Kasari, 2002).

Because there is limited evidence-based research on successful interventions, families and professionals often try therapy approaches that are considered experimental. Until empirical data is available, it is important to protect individuals with ASD from potentially harmful treatments. Green (1996) and Herbert, Sharp, & Gaudiano (2003) recommend the following guidelines when considering treatment options. Look out for:

- Grandiose claims(e.g., stating "miraculous" or "cure")
- Underlying theories not based in generally accepted science
- Anecdotes and testimonials rather than good research and real science
- Promotions primarily via web and private publications
- Financial gain for promoters

Evidence-Based Interventions

The exact list of interventions that are considered "evidence-based" varies depending on which criteria are applied. For the purposes of this review, interventions were sorted into four categories:

- Those with good scientific evidence in their favor, meaning that there have been research studies that generally conformed to accepted standards which demonstrated efficacy
- Those with some scientific evidence in their favor, meaning that there have been research studies that conformed to minimal standards which suggested efficacy
- Those that have not been studied using basic scientific standards, so there is no evidence that they work, but there is also no evidence that they are harmful
- Those that have been studied carefully and proven to not work, and those that have been demonstrated to be harmful

Admittedly, these criteria are less rigorous than those documented for the identification of "educational practices supported by rigorous evidence" in the No Child Left Behind (NCLB, 2001) Act of 2001 or recommended by the American Psychiatric Association (2000). However, if these more rigorous criteria were used, no ASD-specific interventions would be considered evidence-based (see Chorpita et al., 2002; Lord et al., 2005). Treatments were categorized as follows based on expert opinions in Myers et al., 2007; Chorpita, et al, 2002; Green, 1996; Herbert, Sharp, & Gaudiano, 2003; New York State Department of Health, 1999; Rogers, 1998; Rogers, 1999; Smith; 1996; Smith, et al., 2006; and on the current review of the literature. Although examples of treatment approaches or packages are given in this document, these are meant to serve as representative examples and not exhaustive lists, as it was not possible to note all the interventions that currently exist.

Good Scientific Evidence

Approaches that rely on principles of applied behavior analysis (ABA) have been found to be effective. Applied behavior analysis is a term used to refer to the application of known principles of learning in order to alter socially important human behaviors. ABA is not synonymous with a particular package or program, despite frequently being used in that manner. A variety of different programs use these principles to address skill building in ASD. These programs include interventions that are highly structured and adult-driven (e.g., UCLA Young Autism Project) and those which are more based in the "natural environment" and child-driven (e.g., Pivotal Response Training). Programs based on principles of applied behavioral analysis include Functional Communication Training, Pivotal Response Training (PRT), incidental teaching, Lovaas/Discrete Trial Training (DTT), UCLA Young Autism Project, Early Intensive Behavior Intervention, and Verbal Behavior Analysis. Although there are a large number of studies demonstrating that ABA approaches are effective in teaching new skills to individuals with ASD, there are no studies comparing different ABA intervention packages (e.g., UCLA YAP compared to Pivotal Response Training) or comparing ABA to other intervention approaches (Matson & Minshew, 2006; Schreibman & Ingersoll, 2005). A handful of studies have demonstrated that intensive ABA programs are associated with greater skill gain than similarly intensive treatment-as-usual programs (Green, 1996; Cohen, Amerine-Dickens, & Smith, 2006; Smith, et al. 2006). Taken together, although there is not enough support for an individual specific package or program, there is adequate evidence to support the use of behavior analytic techniques.

Other approaches that have good scientific evidence include several social skills approaches including peer-mediated social skills training (e.g., Learning Experiences: An Alternative Program for Preschoolers and Parents – LEAP) and video modeling of social skills, as well as some developmentally-based play interventions (e.g., the Denver Model).

There are limited evidence-based studies of medical interventions for individuals with ASD, and those that exist frequently produce conflicting results. However, the US Food and Drug Administration has recently approved risperidone (brand name Risperdal) as the first medication labeled for treatment of symptoms (e.g., irritability, aggression, self-injury, and tantrums) in children and adolescents with ASD. Approval was based on multiple studies (Myers et al., 2007).

Limited Scientific Support

Examples of interventions that do have <u>some</u> scientific backing, but not at the level of the first category, include structured teaching techniques (e.g., University of North Carolina TEACCH program) and cognitive behavioral interventions (e.g., anxiety reduction techniques, social stories, social scripts).

Few Scientific Studies Conducted

Examples of interventions that currently have <u>no</u> scientific support for use in ASD, <u>but</u> also have no evidence that they are ineffective or harmful include relationship focused interventions such as the Responsive-Teaching curriculum (RT) and Relationship-

Development Intervention (RDI); other developmentally based interventions such as the Developmental Individual-Difference Relationship Based model (DIR), "floor time," sensory-motor therapy, sensory integration therapy, and music therapy. Medical interventions without research support include diets such as the gluten- and casein-free diet and vitamin therapies such as Vitamin B6 and magnesium treatments (however effects of long-term use are not known and therefore medical professionals caution that the potential for harm is unclear).

Evidence Against

Examples of interventions that have been scientifically demonstrated to not work and/or they pose significant health risks or have been proven harmful include Facilitated Communication, Auditory Integration Training, Psychoanalysis, Holding therapy, Secretin and other hormones such as ACTH, Chelation, immune therapies such as DMG and IVIG, and anti-yeast therapies (Myers et al., 2007; Herbert, Sharp, & Gaudiano, 2003; New York State Department of Health, 1999).

Critical Elements of Effective Intervention

When choosing an intervention approach, families are cautioned that it is not the "brand name" of the program that should be promoted and sought after, but rather the *core key elements* that have been demonstrated to be effective. Although there is limited evidence-based research to support that there is one best approach to intervention, general conclusions about the common elements in each age range (early years, school-aged, and adulthood) are outlined in the following sections, and example interventions are briefly reviewed.

Early Childhood Interventions (Birth to 5 years)

Caveat: It should be noted that the current funding streams at the federal level (IDEA; Federal Register, 2006, Part C, 0-2; Part C, 3-21.), *and therefore the implementing systems at the state level, make what scientific research considers to be an artificial distinction between services for children from birth until the day they turn three years of age and children from the day they turn three years old until the day they turn five. The scientific research does not support this distinction, nor do the studies published divide their participants in this manner. The early childhood research instead examines children from birth to age five, which is therefore reflected in the current review of that literature.*

The Problem: Although it has been demonstrated that intensive early intervention with certain specific characteristics and involvement of parents makes a significant impact on the development of children with ASD, state-based early intervention programs and preschools tend to rely heavily on models of intervention designed for children with typical social motivation and with less need for the intensity of services required to impact children with ASD. This situation is compounded by the lack of training for providers (both workshops/in-services and ongoing consultations) in the symptoms of ASD and in ASD-specific techniques of intervention. Arguments over specific brand name programs have overshadowed the evidence in favor of critical elements of intervention which are subsequently rarely applied. Finally, the fact that funding streams

to support services change when a child turns three years of age and the fact that staff are often not professional trained leads to poorly managed transitions, fragmented services, and frequently, a loss of skills.

Why teach at these early ages?
When intervention is started at younger ages, outcome is significantly better (Handleman & Harris, 2000; The National Research Council, 2001).This makes sense given the research indicating that the earliest years of life are marked by incredible rates of learning and appear to be a "sensitive period" for maximizing impact of early interventions (reviewed in Dawson, Ashman, & Carver, 2000).With early and specific intervention that is intensive (at least 25 hours a week), 75-95% of children with ASD learn to talk, and 50% of children with ASD succeed in regular education kindergarten with little support (Wetherby & Woods, 2006; Smith, et al. 2000).Good early intervention may save a million dollars in life-time care for each individual with ASD (Jacobson, Mulick, & Green, 1998).

When should intervention begin?
General developmental intervention should begin as soon as a concern regarding a child's development has been identified. Beginning intervention immediately upon the identification of a developmental concern allows progress to begin even while the child is awaiting further evaluation. In Alabama, any infant or toddler age birth to three may be identified by a parent or a family member who is concerned about their child's development. Those children with a delay of 25% or more in cognitive, physical, communication, social, emotional, or adaptive development or who have a diagnosed physical or mental condition are eligible. Further, experts recommend that ASD-specific intervention begin as soon as a diagnosis on the autism spectrum is seriously considered. Due to limited diagnostic resources, waiting lists at diagnostic clinics are often long and valuable intervention time is wasted while the child awaits a formal diagnosis. If the child has an ASD, progress will be significantly improved with ASD-specific intervention during these valuable learning years, while if the child does not have an ASD, treatment with ASD-specific interventions is not harmful (Dawson, Ashman, & Carver, 2000).

Who should intervene?
A critical element in ensuring progress for children with an ASD is for all interventionists to have training in the characteristics of ASD and also in evidence-based techniques. All staff engaging in treatment of the child must be well-trained (see school-aged section below for a discussion of qualifications of teachers and aides). Although both the Early Intervention system and the school system have minimum educational requirements for professionals in their hire, these requirements do not include ASD-specific training. Little research has examined the application of interventions by actual interventionists, instead typically training less "qualified" providers or trainees to apply the treatment being researched. In addition to having well-trained staff, there is significant research demonstrating that teaching parents to intervene with their young child with ASD is effective (McConachie & Diggle, 2007). Research has begun to suggest that teaching parents to work with very young children with ASD in their natural environment, embedded in their day-to-day routines, works very well to increase social communication

and is in keeping with mandates of IDEA 2004, Part C (Wetherby & Woods, 2006). There is also evidence that teaching parents to intervene with their young child with ASD is effective when added to school-based or center-based intervention (McConachie & Diggle, 2007). The National Research Council's Committee on Educational Interventions for Children with Autism (2001) recommends initial training sessions as well as ongoing consultation with both parents and with interventionists/staff.

Where should the intervention take place?

As previously discussed, research on the early years (birth to 5 years) typically does not distinguish among these ages, refusing to make the artificial break at three years of age that typical service provision does. Instead most programs recommend balancing individual (one-on-one) skill-building therapy (either home- or center-based) with small group therapy (more classroom based). This balance of services may vary depending on the ability of the child and on the extent and nature of previous interventions. Although some children may be ready to enter a small preschool classroom with peers with typical development and learn in that environment, others may require intensive one-on-one intervention in order to be ready for that setting. Generalizing skills learned in one environment to other environments is exceedingly important; thus implementation of interventions by parents in the home setting is vital. It is important that across settings, a structured and supportive environment that is understandable to the child be maintained. Transitions between settings must be effectively planned for, supported, and managed. By law, transition services from infant and toddler services to three-year-old services are also required and available in all education agencies (IDEA, Federal Register, 2006, 34 CFR Parts 300 and 301, 72, Section 1412 (a) (9).

How should we intervene?

Critical elements regarding how to best teach very young children with ASD include an emphasis on intensity. Although there is no Federal or State law mandating the amount/time of special education services required for a child with any disability, research has clearly demonstrated that at least 25 hours a week of active engagement in planned programming is required for best outcome. Active engagement is defined as the child working toward individualized goals in an effortful manner. It does not include simply being present in a particular setting (e.g., simply sitting in the classroom does not count toward the 25 hours). Further evidence regarding the difficulty of maintaining gains indicates that children with ASD must be engaged in active learning 12 months (52 weeks) of the year. The use of systematic, planned, and developmentally appropriate instruction is critical. Individualized objectives should be "observable, measurable behaviors and skills," and ongoing measurement of progress toward objectives must be documented frequently (every 3 months) so that changes in the intervention program may be made if progress is not forthcoming. Children need to be engaged in activities that are specifically designed to target their individualized objectives and that use good teaching strategies such as those used in behavior analytic approaches. The developmental appropriateness of both teaching techniques and objectives must be considered, as progress will be optimized by following a developmental sequence. Techniques that are evidence-based for children with ASD include those based in the behavior analytic principles, those that specifically target social skills development, those that rely on the

principles of structured teaching, and those that take into account the typical developmental sequence.

What should be taught?

What is taught at this age should include all aspects of development in which the child struggles. Children with ASD who speak prior to five years of age have better outcome than those who do not; thus, focus in the youngest ages should be on developing a spontaneous, functional communication system with an effort to stimulate verbal, nonverbal/gestural, and affective modalities. The significant social growth seen during typical development in the first five years of life points to the developmental necessity of explicitly teaching those skills as well. As discussed above, children with ASD are not attuned to their social environments and are missing key learning opportunities. They are not attending to, imitating, or motivated by attention from their parents or peers and these deficits significantly impact their learning. Teaching these core skills explicitly, but from a developmental standpoint, is important so that more complex and later developing skills are built upon the solid foundation of earlier developing basic skills. As with any child, it is also important to attend to the cognitive, motor, and adaptive/self-help skills that are delayed in their development. Further, the teaching of organizational and other classroom skills is typically necessary prior to introduction into a classroom or group setting. Any disruptive behavior will best be addressed in context utilizing a functional approach and focusing on developing missing skills or replacement behaviors. Behavioral strategies focused on positive behavior support with the goal of increasing appropriate behaviors are recommended over strategies focused on punishment and solely decreasing unwanted behaviors (Horner et al., 2002).

Examples of Programs including the Critical Elements

This section briefly describes a few programs that have received empirical support. **It is not intended to be an endorsement of these programs over any others, since there are no cross-program comparison studies.** The descriptions that follow are meant to give the reader a sense of how critical elements are already woven into existing models of intervention. Each of these programs exemplify the use of the critical elements of intervention outlined in this section, thus the description here will highlight the unique aspects or techniques that define them. Perhaps the best program, as suggested below, would be one that combined elements of the four programs outlined here. Pivotal Response Training (PRT) is based in the principles of applied behavior analysis, operates in a naturalistic manner (therapy occurs in the child's natural environment and rewards are obviously connected to the behavior the child is asked to make), and targets the "pivotal behaviors" of motivation and responsivity to multiple cues that influence the development of broad learning behaviors. It is especially aware of intervening in the areas of communication, play, and social development. The Learning Experiences, an Alternative Program for Preschoolers and their Parents (LEAP) Preschool is perhaps best known for its peer-mediated social skill program, and uses both a behavioral approach and attention to typical developmental trajectories. The Denver Model is developmentally oriented and relies on play and affective relationships with others in order to teach social, communicative, emotional, and other skills. The University of North Carolina's Treatment and Education of Autistic

and Related Communication Handicapped Children (TEACCH) is based on structured teaching approaches which present clear, organized environments using concrete and visual information.

Summary

Although one package or program of intervention for the youngest children with ASD has not been demonstrated to be fully evidence-based or better than the others, common critical elements from the various interventions have been identified. Given that these elements are in one form or another studied across different programs, the elements are themselves evidence-based. The following list outlines the critical elements, as discussed above, for intervening during the early years as determined by Myers et al., 2007; Dawson & Osterling, 1997; Koegel, Koegel, & McNerney, 2001; The National Research Council, 2001; Rogers, 1998; Rogers, 1999; Schreibman, 2000, and by the current literature review.

- Intervention begun as soon as an ASD diagnosis is seriously considered
- Implementation by highly trained staff (trained in features of ASD and in ASD specific techniques of intervention)
- Family involved/Parent education
- Individualized attention (1:1 or very small group – 1:3) in frequent intervals
- Inclusion with peers with typical development as appropriate in working toward goals
- Highly structured/supportive environment and routine
- Generalization of skills across environments/Working in the natural environment
- Transitions between programs must be effectively managed
- Intensive: Active engagement in planned programming >25 hours/week, 12 months/year
- Systematic, planned, developmentally appropriate instruction
- Working toward specific *individualized* objectives/goals
- Ongoing assessment of progress (every 3 months) and alterations of programming if adequate progress is not being attained
- Curriculum addressing these areas, with special attention to core features of autism:
    - Functional, spontaneous communication (verbal, nonverbal, symbolic)
    - Receptive language
    - Social instruction – age appropriate
    - Imitation
    - Play skills, especially with peers
    - Attention to the environment/Response to appropriate motivators
    - Cognitive skills taught in context – Generalization
    - Fine and gross motor skills
    - Independent organizational skills (completing tasks, asking for help, following instructions)
    - Functional academic skills when appropriate
    - Self-help/Adaptive skills
    - Problem behaviors addressed in context, in a positive manner, with a focus on developing replacement behaviors

The Solution: The National Research Council Committee on the Educational Interventions for Children with Autism (2001) identified the critical elements necessary for successful early childhood intervention. They recommend treatment programs that are:

- 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)
- Based on empirically-based intervention techniques
- Include parents in treatment planning and offer parents training in empirically-based interventions

The ideal early intervention program may require an integration of approaches including techniques that have received the best empirical support thus far, including:

- Applied behavior analysis
- Developmentally based social relationships techniques
- Structured teaching

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.
For example, a preschool classroom whose teachers have training and ongoing consultation in Pivotal Response Training, the Denver Model, and University of North Carolina's TEACCH program are all likely to include the critical elements outlined above. Although these techniques are recommended specifically for children with ASD, they will have a positive impact on all children served by these programs and their providers, leading to a net gain in overall quality and outcome. It further appears that a common funding stream for children birth to five years of age should be considered at the federal level to provide this type of continuous, comprehensive program.

School-Aged Interventions (5-21 years)

The Problem: Given the current state of the literature, at this time it is not possible to identify services for school-aged children that are strongly evidence based. However, a number of existing interventions do have some scientific evidence backing their use in the treatment of ASD. Research has clearly demonstrated that educational personnel require a clear understanding of ASD and associated interventions in order to implement successful school-based treatments. However, this type of comprehensive training is rarely available. Further, the success of school-based interventions requires an individualized treatment plan that is based on a thorough understanding of the student's personal strengths and weaknesses.

Educational Considerations

Much of the educational research focuses on strategies to improve early intervention programs for young children with ASD, resulting in a paucity of well-researched programming for older children and adolescents (Johnson et al., 2007). Thus, there is limited research about specific "packages" for school-aged children. However, there are national guidelines regarding qualifications for school-based services and Individualized Education Program (IEP) goals that may be most effective, and these will be reviewed in this document.

In response to questions about which students should qualify for special education services, the National Research Council's Committee on Education Interventions for Children with Autism (2001) suggests that "Children with any autistic spectrum disorder…regardless of level of severity or function, should be eligible for special educational services within the category of *autistic spectrum disorders*" (p. 213). Further, the National Research Council suggests that it is the responsibility of the school system to educate parents about their child's diagnosis and about the services that they are qualified to receive. The National Research Council also recommends that schools supply families with "written information concerning the nature of ASD and eligibility categories, the range of alternatives within best practices in early education of ASD, sources of funding and support (e.g., a support guide and bibliography), and their child's rights," in addition to written results of their child's assessment (p. 216).

It should be noted, however, that a clinical or medical ASD diagnosis in itself is not sufficient to qualify a child for school-based services, and conversely school personnel do not make diagnoses but rather make eligibility determinations (Dahle, 2003). According to IDEA Law (2004), a student must show evidence of adverse educational performance in areas such as academic, social, adaptive, functional, and/or emotional domains in order to meet criteria for educational eligibility. Although broadly defined in the law, frequently *educational performance* is narrowly defined by the child's obtained grades. At minimum, an evaluation for special education eligibility for autism must include vision and hearing screenings, performance measures, behavior and/or adaptive rating scales, structured and unstructured observations in the educational setting, a structured interview with parents, evaluation by a medical doctor or other professional, and a speech/language evaluation according to the Alabama Administrative Code (2007).

When children enter school-based services, much of the responsibility for each student's outcome and progress is placed upon the school, teachers, and related professionals (Iovannone, Dunlap, Huber, & Kincaid, 2003). According to IDEA (2006), the IEP that is designed must demonstrate an "appropriate education," which is defined as the pupil progressing toward his annual goals. It should be noted that there is no requirement for particular services or methods, but only that the child make progress toward his goals. Further, due to the lack of evidenced-based interventions, educators are not mandated to use interventions with empirical support if the student is making average yearly progress. Case law has consistently upheld a school's right to design their own individualized education program based on the individual needs of the student with the parents' participation. The goals for an individual child written into the IEP can be based on the

general curriculum, the use of curriculum guides, or functional curriculum guides. While the general curriculum and curriculum guides allow the teacher to accommodate instruction without altering content, the functional curriculum guides are for students seeking an alternative diploma who do not complete the general curriculum or take typical standardized tests. In this case, the work is modified so that it is parallel or similar to the general education curriculum.

The American Academy of Pediatrics (Myers et al., 2007) urges that specific goals and objectives and descriptions of the needed supports be outlined in each student's IEP and that these goals and objectives determine the type of educational placement (i.e., self-contained special education classrooms, full inclusion, or a combination thereof). It is important that school districts and parents at the primary and secondary levels work together to identify programming that is matched to the individual child's needs, developed and implemented to promote educational gains, and not be limited only to current program availability (Iovannone et al., 2003; Mandlawitz, 2002). A good IEP for students with ASD requires an understanding of this diagnosis that allows school professionals to "move beyond the standard, procedural approach to IEPs and to make the process a dynamic one" (Smith, Slattery, & Knopp, 1993, p. 2). Recommendations regarding IEP development include (Iovannone et al., 2003; Wilczynski, Meousek, Hunter, & Mudgal, 2007):

- Including specific curriculum content that emphasizes skill-building in each of the three symptom domains (communication, social, and repetitive and restricted behaviors and interests) regardless of the specific ASD diagnosis as well as a functional approach to behavioral difficulties that are positive and but build upon a student's existing skills
- Addressing associated features such as anxiety, depression, inattention, learning difficulties, health and safety concerns, and sensory sensitivities or under responsiveness
- Addressing the variability in symptoms across different circumstances
- Emphasizing the ability to generalize skills (e.g., if a skill is mastered in one setting then change the goal to increase the skill in a different setting)
- Adding academic and adaptive goals and objectives in addition to behavioral targets
- Including only objectives that can realistically be taught and show progress within the specified time frame
- Considering the developmental appropriateness of goals and objectives and fostering an even pattern of developmental progress
- Addressing family and student preferences and interests
- Determining the appropriate level and intensity of instruction based on the student's strengths and weaknesses
- Providing systematic instruction based on outcomes, focused teaching strategies, and using data about student performance to guide daily instructional decisions
- Creating a comprehensible and structured learning environments that allow students to predict a daily routine and understand behavioral expectations throughout the day

- Including the family as active participants and partners in developing and implementing the student's educational programming

There is much discussion in educational and research groups regarding inclusion of individuals with ASD in regular education settings. Inclusion for individuals with ASD has been associated with better outcomes in terms of social development and academics, although results of the existing research are mixed (Harrower & Dunlap, 2001; Schreibman, 2005). The available evidence regarding interventions targeting increased and improved social interactions for individuals with ASD makes it clear that inclusion and integration with peers with typical development is warranted to promote treatment effects, but there are some qualifiers for this statement (Bellini et al., 2007; McConnell, 2002). Specifically:

- It is not helpful to include a child with ASD fully unless the child already has good skills for interacting appropriately with the adults and the other children (Myles, Simpson, Ormsbee, & Erickson, 1993).
- It is important that the peers also be socially competent (McConnell, 2002).
- Successful inclusion is related to the level of expertise of the student's entire educational team.
- Without proper training and understanding of ASD in the classroom, a student's symptoms of ASD may limit the educational experience for the included child as well as the rest of the class (Goodman & Williams, 2007).

Harrower and Dunlap (2001) identify that inclusion may be facilitated by the use of antecedent procedures (e.g., picture schedules), delayed contingencies to promote generalization, self-management strategies (e.g., self-monitoring), and peer-mediated interventions (e.g., peer tutoring). Overall, it may be concluded that "inclusion is a necessary, but not likely sufficient, condition for social interaction interventions" (p.367) with children with ASD (McConnell, 2002).

An additional important consideration in IEP development is transition within the education system. This is an important event requiring advanced planning and careful consideration each year, but particularly during the transition between preschool and kindergarten and from school attendance to adulthood and services outside the school system (Forest, Horner, Lewis-Palmer, & Todd, 2004; Volkmar, Cook, Pomeroy, Realmuto, & Tanguay, 1999). IDEA (2006) requires transition planning by 16 years of age. Legally, however, if a child requires transition planning at an earlier age or as part of the IEP development, the process should be initiated when it is appropriate for the child. Decisions regarding post-secondary placement and vocational paths are made during this time, and it is recommended that planning for transition and beyond include a component of ongoing skill development and that independent living skills and sexuality education be taught. The NCLB Act (2001) requires that in addition to academic development, students must also be taught to develop equal opportunity, full participation, independent living, and economic self-sufficiency. Both IDEA (2006) and the NCLB (2001, P.L.107-110) require that the outcomes that education offers to students without disabilities – employment and further education – should be available to students with disabilities as

well. Overall, the transition plan should represent "a shift from academic to vocational services and from remediating deficits to fostering abilities" (Myers et al., 2007, p.1167).

Training and Support of Education Personnel

Students with ASD present challenges for educators that are different from many other students served by special education or general education. Ideally, teachers "must be familiar with theory and research concerning best practices for children with ASD, including methods of applied behavior analysis, naturalistic learning, assistive technology, socialization, communication, inclusion, adaptation of environment, language interventions, assessment, and the effective use of data collection systems" (The National Research Council, 2001, p. 225). Unfortunately, there is a deficit in the number of special educators available, especially those trained to work with low-incidence disabilities such as autism. It is predicted that by next year, we will have a loss in the work force of over 350,000 experienced special educators. It is of additional importance that all professional staff working with students with ASD understand the rationale behind ASD-specific interventions so they may not only apply these correctly but may also monitor, evaluate, and modify the approach as they are working with a particular student (Jones, 2006). This should also apply to a student's assigned aides such that there is "an infrastructure of expertise and support for the child beyond the immediate presence of the aide. Specific duties of the aide should be outlined, the strategies to be used should be defined, and the aide should receive adequate training" (Myers et al., 2007). Regardless of their position, school personnel who do not have appropriate training in ASD-specific interventions and techniques may not value the intervention or may administer the technique poorly and stop using it because they perceive that it does not work (Tincani, 2007). Thus, it is important that states develop minimum standards for school personnel working with individuals with ASD. Specifically, it is recommended that "at a minimum, teachers should have some special preparation (e.g., pre-service course work, equivalent in service training, workshops, and supervised practice in research-based practices in ASD) and should have well-trained, experienced support personnel available to provide ongoing training and additional consultation" (The National Research Council, 2001, p. 224). Further, each team member's input should be valued and integrated into the student's programming (Tincani, 2007).

Specific Interventions

The No Child Left Behind Act (NCLB, 2001) requires the use of "evidence-based strategies" while IDEA requires "scientifically based instructional practices" in the development of both the methodology and/or the interventions used in writing an IEP. While the criteria for NCLB are definitively stated, the "scientifically based instructional strategies" required in IDEA are more loosely written, and the definitions are more widely speculated in the literature. Simpson (2005) discusses the conflict between NCLB's mandate for evidence based research practices and the current state of research regarding ASD. There is very little published research evaluating educational programs for older children and adolescents, making it difficult to meet NCLB's guidelines. For this reason, the most recent statute of the IDEA Law (2006) stated that services and aids must be "based on peer-reviewed research to the extent practicable." The research that does exist regarding ASD-specific interventions primarily targets specific skill areas,

such as social skills training or peer supports. It is important to note that while many of the techniques described below were developed specifically for use with individuals with ASD, each of these strategies does not necessarily require significant changes to the classroom environment. In fact, classwide application of many of these techniques could be helpful in both special education and general education settings (Goodman & Williams, 2007). While there is often confusion and difficulty when attempting to adapt research-based interventions for practical application in the classroom, many authors are beginning to summarize the existing research and provide guidance (e.g., Goodman & Williams, 2007 or Harrower & Dunlap, 2001).

In a review of single-subject design studies to identify evidence-based practices for educational and intervention practices for young children with ASD (average age = 58 months), Odom and colleagues (2003) identified that techniques involving *adult prompting* and *differential reinforcement* could be considered well-established; *peer-mediated interventions, visual supports, self-monitoring and self-evaluation,* and *family involvement* are viewed as emerging and effective; and *positive behavior supports, videotape modeling,* and *use of child choice and preferences in instructional tasks* would be classified as probably efficacious. Specific aspects of some of these interventions are outlined below.

Social skills training has been a popular intervention for individuals with ASD because it targets a range of basic skills underlying social interactions, which are inherently difficult for individuals with ASD. Social skills training utilizes behavioral strategies such as modeling and repeated practice and may be conducted on an individual or group level. These techniques may be implemented in the home, school, or clinical environments. Bellini and colleagues (2007) reported low to moderate treatment effects and moderate maintenance effects across both individual and group interventions. Individual interventions in the school environment were associated with slightly better generalization than group-based interventions but this was still low. However, in cases where interventions were successful at improving social skills, these skills were maintained at a moderate level. Interventions attempting to improve social interactions by teaching related skills such as play and language resulted in the greatest effects while peer-mediated interventions were lowest. Interventions that occurred in the typical classroom setting for the child resulted in moderate treatment and maintenance effects but low generalization, while pullout interventions resulted in poor intervention, maintenance, and generalization effects, suggesting a need for these interventions to occur in the natural social environment (Bellini, Peters, Benner, & Hopf, 2007).

Video modeling and video self-modeling are additional techniques that have been found effective for improving social-communication skills (e.g., conversation and play skills), functional skills (e.g., self-help or purchasing skills), perspective-taking skills, and behavioral functioning (e.g., prosocial behaviors and on-task behavior) in children and adolescents with ASD regardless of specific diagnosis (Bellini & Akullian, 2007; Delano, 2007). A recent meta-analysis by Bellini and Akullian (2007) concluded that these techniques produce acquisition of skills that are maintained over time and can be generalized across settings (i.e., home, school, community, and clinics) and with various

models (e.g., self, parents, peers, siblings). While video modeling does seem to hold some promise, it has been noted that much of the research has focused on children 12 years old or younger (Delano, 2007). The authors suggested that the success of these interventions may be in the integration of visually cued instruction, which is known to be effective with individuals with ASD, and modeling, which is known to be an effective technique for impacting behavior (Bellini & Akullian, 2007). An additional benefit of this strategy is that it is relatively brief.

Overall, the current literature regarding group-based social skills interventions for school-aged children and adolescents with ASD suggests efficacy of specific skill-based instruction (White et al., 2007). Rogers (2000) identified several strategies for improving social skills in children with ASD, including pivotal response training, adult prompting, social skills groups, social stories, video modeling, peer-mediated instruction, and environmental modifications. Matson et al. (2007) suggest that modeling, social reinforcement, and feedback regarding skills may be preferred for older higher-functioning children with opportunities to practice skills in multiple settings. On the whole, the most effective strategies for teaching social skills appear to be based on a solid understanding of the specific characteristics of ASD and the existing literature and these interventions must be specifically tailored to the student's individual strengths and weaknesses and to be applied frequently to facilitate and maintain treatment effects (Matson et al., 2007; Rogers, 2000; White, Keonig, & Scahill, 2007). In a recent review of empirical studies of group-based social skills training with school-age children or adolescents, White and colleagues (2007) identified many "promising teaching strategies" (p. 1864) for individuals with ASD, including fostering awareness and self-esteem, making social rules clear and concrete, teaching social scripts, using modeling and role-play to teach skills, and involving peers, parents, and multiple individuals to promote generalization. The authors concluded that the preliminary evidence suggests that social skills are impacted by group interventions but that this is often limited to only those skills that are taught and practiced very explicitly. In addition, while these skills show improvement in the clinical setting in which they are practiced, generalization to the school or other natural environments is generally poor. In response to this finding, Bellini et al. (2007) recommend increased intensity of interventions, possibly by identifying "opportunities to teach and reinforce social skills as frequently as possible throughout the school day" (p. 160). They also suggest that schools identify social skills interventions that can be "implemented in multiple naturalistic settings" (p. 160) as well as "systematically matching the interventions strategy to the type of deficit exhibited by the child" (p.161). Further, school personnel should "create an explicit plan for promoting generalization when developing a social skills intervention."

The use of Social Stories™, a technique developed by Carol Gray, has grown in popularity in school and clinical settings for higher functioning individuals with ASD. These may be used to discuss following routines, academic activities, social situations, and other situations encountered by individuals with ASD (Gray & Garand, 1993). A recent review of few studies evaluating the use of Social Stories™ with individuals with ASD indicated that this technique was most often used with individuals with Asperger's

syndrome and that the intervention showed modest and inconsistent effects with highly variable response (Reynhout & Carter, 2006).

The TEACCH method of "structured teaching" involves modification of the environment, visual supports, and the implementation of structured activities and routines to build skills. This approach is widely applied but has not been studied in many controlled trials, but has shown success with individuals with ASD (Myers et al., 2007). One strategy used by TEACCH, the use of visual schedules, has been demonstrated to reduce the latency time between activities and in increasing students' ability to transition independently (Dettmer, Simpson, Myles, & Ganz 2000), which is very important in the classroom environment.

In addition, under IDEA (2006), a student may qualify for related services if it can be demonstrated that a child "needs" it in order to benefit from special education. Related services may include speech-language pathology and audiology services, interpreting services, psychological services, physical and occupational therapy, social work services, school nurse services, counseling services, including rehabilitation counseling, orientation and mobility services, and medical services needed for evaluation and diagnostic purposes.

The Solution: The literature strongly recommends that school personnel receive pre-service and in-service training regarding ASD symptoms and specific intervention techniques. Further, there should be a system for monitoring and assessing both a student's response to intervention and the staff's implementation of programming. This will require ongoing consultation and supervision of school-based staff and could best be accomplished by establishing a system of highly-trained individuals who may train others within their local or regional educational system. Interventions for school-aged students with ASD should include careful consideration of the specific symptoms of ASD and a focus on ensuring that students are able to generalize behaviors learned at school to community settings (e.g., generalize math instruction in coin values to making community purchases). This may be facilitated by inclusion but it is necessary that the student with ASD and those involved in the inclusion setting (e.g., teachers and peers) receive the support needed to ensure success. Specific school-based interventions that are recommended and have some research support include:

- Social skills (e.g., Social Stories™, scripts, video modeling)
- Visual supports (e.g., schedules, structured teaching)
- Related services (e.g., speech therapy, occupational/physical therapy)
- Peer education and support

Adult Interventions (21 years and up)

The Problem: 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 (Heller, Factor, & Hanh, 1999). 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.

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. However, 40-60% of individuals with ASD do not have mental retardation. Although they still have substantial difficulties in social communication, adults with high functioning ASD do not have a funding source for long term support. Further, 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 and there is a significant lack of qualified service providers with expertise in working with this population. An individual's ability to work and live in the community is strongly influenced by the service provider's depth of knowledge about ASD.

ASD is a lifelong disorder characterized by social and communication deficits and stereotyped or repetitive behaviors. By age 21, young adults with ASD are no longer served by the public school system. With a growing number of individuals being diagnosed with ASD and the trend moving away institutional facilities towards inclusion and community treatment of developmental disorders, there is a significant need for services targeted to adults with ASD who are living in the community. However, many families find that once their child enters early adulthood, few service providers or agencies exist to help address the complex needs of adult with ASD. In a longitudinal research study conducted by Gray (2002) one parent commented:

> "It's very bleak at the moment. There's nothing out there for these children, so it's virtually up to the parents to provide for them. We could cope with [my son] if we had somewhere he could go during the daytime, right? To have an 18-year-old at home who has gone to school from the time he was probably 2 years of age … all of a sudden at home. He's going to go around the twist … If they had centers that catered for what they needed, look, the parents would pay, I'm sure of it."

While there are a few state agencies, such as Vocational Rehabilitation, who provide specific services to adults with ASD like job training, their personnel may lack the ASD-specific knowledge and training that is necessary to truly help the individuals succeed.

Because of improvements in early diagnosis and intervention, more and more adults with ASD possess the necessary intellectual abilities to attend college, hold a job, or live independently. However, the social, communication, and behavioral symptoms of ASD have the potential to impede adults with ASD in being successful. Adults with ASD often need continued intervention and social skills training in order to be help them in social interaction and community living. Unfortunately, the reality is that without individualized support and transition services, many individuals with ASD will be able to realize their intellectual potential by attending college, holding a job, or living independently.

The placement most suitable for an adult with ASD can vary widely dependent on the individual's intellectual capacities and impairment severity. Depending on the individual's skills and abilities, anything from a supported group home to a college education may be indicated. Below is a brief summary of the literature regarding various placements and the advantages and disadvantages of each.

Residential Treatment Facilities

Residential treatment facilities are appropriate placements for even the lowest functioning individuals with ASD; however, state funding is not always available and private tuition may be prohibitively expensive. A review of the empirical literature examining the effect of a residential treatment intervention for adults with ASD identified several key components and potential benefits of residential treatment (Holmes, 1990; Jabarin, Crocombe, Gralton, & Carter, 2001; Van Bourgondien, Reichle, & Schopler, 2003).

- On-site supervision and support
- A structured environment with consistent rules and expectations which may help alleviate anxiety and sensory overload
- Trained staff members who can manage self-injurious behaviors and violent or aggressive outbursts

Van Bourgondien, Reichle, and Schopler (2003) found that individuals with ASD in a model residential treatment program at the Carolina Living and Learning Center (CLLC) experienced and increase in programming and structure upon moving to the CLLC. Also when compared to peers with ASD in family homes, group homes, or institutions, individuals with ASD in the CLLC program showed significant increases in communication, socialization, and daily living skills and a significant decrease in problem behaviors. Van Bourgondien, Reichle, and Schopler (2003) also identified treatment components of the model autism program that improved outcomes for individuals with ASD:

- Presence of structure and individualized programming in communication and social skills development
- Use of visual systems to promote independence
- Use of developmental planning
- Positive, preventive behavior management strategies

University of North Carolina's TEACCH program has been identified as the most promising model for application to adults with ASD (Jabarin et al, 2001) and has been used successfully in several residential programs including Maple House and Carolina Living and Learning Center.

Vocational Rehabilitation/Transition from School to Employment

The 2004 Individuals with Disabilities Education Act (IDEA) specifically requires a transition plan for children at age 16. IDEA specifies that transition services must be results-oriented, supportive, student-centered, and comprehensive and must help to address the skills and accommodations needed for transitioning post-high school. Vocational Rehabilitation is a nationwide, federal program for helping people with disabilities find employment. Each state has a Vocational Rehabilitation agency or department and many have local offices. Most state agencies provide diagnostic services, vocational evaluation, counseling, training, medical services and equipment, placement technology, and support services. However, the reality is that not all Vocational Rehabilitation counselors have the knowledge and training necessary to help individuals with ASD build relevant job skills and find and maintain the most suitable employment (Holtz, Owings, & Ziegert, 2006).

Holtz, Owings, & Ziegert (2006) found that there are three main types of job that may be appropriate for an individual with ASD depending on his or her level of functioning:

- Competitive Employment
    - Full-time or part-time job with market wages and responsibilities
    - Usually no long-term support
    - Suitable for high-functioning individuals with ASD who are already fairly skilled
- Supported Employment
    - Work in a competitive job alongside neurotypical individuals
    - Ongoing support services on the job
    - Can be funded through state agencies if families strongly advocate for funding
- Secured or Segregated Employment
    - Work in a self-contained unit, not integrated with neurotypical employees
    - Generally supported by a combination of federal and/or state funds

Holtz, Owings, & Ziegert (2006) also identified workplace-specific social and communication skills to be targeted during transition including:

- Listening skills
- Recognizing when help is needed and obtaining help when necessary
- Level of response to others
- Eye contact during regular interaction
- General manners such as responding to greetings and not interrupting others
- Awareness of others' personal space
- Understanding the difference between private and public behaviors

- Flexibility to handle changes in schedule or environment
- Understanding of appropriate and inappropriate conversation topics and behaviors

Post-Secondary Education

Despite average to above-average intellectual abilities, students with high-functioning autism (HFA) or Asperger's syndrome (AS) often fail in their attempts to earn a post-secondary degree. Nordesjo (2002) estimates that approximately 4 in 1,000 college students have a diagnosis of AS. Typical college-level student support systems do not address the specific array of social and behavioral difficulties that students with HFA or AS face (Farrell, 2004). Dillion (2007) suggests that a collaborating with a rehabilitation agency or a providing a mentor that gives individualized support to the student may be effective in addressing the needs of students with HFA or AS. Dillion (2007) identified several key components in supporting a college student with HFA or AS:

- Collaborative approach with student, parent, mentor, faculty, and support agencies participating
- Individualized response to the unique characteristics and experiences of each participant
- Flexible intervention that matches the response with the needs of participant
- Variable support to encourage independence and self-advocacy and not dependence on mentor
- Facilitation of social support network, possibly through support group meetings

Adreon & Durocher (2007) suggest having the student slowly transition into college life by taking a few courses during the summer term, taking a reduced course load for the first semester, and/or visiting the campus before the start of the school year in order to acclimate to the campus. Students with HFA or AS may feel more comfortable taking some introductory classes at a community college before moving to a 4-year college or university. Throughout the literature, the importance of teaching self-advocacy, independent living skills, and career planning to help students transition from college to the "real world" was stressed. Students with HFA or AS may experience common socio-emotional issues such as stress, anxiety, and depression that should be monitored and treated as necessary.

Existing Post-Secondary Education Support Services for Adults with HFA or AS

In order to address the complex needs of college students with HFA or AS, several colleges and universities have developed support programs specific geared toward students with HFA or AS. Marshall University in collaboration with the West Virginia Autism Training Center created the first ASD-specific support program for university students with a documented diagnosis of HFA or AS. The Marshall program provides positive behavior support and opportunities for social and life skills development. Each student with HFA or AS is provided with a graduate student who meets with him or her daily to discuss reviewing assignments, time management, and classroom etiquette as well as assigned "check in" times with staff "to review schedules, discuss concerns, receive tutoring, and celebrate successes. The Kelly Autism Program at Western

Kentucky University also provides similar supports by pairing each individual with ASD with a mentor who assists them with academics, time management, daily living skills, and social programming. In 2007, the University of Alabama Autism College Transition and Support (UA-ACTS) program was developed to provide comprehensive academic and social support and transition services for students with a diagnosis of HFA or AS. The UA-ACTS program is the only ASD-specific university support service in the state of Alabama or the south.

Improving Communication Skills through College Based Inclusion

As more and more adults benefit from early intervention, there has been significant progress in their language functioning (Alpern & Zager, 2007). However, Howlin, Mawhood, & Rutter (2000) followed individuals with ASD from childhood to adulthood and reported that language impairment continues to be "central to the disorder and might underlie many other areas of dysfunction" (p. 572). Language deficits can impair friendship formation, vocational success, and ability to attain a post-secondary education (Alpern & Zager, 2007). For this reason, Alpern & Zager (2007) designed an intervention designed to address the continuing language deficits of adults with ASD. Four main areas were targeted: joint attention, social reciprocity, language and related cognitive skills, and behavior and emotion regulation. The intervention was targeted to the specific needs of the individual (Alpern & Zager, 2007). For example, an adult with a vocational placement may learn the following communication skills (Schall, Cortojo-Doval, Targett, & Wehman, 2006):

- Requesting more work
- Requesting help
- Requesting clarification when given conflicting jobs
- Talking to co-workers about mutually interesting topics
- Learning how to communicate correctly with people of different "ranks" in their lives

In a review of successful communication intervention programs, Alpern & Zager (2007) found that the following components were most crucial:

- Support-based and skill-based programs in which students are taught the necessary skills and are then encouraged to practice them in a structured environment
- Significant time investment in order to practice and develop the skill
- Motivation of the students with ASD to communicate with others
- Inclusive setting combining adults with ASD and typical development

In one such setting, a model college based inclusion class (CBIC), student with ASD between the age of 19 and 21 who were enrolled in the local school district were paired with a local university. The student with ASD received speech-language services twice each week from an undergraduate at the local university. Students had both individual and group sessions. After 8-weeks of intervention, the adults with ASD showed significant improvements on the Comprehensive Assessment of Spoken Language (CASL). Further, teacher reports showed that the students with ASD were able to generalize their skills to other settings as they showed improvements in language and

conversation abilities outside of the university. Such findings suggest the potential impact that continued speech/language interventions may have in adulthood.

Emerging Geriatric Population

In 2004, there were estimated to be more than 525,000 individuals with developmental disabilities such as autism over the age of 60, and this number is expected to double by the year 2030 (Heller & Factor, 1999). With the introduction of early diagnosis and intervention, greater numbers of adults with ASD are employed and thus eligible for retirement. In order to address the unique needs of adults with ASD who are transitioning to retirement, the North Carolina Center for Recreation and Disability Studies developed a Supported Retirement Services (SRS) program. The major goals of the SRS program were to provide leisure education and community based skills training in order to assist adults with ASD in developing strategies for community participation and social supports in the community (Hodges, Luken, & Hubbard, 2004). In the SRS program, a recreation therapist works with the adult with ASD to develop a schedule of leisure activities based on his or her interests. As part of the program, adults are required to attend therapeutic recreation services twice a week, attend pre-retirement class once each week, and commit to being out of the house for 6 hours a day, five days a week. In a case study examining the efficacy of the SRS program, Hodges, Luken, & Hubbard (2004) found that an adult with ASD was able to successfully retire after 3.5 months.

While the North Carolina SRS program provides a model for supporting aging adults with ASD, there are few programs of its kind. Doka & Lavin (2003) note that as adults with ASD and other developmental disabilities age, there is an increased need for services but a decreased number of service providers that can meet their needs. The needs of adults with ASD are varied, but may include access to healthcare, retirement counseling, long-term care in a nursing home, and/or independent living support as their caregivers die. The emerging geriatric population with ASD will warrant special attention in future years.

The Solution: Because there is a wide range of outcomes for adult individuals with ASD, no single treatment approach or intervention is appropriate for all adults, nor is there sufficient empirical evidence to demonstrate that a single approach is most effective. However, there are some key components of successful interventions and support services for adults with ASD that include:

- An intervention approach that is individualized enough to meet the needs of the individual while allowing for maximum independence and decreasing levels of support as the individual gains new skills and experiences
- Collaborative approach among the individual, parent, mentor, and support agencies
- Individualized intervention that is flexible enough to match the individual's response with his or her needs
- Emphasis on self-advocacy and independence rather than reliance on the mentor
- Level of support that decreases over time as the individual gains training and experience

- Continued social skills training and social support, possibly by facilitating social skills groups
- Coordinated system of intervention and support that addresses academic transition, job training, daily living skills, communication, and social skills

Due to improvements in early diagnosis and intervention, there is an increased need for placements and supports for higher functioning individuals with ASD such as college support programs or job coaching. Further, individuals with ASD continue to age, there will be an increased need for geriatric services and placements that can meet the unique needs of adults with ASD.

The Solution: Because there is a wide range of outcomes for adult individuals with ASD, no one treatment approach or intervention is appropriate for all adults, nor is there sufficient empirical evidence to demonstrate that a single approach is most effective. However, the following recommendations are most supported by the literature:

- A coordinated system of intervention and support that addresses academic transition, job training and coaching, college support daily living skills, communication, and social skills
- An autism specific waiver for individuals without MR that would enable individuals to access residential and support services
- Training for adults service providers on empirically validated supports (education, job, living, etc) and behavioral strategies
- Collaborative approach among the individual, parent, mentor, and support agencies with an emphasis on developing maximum independence as appropriate to each individuals' developmental and cognitive level
- Emphasis on self-advocacy

Medical Interventions

The Problem: 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), including dental preventive care, problematic for individuals with ASD and their families. As in other areas of intervention, there is a lack of research into the effects of psychopharmacologic agents on individuals with ASD. In addition, there is a proliferation of alternative medicine treatments, on which scientifically-validated studies are almost non-existent, raising concerns regarding their safety. Finally, families often express concerns about the lack of access to medical services due to the failure of their insurance companies to cover some or all of their child's therapy services.

Insurance

Little research exists documenting the effects of insurance coverage, or lack thereof, on specific outcomes in people with ASD. However, common sense dictates that without financial backing, effective interventions are out of reach of most Americans. Readers are reminded that good early intervention may save a million dollars in lifetime care for each individual with ASD (Jacobson, Mulick, & Green, 1998). Coverage by insurance varies depending on the carrier and the specific policy, and individuals are encouraged to explore specific coverage and limitations with their carrier. It should be noted that there

are carriers and policies that have specific exclusions for autism. Most policies cover services for autism under their Mental Health riders, which typically have more limits (e.g. smaller number of sessions covered, lower caps on fees, fewer professional disciplines covered) than coverage for Medical disabilities. Coverage of autism services under the Mental Health rider exists despite solid research evidence that ASDs are neurological disorders. Many policies also do not cover the services of the types of providers who typically implement evidence-based interventions; for example, ABA trained therapists who provide the day-to-day intervention are not typically covered, although the Psychologist who directs the ABA program may be.

Physician Training

Training for physicians in the behaviors associated with ASD and effective interventions has been limited, leading to a lack of appropriate care and referrals (Rhoades, Scarpa & Salley, 2007). The recent clinical report by the American Academy of Pediatrics on *Management of Children with Autism Spectrum Disorders* seeks to remedy this lack of knowledge (Myers et al., 2007). Physical examinations and medical treatments will need to be approached within the context of the behaviors associated with ASD (Volkmar, Wiesner & Westphal, 2006). General practitioners will also benefit from knowledge of educational, behavioral, and medical interventions that have an evidence base.

Interventions initiated by physicians for people with ASD

There are limited evidence-based studies of medical interventions for individuals with ASD, and those that exist frequently produce conflicting results. However, the US Food and Drug Administration has recently approved risperidone as the first medication labeled for treatment of symptoms (e.g., irritability, aggression, self-injury, and tantrums) in children and adolescents with ASD. Approval was based on multiple studies (Myers et al., 2007).

Although there is not a medication that targets ASD itself, the use of medical interventions to address the associated symptoms of autism has a long and fairly effective history. It is recommended that there be a careful assessment of target behaviors through multiple reporters, an assessment of available environmental supports, an evaluation for medical factors that may be exacerbating the problem (e.g., a painful ear infection), and then a consideration of psychotropic medication (Myers et al., 2007; Tsai, 1999). A choice of medication should be guided by the likely ability to alter the target behavior, potential side effects, and practical considerations (e.g., cost, dosing). Using medications to address specific symptoms can be very effective; for example, people with ASD with inattention and impulsivity may benefit from the use of stimulant medications that are typically prescribed to treat Attention-Deficit/Hyperactivity Disorder, and those with symptoms of anxiety may benefit from the use of SSRIs typically used to treat depression and anxiety (Arnold, et al., 2000; Leskovec, Rowles, & Findling, 2008; Posey & McDougle, 2000). Following initiation of a medication trial, continued monitoring must be implemented to determine if the targeted behavior is actually changing and what side effects are being experienced (Myers et al., 2007; Tsai, 1999).

Associated Medical Concerns

Poor sleep rhythms are common among people with ASD and may need to be addressed by both medical and behavioral interventions in order to allow both the person and their family adequate rest. The use of melatonin has been examined and appears to be helpful in regulating sleep. If medication is being considered in order to treat another behavioral problem, consideration may be given to choosing a medication that also targets sleep. Restricted eating patterns also present a frequent medical and nutritional challenge frequently; consultations are warranted in these instances.

There is a higher rate of seizures in people with ASD, with higher rates being associated with more severe mental retardation and motor deficits. Gastrointestinal problems have not been clearly associated with ASD above and beyond the rate expected given highly restricted diets.

Use of complementary and alternative medicine (CAM) is very common in ASD. Health care providers must obtain adequate education on these various treatments so that they can help guide families to make informed decisions. Unfortunately this is an area replete with false and exaggerated claims (please see the previous commentary on pseudoscience).

The Solution: Implementing continuing medical education requirements to increase the knowledge of medical and dental practitioners regarding medical and behavioral management issues of individuals with ASD. A postgraduate training curriculum should be developed to address the specific problems faced by patients with developmental disabilities and ASD to educate residents in pediatric dentistry, child psychiatry, pediatrics, and family practice. In addition, consultation teams should be available at regional ASD centers to assist medical personnel regarding management of patients with ASD on both an outpatient and inpatient basis. These consultation teams could be involved from the initial evaluation to the formulation of cognitive and behavioral plans. Finally, healthcare providers need more information regarding alternative treatments so that they can best guide the families who turn to them for advice in their pursuit of evidence-based treatments for their family members with ASD.

SECTION 4: LITERATURE REVIEW OF FAMILY SUPPORT NEEDS

The Problem: Families experience significant emotional and financial stress as they attempt to care for their family member with ASD. It is difficult for families to navigate the complex and often confusing system of services provided. Although parents and siblings often serve as advocates for their family member with ASD, they are typically not involved in or educated about their family member's treatment. That is, they are not given specific education about symptoms of ASD and how to help their family member at home. In addition, parents and siblings typically shoulder a large financial burden for the care of their affected family member. As a result of these stressors, parents and siblings are more likely to suffer from significant depression and marital discord.

Parents usually bring their initial concerns to medical providers such as pediatricians. Unfortunately, a survey of 146 ASD caregivers found that the medical providers are reported to lack the training necessary to offer caregivers additional education about the autism diagnosis or to offer evidence-based treatment recommendations (Myers et al., 2007). The American Academy of Pediatrics (Myers et al., 2007) recommends that after receiving a diagnosis, parents should initially be encouraged to make use of natural supports, such as their spouses, family members, friends, neighbors, or church members. At the time of diagnosis or intervention, medical or psychological personnel should also provide education about formal supports including The Autism Society of America and publicly funded, state-administrated programs such as early intervention, special education, vocational and residential/living services, and respite services.

Even after families adjust to the initial diagnosis, the lifelong, or chronic, nature of the disorder causes ongoing stress and requires frequent coping in families. A number of studies have demonstrated that having a child or sibling diagnosed with ASD can be a more significant stressor than having a child or sibling with typical development, another disability, or a chronic life-threatening illness such as cerebral palsy (Bagenholm & Gilberg, 1991; Bouma & Schweitzer, 1990). Among families with one or more children diagnosed with an ASD, divorce rates by some estimates may be as high as 90%. Family members may feel increased pressure to serve as a primary caregiver for the child or sibling with ASD (Bouma & Schweitzer, 1990). In fact, the amount of stress a family feels in response to increased caregiving burdens may be proportional to the number of members in a family, such that single mothers who are forced to shoulder the caregiving burden alone experience significantly more stress than large families with multiple caregivers who can share caregiving responsibility (Bouma & Schweitzer, 1990). The American Academy of Pediatrics (Myers et al., 2007) suggests that it is important to help parents find effective respite caregivers so that they can have an occasional break or night off. This may help preserve the emotional health of the family members and remove some of the associated stress from the increased caregiving burden. In addition to increased caregiving stress, having a family member with ASD often leads to increased financial stress. For example, Gray (2002) found that even ten years after the initial diagnosis, mothers of children with ASD were often unable to work full-time, as they were required to continue primary caregiving responsibilities. This decrease in maternal income coupled with the expense of continued therapy and intervention services often

leads to increased financial stress within the family system. To help family members cope with the financial burden of caring for a child with ASD, it is recommended that professionals inform parents about Medicaid, in-home and community-based waiver services, Supplemental Security Income benefits, and other financial subsidies (Myers et al., 2007). However, professionals themselves often lack this type of comprehensive knowledge about these types of statewide and federal services.

The National Research Council's Committee on Educational Interventions for Children with Autism (2001) recommends that professionals providing intervention to children with ASD should consider the family members valued members of the treatment team and should make an effort to include them in decision-making and caregiving decisions. Education about autism and training in behavioral skills has been demonstrated to help parents feel more effective with their children with autism and to reduce stress, anxiety, and family dysfunction (Tonge, et al., 2006). The American Academy of Pediatrics (Myers et al., 2007) outlined several ways in which professionals can help include family members in the treatment process:

- Educate them about ASD and the treatments used
- Give them training necessary to provide intervention to their child with ASD
- Help them to navigate medical/psychological system
- Provide ASD resources and support group information
- Give them the information to effectively advocate for their child's needs (e.g., information about Early Intervention or Individualized Educational Plans)
- Recommend or refer them for individual or family therapy when appropriate

In addition to supporting parents of children with ASD, there is a growing awareness that siblings also need support. In addition to a need for emotional support associated with being a sibling of a person with ASD, siblings often share some of the language and social difficulties experienced by the family member with ASD. Because of the genetic nature of this disorder, it is common for siblings to display the "Broader Autism Phenotype" in which some symptoms, but not the entire disorder are present. There is little methodologically-sound research on interventions and/or support groups for siblings of a child with ASD. A few studies have been conducted examining the effectiveness of sibling support groups. Overall, parents and the participating siblings generally rate support groups favorably and indicate that there are some benefits for the participating siblings (Marcus, Kunce, & Schopler, 2005; Smith & Perry, 2005).

The Solution: Medical, psychological, and related personnel should both provide support to family members and include family members as part of the treatment team. The American Academy of Pediatrics (Myers et al., 2007) recommends the following approaches for working with families:

- Educate families about ASD and the treatments used
- Give family members training necessary to provide intervention to their child with ASD
- Help families to navigate medical/psychological system including providing information about financial support and subsidies that are available
- Provide ASD resources and support group information

- Give families the information to effectively advocate for their child's needs (e.g.., information about Early Intervention or Individualized Educational Plans)
- Recommend or refer family members for individual or family therapy when appropriate

To provide this type of support to family members, it is likely that professionals themselves will need continuing education about the federal and statewide support programs that are available to families. Finally, additional empirical research is necessary to examine the effectiveness of parent and sibling support groups and to determine the components of family intervention that are most likely to lead positive outcomes for the family unit.

SECTION 5: REVIEW OF EXISTING STATEWIDE SYSTEMS OF CARE

The Problem: On May 16, 2005, the Interagency Autism Coordinating Committee reported an urgent need to coordinate care across agencies. ASD is lifelong disorder, yet services for children and young adults with ASD are often fragmented. In Alabama, at least three different state agencies provide services to children and young adults with ASD from birth to age 21. Further, it is often necessary for individuals with ASD to access psychological and medical care from multiple professionals, such as ASD diagnosticians and interventionists, speech-language pathologists, psychiatrists and other medical doctors, physical therapists, and school psychologists, in order to receive the highest standards of care. Because these professionals and agencies usually work independent of one another rather than working collaboratively, the healthcare system can be costly and confusing for individuals and families, resulting delays in screening, diagnosis, and intervention.

Addressing the needs of individuals with ASD and their families is not an issue unique to the state of Alabama. Fortunately, there are several existing models of how states across the country have developed coordinated systems of care and services to address this population. A sample of these statewide programs is presented here, with an emphasis on states of similar sizes and resources as Alabama. It should be noted that many of these programs focus on serving individuals with ASD but also serve individuals with other developmental disabilities. Further, they often function within existing state systems (e.g., state Department of Education).

North Carolina

One of the oldest existing statewide programs for individuals with ASD is North Carolina's Treatment and Education of Autistic and Related Communication-Handicapped Children (TEACCH), which was first supported by funds from the North Carolina Legislature since 1970. In recent years the funding mechanism for TEACCH has grown to include state and federal funds, grants, training revenues, endowments, and donations. Because TEACCH is affiliated with the University of North Carolina, donations are tax-deductible for givers. Most clinical services from the TEACCH centers are free to citizens of North Carolina.

The structure of TEACCH includes an administration unit located in at the University of North Carolina in Chapel Hill and nine additional regional centers across the state. TEACCH focuses on clinical service, training of professionals and parents, and research with individuals with ASD. TEACCH serves individuals of all ages and skill levels with an ASD diagnosis. Clinical services include diagnostic evaluations, parent training and parent support groups, social play and recreation groups, individual counseling for clients who are high-functioning, and supported employment. TEACCH also directs a preschool Early Intervention Program and a supported employment unit as well as the Carolina Living and Learning Center (CLLC), which is an integrated vocational and residential program for adults with autism. The CLLC has two separate homes housing 15 adults with autism and the primary source of operating funds is Medicaid. TEACCH also conducts training at the state, national, and international levels and provides consultation

for teachers, residential care providers, and other professionals. Research activities include psychological, educational, and biomedical studies. Educational training is provided to students across disciplines (education, psychology, psychiatry, pediatrics) at the University of North Carolina.

More information about the TEACCH program is available at their website: www.teacch.com.

Florida

The Florida Legislature authorized and funded a Task Force on Autism in 1987 that generated a report in 1988 with the primary recommendation of developing comprehensive, regional resource and training centers to serve people with ASD and their families throughout the state. A demonstration project was funded in 1990 with support from the Legislature and other sources and the Florida Legislature first authorized funds in 1993 to establish the Center of Autism and Related Disabilities (CARD). Since that time, CARD has grown to include seven regional sites that are University based throughout the state. Funds are received through the Florida Department of Education. All services are free for individuals with autism and related disabilities, to their families, and to professionals who work with them. Community members interested in autism and related disabilities are also welcome to attend CARD events and can call the Center for more information. A constituency board comprised of family members representing persons with autism and related disabilities meets quarterly with the Center staff to provide guidance on policies, priorities and activities. The specified mission and purpose of CARD is “to provide support and assistance with the goal of optimizing the potential of individuals with autism spectrum disorders.” CARD serves children and adults of all levels of intellectual functioning who have autism spectrum disorder (including autism, Asperger's disorder, childhood disintegrative disorder, Rett's disorder, or pervasive developmental disorder not otherwise specified); an autistic-like disability (documented on an evaluation that describes the characteristics that are being considered "autistic-like" by the evaluator); a dual sensory impairment; or a sensory impairment with other disabilities. They also serve children aged 0 to 5 years with a developmental disability diagnosis with documented evidence of autistic-like behaviors. CARD programs, services, and priorities are a reflection of statewide coordination, planning, and development efforts and were intended to complement existing state and local resources. CARD is a community based, nonresidential program, which means that CARD staff visit constituents in their homes, schools or wherever assistance is needed. The primary focus is to provide individualized, direct assistance to these individuals and their families, including technical assistance and consultation, professional training programs, and public education activities. CARD is involved in community awareness activities, including public presentations, a lending library, the statewide conference, and training. For individuals and families they provide information about ASD, a directory of service providers and referral information, support groups, help with planning for the future, assistance in coordinating services, and individualized consultation regarding interventions across settings. CARD provides school consultations and observations, including functional behavior assessments and behavior support plans. For professionals, CARD provides local workshops and conferences, individualized consultation in schools,

daycares, and adult services programs, and assistance in program development and enhancement.

The specific activities and services offered by each center appears to vary somewhat, but there are basic services for individuals and families, professionals, and community awareness. CARD does not conduct diagnostic or provide direct treatment, crisis management, or promote one intervention method or a single approach. Instead, they provide information and training on a variety of strategies and methods at an individual level. CARD can provide an "introductory meeting" to discuss the various forms of pervasive developmental disorder, diagnostic indicators and evaluation procedures to help families approach the evaluation experience. They will also meet with families after a diagnostic evaluation to explain results, to answer remaining questions, or to provide other information. Contacts range from brief phone consultations to more extended services that are initiated following a telephone intake and resulting services.

More information about the CARD programs may be found at the following websites:
http://www.hscj.ufl.edu/peds/aut/about_card.asp
http://www.fldoe.org/ese/pdf/hist_letter.pdf (Legislative History of Florida's ESE Program)
http://www.coe.fau.edu/card/about.htm
http://www.card.ufl.edu/faq.htm
http://autism.fsu.edu/faq.php
http://www.umcard.org/questions.htm
http://www.umcard.org/about.htm
http://card-usf.fmhi.usf.edu/faq.asp

Indiana
In 1981, the Indiana Legislature appropriated funds to establish a statewide resource center on autism. Initially, the Indiana Resource Center for Autism (IRCA) focused on bringing children with autism who were living in out-of-state facilities back to Indiana. Currently, IRCA is a division of the Indiana Institute for Disability and Community, which is funded in part by its distinction as a member of the Association of University Centers on Disabilities (AUCD) and as the Indiana University Center for Excellence in Developmental Disabilities (UCEDD), which involves a partnership with the Indiana Protection and Advocacy System and Indiana's Governor's Council on Disability, both state agencies receiving federal and state funds. IRCA is University-based and the activities include outreach training and consultations, research, and development and dissemination of information regarding ASD. IRCA works with communities, organizations, agencies, and families in a range of settings. IRCA staff train teams of individuals in special education planning districts to support school-based teams in providing supports for individuals with ASD and conduct individual consultations. Some of the products of the center, such as written and video materials, are available free of charge and some must be purchased. A newsletter is published three times a year and IRCA has a lending library that that is available free to Indiana residents. Training workshops and presentations from IRCA staff are free and open to the public. IRCA also conducts a Needs Assessment survey every three years regarding ASD from families and

professionals. However, similar to the model in Florida's CARD locations, IRCA is not a direct service provider and are engaged in proactive rather than crisis management efforts. They are also clear to state that they do not promote a single intervention or approach but focus on addressing an individual's specific needs (Pratt, 2007).

More information about the Indiana program is available at the following websites:
http://www.iidc.indiana.edu/wel3.htm
http://www.iidc.indiana.edu/wel7.htm

Ohio
The state of Ohio has an Ohio Center for Autism and Low Incidence (OCALI) that serves families and professionals working with students with autism spectrum disorders and other disabilities. OCALI provides training and technical assistance, including a lending library and publications that are available by request or at their website). Ohio also has an Autism Scholarship Program administered through the Ohio Department of Education that can be applied for by parents to allow them to choose to send their child to a special education program other than the one they are zoned for to receive IEP services. Recently, the 2008-09 state budget bill involved earmarked funds from the Special Education Enhancements line item in the Ohio Department of Education budget for OCALI to contract with an additional organization to provide transition services for individuals with autism (amount of $325,000 each fiscal year). An additional earmarked fund in the "Help me Grow" line item in the Department of Health budget will develop the Autism Diagnosis Education Pilot Program, a program intended to educate professionals in health care, education, and childcare, and parents and community-based service providers regarding ASD. This program is also intended to promote appropriate diagnosis and to encourage regional coordination of ASD services. Funds for this program included $500,000 for 2008 and $325,000 for 2009.

More information about the Ohio program is available at the following websites:
http://www.ocali.org/about/
http://www.ode.state.oh.us/GD/Templates/Pages/ODE/ODEDetail.aspx?page=3&TopicRelationID=967&ContentID=6678&Content=39417
www.ocecd.org/ocecd/h_docs/FORUM/07_0708_NewStateBudget.cfm

Other Programs
There are a number of other states who have started addressing ASD at the state level that are presented here in brief.

Legislation in *Texas* established the Texas Council on Autism and Pervasive Developmental Disorders in 1987, with administrative support provided by the Texas Department of Aging and Disability Services. The Council's function is to advise and make recommendations to state agencies and the legislature that address the needs of individuals with ASD of all ages and their families. The Council also strives to ensure that services for individuals with ASD are coordinated. The Council meets at least quarterly and develops a State Plan every two years that includes an updated needs assessment and recommendations. This Council is advised by the Statewide Task Force (See http://www.autismcouncil.org/).

Massachusetts has a Children's Autism Medicaid Waiver (approved in 2007) that will eventually support intensive in-home services (e.g., ABA, DIR/Floortime) and other services for up to 80 children with an ASD diagnosis and who are Medicaid eligible. The federal government will reimburse Massachusetts 50% for the cost of intensive in home services. The 2008 FY budget also included earmark for $200,000 for a state contract with a non-state agency to provide training and support to families, educational collaboratives, and public school districts on methods for coping with behavioral challenges associated with children who have ASD. (See http://www.massadvocates.org/uploads/ou/ob/ouobqp-IEbKLXT5sIOL4Vw/WAIVER-UPDATE-WEB-10-11-07.pdf).

In *New York*, the New York Autism Network (NYAN) was a statewide coalition/consortium established and funded by the New York State Department of Education to identify and implement effective inclusionary educational programs for children and adults with Autism and related disorders and consisted of four regional centers with a shared focus of promoting effective educational approaches for students with autism by supporting families and professionals, developing regional networks, providing technical assistance, and conducting conferences related to pervasive developmental disorders. Each of the Regional Centers worked cooperatively with existing regional information and referral, training, and planning organizations. NYAN was funded from September 1997 through December 2001 by the Office of Educational Services for Individuals with Disabilities, New York State Education Department by a grant to the University at Albany, which, in turn, funded each of the regional Centers through sub-contracts. Further, the Department of Health (Division of Family Health, Bureau of Early Intervention) published a *Clinical Practice Guideline Quick Reference Guide for Parents and Professionals* specific to ASD and early assessment and intervention (0-3 years) that is available online or free of charge to NY residents. This evaluates and reviews the literature regarding intervention and assessment. The New York Autism Network developed the *Autism Program Quality Indicators (APQI;* New York State Education Department, 2001) based on a review of the literature and input and review by regional advisory groups and national experts. The APQI is a guide for self-review and quality improvement evaluation for schools and programs for students with ASD and evaluates various aspects including development of the IEP, curriculum, instructional activities and methods, family involvement and support, inclusion, and personnel, among others. This was used to identify 5 schools with effective practices for instructing school-age children with ASD and provided grants to these schools to provide training to other schools. Use of this guide is available by request and permission from the New York State Education Department and has been used extensively in New York and in other states by both schools and parents to evaluate programs and services for students with ASD. Recently, the Office of Vocational and Educational Services for Individuals with Disabilities (VESID) funded development of training programs in 2001 for teachers and paraprofessionals at 17 colleges and universities.

The *California* Department of Developmental Services has an ASD Initiative, established in 1997 with goals to establish and carry out comprehensive public policy on the

diagnosis, treatment and prevention of autism spectrum disorder, to identify and promote best practices in assessment and diagnosis, treatment, education and training, to promote partnerships, both public and private, for research and practice, and to provide current, updated information to families and practitioners. The Dept. of Developmental Services published 2002 Best Practice Guidelines for Screening, Diagnosis and Assessment of ASD. The Governor's 2006/2007 Budget expanded the ASD Initiative to provide training to clinicians and other professionals on the already published best practice guidelines, develop and publish "ASD Guidelines for Effective Interventions," and establish state and regional ASD Resource Centers. The 2007-08 budget includes $500,000 for an independent evaluation administered by State Department of Education to identify best practices for districts to address the needs of students with learning disabilities and the needs of students with autism.

Recently in *Pennsylvania*, the 2007-08 budget included funding to serve adults with autism through the Autism Capitated Assistance Program, which is a prepaid inpatient health plan. The state budget also includes funding for statewide training and technical assistance, information outreach, assessment procedures, and program monitoring for adults with autism. (See: http://www.state.pa.us/papower/cwp/view.asp?A=11&Q=465580).

The Solution: The National Research Council's Committee on Educational Interventions for Children with Autism (2001) 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. A network of regional centers could work with the various federal, state, county, and city agencies in order to accomplish that task. States that have successfully implemented a regional center system include North Carolina, Florida, and California. Different states have focused on various service delivery programs, with some regional centers focused on providing diagnostic services, some focused on consultation services, and some focused on intervention services. Regional centers have typically relied on state funding mechanisms to support their mandate, as costs cannot be reasonably shouldered primarily by families or local school systems, nor can they continue to be written off by providers. The most effective programs appear to establish university affiliated regional centers in partnership with public and private agencies and provide the following programs:

- Interdisciplinary, regional 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.

University-based regional centers in the Southeastern United States (Florida and North Carolina) are recommended as model programs. In addition to providing diagnostic, treatment, and consultation services, university-based regional centers are able to provide both continuing education for current providers and provide degree and certificate training to grow the work force specializing in ASD. Further, university-based programs will provide continued research on the development and effectiveness of new treatment approaches.

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Appendix B
Community/Family Forums and Survey Information

Written Comments from Forum Participants Summarized by Service Category and Alabama Autism Task Force (AATF) Subcommittee

Method

Seven community forums about autism spectrum disorders were held during the fall of 2007 in familiar public settings (library, churches, community agencies) in Birmingham, Gadsden, Huntsville, Mobile, Montgomery, and Tuscaloosa. Forums were promoted through state and local agencies (DMHMR, city and county school systems), nonprofits (Autism Society of Alabama, United Cerebral Palsy, Easter Seals), clinical service providers (UA Psychology, UAB Sparks Clinic, Mitchell's Place, Glenwood Mental Health), and news media. Three hundred fifty-two attended afternoon and evening forums, each lasting 90 minutes. This narrative summary represents only comments received from family members and professionals who attended a community forum. It is likely that those who could not attend would express different opinions.

The UAB Office for Institutional Review Board approved the protocol for community forums. Forum facilitators included academic and clinical professionals assisted by local parent advocates. Facilitators used a script to introduce the Alabama Autism Collaborative Group, present purpose of the forum and uses of data, identify source of funding, and guide discussion across settings. Forum participants had multiple opportunities to share their opinions and experiences aloud within the group and confidentially in writing.

Investigators developed structured questions to guide group discussion after reviewing professional literature. Facilitators grouped questions into six service categories: **diagnosis, early intervention, medical services, school-based services, family support, and adult services**. Sample questions include: a) who was most helpful to you when you were seeking a diagnosis?; b) describe your experiences transitioning from the early intervention program to your local school system; and c) describe your experiences with employment support programs for individuals with ASD in your community.

Family caregivers and consumers were encouraged to submit additional anonymous comments to facilitators using post-it notes provided at the beginning of each forum. Facilitators distributed comment sheets at the conclusion of the forum and invited participants to return these within one week via Email, US Mail, or fax. In addition, forum facilitators invited participants to complete anonymously the ASD Family/Community Forum Questionnaire in writing or through a secure website. More than 200 have done so.

Investigators reviewed the main emphasis of each written comment submitted during the seven community forums, and then conferred with one another in order to code data thematically. Facilitators separated written comments containing two main ideas for coding. Comments were grouped by similarity and organized according to the five working subcommittees of the Alabama Autism Task Force (AATF), specifically *Training and Education, Healthcare, Family Support, Systems of Care, & Intervention*.

The first AATF subcommittee is concerned with professional development of teachers, paraprofessionals, mental health workers, physicians, early interventionists, and family education. The healthcare subcommittee examines issues related to health

insurance coverage, diagnostics, and access to specialists. The third AATF subcommittee, family support, focuses on respite care, psychological services, parent and sibling support, therapeutic recreation and summer programming. The systems of care subcommittee examines issues related to early intervention, services offered through public education and rehabilitation programs, Medicaid reimbursement, and residential care. The final AATF subcommittee, interventions, includes access to and provision of behavioral, biomedical, occupational therapy, speech and language therapy, and physical therapy. The narrative of this summary report presents comments in rank order, most to least identified as family members' concerns.

Results

Early Screening and Diagnosis

Family members, consumers, and providers anonymously submitted 59 notes related to the category of **diagnostic services.** Comments were grouped by similarity and organized according to the five working subcommittees of the Alabama Autism Task Force (*Training and Education, Healthcare, Family Support, Systems of Care, & Intervention*). Thirty-five of the comments addressed obtaining diagnostic and intervention services. Sixteen comments related to training and education of professionals and family caregivers about ASD. Six notes described issues related to negotiating systems of care for their family member with autism. Family comments about diagnostic services are presented in rank order, most to least identified as concerns. Verbatim quotations are included to illustrate the nature of respondents' written comments.

Intervention Subcommittee

Thirty-five participants expressed concerns about receiving an early and accurate diagnosis without extensive effort or delay. Although some caregivers identified helpful agencies and individuals, others residing in rural areas complained of traveling to cities to receive clinical services. Individual names were omitted from this summary report. Selected quotations:

- Mitchell's Place did her diagnosis at age 4 years. To me, they 'hit it right on the head with the diagnosis.'
- One of my best friends, who is the special education teacher at the school where I teach, was the most helpful in leading me toward a diagnosis.
- Help came (to us) from ARC of Jefferson County and Glenwood and my mom, (who was first to act).
- Behavioral Health services in Birmingham Children's Hospital (was most helpful).
- (We had a) very good experience with clinicians at Sparks Clinic. All of our early intervention therapists were wonderful -- lots of insight and suggestions. Our speech therapist at EI, was the most helpful person to us as far as investigating therapies, providing materials, (and offering) suggestions for whatever issues we were having at the time.
- We need a database (national) to pool signs and symptoms and treatment options.

- Early intervention personnel missed the autism diagnosis even when I as a parent asked 'Could this be autism?' (There is a) long wait list to see qualified personnel who (can) diagnose.
- (My child was) not diagnosed until school-aged; (I) was told it was a phase that he would grow out of.
- (We) need earlier diagnosis of children; reduce wait time to get in.
- (We can improve) early screening and provide literature for caregivers describing signs and symptoms of autism, especially before age 5 years. (Another idea is to) develop a questionnaire for pediatrician's offices specific to ASD for parents to complete at well baby/child visits.
- (We need to improve) timeliness of getting a diagnosis! 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!
- (Too much) time spent realizing there is a delay and getting the appointment to get a diagnosis -- way too long for families to wait.
- Vanderbilt's Treatment and Research Institute for Autism Spectrum Disorders welcomes families from Alabama on a sliding scale. Many families have benefited from this service, but it is too far away. Parents report that UAB's Sparks Clinic is not of equal quality.
- Pediatricians told us it was socialization. We had trouble getting psychological services because of his age. When we first got a diagnosis, it was severe ADHD and ODD. Sparks Clinic later diagnosed him with severe ADHD and OCD. When we took him to a psychologist who specialized in OCD, she diagnosed him with, and later a neurologist confirmed the diagnosis.
- We made two separate sets of visits to Sparks Center and they had no idea even after I brought it up. School system also missed it at age 4 years.
- Children in Etowah County have to go to Birmingham for all differential diagnoses! They are put on waiting lists for 6 months or longer! We would love, love, love to have a satellite office for Sparks Clinic or Mitchell's Place, ANYTHING to assess autism and/or provide resources to parents and us as therapists.

Training and Education Subcommittee

Sixteen participants expressed concerns about the training and education of clinicians, educators, and family caregivers regarding ASD. A recurrent issue was the misperception that autism is not a disorder that may be diagnosed and treated. Selected quotations:

- (It was) very difficult (due to) total lack of knowledge in early years (32 years ago). Part of difficulty was with professionals in various areas who would not admit that they really didn't know (about autism).
- I think it's really good to speak of Autism Spectrum Disorders, because I still meet many people who think that if a child is speaking, there's no way they can have autism.
- Early intervention was helpful. They paid for (*name*) to come to our home and she did an excellent job evaluating and diagnosing our son.

- (It's) very hard to get an accurate diagnosis for our daughter with Asperger's. One psychiatrist 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.
- Three pediatricians told me there was nothing wrong with my 20-month-old son.
- Pediatricians told me that my child just needed to be in preschool for socialization at ages 4-5 years.
- My child's pediatrician does not believe that ASD is a real diagnosis. I had to beg him for a referral.
- Doctors can't be scared of being wrong. It's better to get services early; actually, it's critical.
- (The) single biggest barrier to early diagnosis - physicians and other professionals disagreeing with parental concerns.
- (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.
- Her former pediatrician refused to believe me that she had autism. Pediatricians need mandatory schooling on autism.
- Early intervention personnel missed the autism diagnosis, even when I as a parent asked, 'Could this be autism?'
- (We) need pediatricians and schools to quit doubting us moms and tell us where to get the best services. Family support and direction is very weak here in Alabama.
- I would have wanted my pediatrician to take ASD seriously, pay attention to my concerns, and diagnose my child.
- She displayed signs of autism at age 2-3 years, but was never confirmed. Public school was not prepared to handle autism.

Systems of Care Subcommittee

Six caregivers who participated in the community forums about ASD identified issues related to systems of care, including obtaining approval from health insurers and coordinating clinical and educational services. Selected quotations:

- BCBS fed pays for 75 visits for year (all therapy). School system provided diagnosis - via preschool at Weatherly.
- BCBS reimbursed 50% for psych services, but will not pay for any of social skills therapy, OT, etc. (We) now have United Health Care Flex Plan where we pay money (into an account) ahead of time. We have found that with letters from MD's, lots of traditionally non-covered services these kids need are covered broadly under the flex plan.
- (It is) difficult to travel to Birmingham; (I) would like to have Behavioral Therapy closer to Gadsden.
- A Mother's Morning-Out (program) director told us she could not tell parents that they suspect autism. If that is a state policy, that will not help.

- 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 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.

Healthcare Subcommittee

Finally, one forum participant wrote, we receive "medical services only if one is persistent and knows one's way through the system."

Early Intervention

Family members, consumers, and providers submitted anonymously 58 handwritten notes related to the category of **early intervention.** Comments were grouped by similarity and organized according to the five working subcommittees of the Alabama Autism Task Force (*Training and Education, Healthcare, Family Support, Systems of Care, & Intervention*). Family comments about early intervention are presented in rank order, most to least identified as concerns.

Twenty-two comments described concerns about accessing therapeutic interventions. Fifteen comments related to access to healthcare coverage, diagnostic and treatment specialists. Forum participants submitted eight comments regarding systems of care for early intervention and eight comments about training and education of clinical and education professionals. Verbatim quotations are included to illustrate the nature of respondents' written comments.

Intervention Subcommittee

Twenty-two forum participants expressed concerns about access to and provision of behavioral, biomedical, occupational therapy, speech and language therapy, and physical therapy for their family member with ASD. Several parents shared success stories, such as:

- I am most satisfied with services offered through the public school -- caring.
- Very satisfied with the Etowah City school system and the Learning Center on Hwy 77. They have helped our child progress in the areas of socialization, becoming more verbal, and developing an overall knowledge base.
- (We had a) wonderful experience transitioning from "Even Start" public preschool to Eura Brown Elementary. All faculty and support systems/personnel have done everything they knew to do to make the transition successful. He is

just in kindergarten -- still having transitional issues that we did not anticipate. I received ABA training from a lady in Huntsville - I took a "team" of 4 for training, and our lady in Huntsville oversees our treatment/helps with plan; to my knowledge, there is no one certified in Gadsden. Last time I checked, there were 2 people in Jacksonville (at the university) who were training in ABA.

- I was most satisfied with speech therapy, sensory therapy through OT.
- My son is 19 years old and we got fairly good services in Virginia when he was a toddler, early elementary, and middle school student. What he learned ages 2 to age 10 years really stuck with him. Sensory and OT and ABA are services that need to be instituted as soon as the child is diagnosed or suspected of having autism.

Most respondents described frustration trying to obtain various interventions to assist their family member. Verbatim comments:

- It was impossible having moved from Salt Lake City, Utah, to get help in the 1990s in Alabama (Gadsden).
- I didn't find out about interventions until it was time for school – age 6 years!
- Need ABA. Drove to Huntsville/Birmingham and continue to drive for services because none offered here. Heard about EI from friend. ABA most important and has worked the most, but no services here. EI did not offer enough services.
- Home therapist (*name*) did not show up the last three months. They pushed talking (rather) than connection. I will take my child to a different place for therapy.
- Nothing was very satisfying - everyone with EI nice, but I don't feel like they really helped my child.
- 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?
- We need more information, more services, more speech, more OT, ABA, RDI, and better informed employees.
- 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.
- My grandchild was diagnosed with PDD-NOS. What, if any, services are available for these children? We get 30 minutes a week in speech therapy only. I need to know what else can he get (sic)?
- Which therapies to choose is so frustrating! Everything promises to be the best. Nothing works for every child.
- Does a special needs child have to go into Head Start program in a nearby county if there is a open spot, instead of getting limited services through the county they live in?
- How long does it take for a child to transfer from Early Intervention into school-based services?

- Got EI before diagnosis. Diagnosis made in Birmingham, but did not receive enough of any therapy. I kept asking what was available.
- Experienced no difficulties with *Hand-in-Hand* -- great job with therapy for speech delay/OT delay! (They) offered therapies specific for autism -- ABA, RDI, etc. I felt totally on my own -- no resources here -- just searched Internet and called parents I knew.
- Our early diagnosis was entirely due to parental concern. We pulled out of early intervention at that time due to inadequate services. He now receives ABA at-home therapy 10 hours a week and speech therapy 2 hours a week. This, including fees for diagnosis, is all paid for out-of-pocket. There is no insurance coverage. We are very concerned because we were recently told by several individuals that if we have a child with autism, we need to LEAVE ALABAMA. Our son was in early intervention 15-23 months and we saw no progress. After implementation of the private ABA and speech therapy (2.5 years, present) the progress we have seen has been tremendous. The intense therapy is working and should be available to all children.
- Have not went through (sic) transition to school system. I think early intervention needs to be able to see a child more often than 2 or 3 times a month.
- Transition. We took one (child) out of public school for K4 and put him in private school. They were not getting him to work to his potential. He returned to K5 at public county school. Our 5-year old is receiving ABA at home from me and goes to Learning Tree 2 times a week.

Healthcare Subcommittee

Fifteen caregivers and providers who participated in the community forums identified health insurance coverage, diagnostics, and access to specialists. Respondents described concerns about choosing among therapies, cost of specialized care, and obtaining sufficient level of services. Verbatim comments:

- We received no early diagnosis -- poor differential diagnosis.
- As a therapist, I've noted that the children I believe need a diagnosis spend 6 months on a waiting list to receive an evaluation (Sparks Clinic, etc.).
- Pediatricians need to be screening children at 18 month check-ups; most can be diagnosed at 18 months.
- I had to wait a long time before anyone called back with EI and I was shuffled around a ton before finally getting called back 2 months later, after I had left several messages.
- We most need a screener for autism in early intervention intake. More money to provide service after diagnosis.
- 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!
- It was the keen eye of a special educator that suggested the possibility of autism. Formal testing was conducted, but no actual diagnosis was provided.
- Originally, my child was diagnosed with a speech delay only. We knew there were more problems, but could not get anyone to go further in looking at his

problem. Finally, at age 8 years, we paid for his testing through a private psychological group. Only after these test results, would the school system meet with us. They had to waive the 6-week school-based observation because he was not failing in his grades at that time. All his teachers had tried to get him help, but were turned down because of his grades. This needs to be changed.

- (My child) didn't get diagnosed until 3 years 3 months; started services at 2 years 2 months.
- Hard/impossible to get diagnosis for my son. (I am) still in the dark about how to get a diagnosis, especially since he is 25 years old.
- Early intervention diagnosis…numerous hearing tests..no one in could believe my child with DS could also have autism. TRIAD/BC/BS (military health insurance plan) refused to pay for diagnosis because of the mental health criteria. They wouldn't pay for MH services even though she had a neurobiological disorder…afraid to hurt feelings.
- We need separate funding for ASD programs. Rate doesn't cover the necessary frequency of services - i.e., SD, OT, PT twice per month and specialized instruction two to four times; this equals 8-10 therapies at $60/visit, between $480-$600 and we are reimbursed only $300-$360 per child.
- We need government/state-funded programs, RDI therapy, etc.
- My son began early intervention-speech therapy at age 15 months due to concerns with language development. He was offered speech therapy 30 minutes every other week. When we expressed concern about autism, we were told by our case worker "sometimes it takes time for the light bulb to come on with our little boys and sometimes with our little boys it is a maturity issue." At 23 months, we sought out an evaluation on our own. We applied to UAB & Vanderbilt. We got into Vanderbilt and our son was diagnosed at age 25 months.
- I would have wanted a more comprehensive review of available therapies from an "official" source - a developmental pediatrician, therapists that give you options, contact numbers, etc.

Training and Education Subcommittee

Eight forum participants wrote concerns about training and education of clinical and education professionals related to early intervention services. Several felt that an ASD diagnosis was overlooked, as a result. Verbatim comments:

- EI professionals should be trained in autism. Diagnosis (was) missed by EI professionals.
- (We) need more well-trained (sic) providers.
- Medical professionals need training for diagnosis. Our child was given a speech delay diagnosis at age 3. Naturally, we were too late for early intervention.
- A knowledge of available services shared across agencies/school systems.
- (We need) ABA parent training.
- ABA! (We need) more of everything. Just (provide home) visits to train parents. I had two diagnosed autistic.
- I had to find the Early Intervention phone number and information on the Internet by myself. MY pediatrician did not have any information on EI at his

office. All he could do was call Sparks for a referral, then I had to do something and I am glad I did it! EI needs to make sure all pediatricians have their number.

- I was informed that the Early Intervention Program was possibly going to get some of the service providers trained in a program called the Playtime Project. This is a floor timing program that I really hope all EI people are trained with.

Systems of Care Subcommittee

Issues regarding systems of care were identified by eight participants across the seven community forums about autism. This category of comments includes services provided through EI, public education, rehabilitation, Medicaid, and residential programs. Verbatim comments:

- (My experiences with EI) have been good! First, UAB - Sparks, CDLD to local system.
- (I found out EI only) by word of mouth from other parents.
- (There is a) lack of coordination of services.
- Early intervention needs to be required to tell all parents what they are federally required to give us (as services).
- Transition from EI to school-based services is a black hole in Alabama. Many public preschools are inadequate and parents do not have confidence in the untrained staff.
- (It is most important to provide) early diagnosis and early treatment. Early treatment should be offered by EI (a comprehensive program including ABA, speech, OT, & PT). We need real early intervention that is comprehensive.
- These children need more than what EI is set up for. We need a team effort in addressing their many needs.
- It is most important for my child to be able to transition into the public school system. It is a worry I try not to have. She is going to be in the 1st grade next year. She is very high functioning and I'm afraid that will make it harder for her to get services…help…I have heard "horror" stories of how hard it is to get services for such a high- functioning child. I just need help figuring things out.

One forum participant wrote about dissatisfaction with current level of family support services: “family therapy upon diagnosis would be fantastic! (We need) more! (EI?) (There is a) lack of quality; we need more training for EI professionals about ASD, in particular.”

Family Support

Those who attended the seven autism community forums anonymously submitted 53 handwritten comments regarding **family support services**. Comments were grouped by similarity and organized according to the five working subcommittees of the Alabama Autism Task Force (*Training and Education, Healthcare, Family Support, Systems of Care, & Intervention*). Participants’ comments about family support are presented in rank order, most to least identified as concerns.

Twenty-eight participants in the seven community forums wrote concerns about lack of family support to care for a relative with ASD. Thirteen comments related to health insurance coverage, diagnostics, and access to specialists. Ten participants submitted handwritten comments regarding interventions for ASD. Six forum participants submitted written comments related to training and education of clinical professionals and other service providers. Verbatim quotations are included to illustrate the nature of respondents' written comments.

Family Support Subcommittee

Four participants in the autism community forums wrote positive comments when asked to reflect on their experiences receiving family support:

- I have been really satisfied that each time I seek resources from the Autism Society (of Alabama); they always go out of their way to address my family's needs and concerns.
- Coldwater Baptist Church hosts a monthly support network.
- There are some recreational activities through Gadsden City Therapeutic Parks and Recreation Program.
- Yes, ASD has influenced family relationships, mostly for the better. Family has been our mainstay. (There have been) marital strains.

Unfortunately, most (22) respondents to this question identified negative experiences. Families perceive there are no supportive services in their community, particularly for strengthening marital relationships, respite care, child day care, after school care, summer programs and therapeutic recreation.

- There is none (family support). (My) family is out of state. (There are) no support groups. ASD has influenced my family relationships. ASD is huge financial strain.
- What are sources of family support? None. We have no support that I know of in my community. (3 similar comments)
- I believe someone tried to start one, but they gave up. (There are) no respite services in our area.
- There are no support groups – nothing. None -- my family all live out of state. (4 similar comments)
- No support networks, now; has been a few years ago – our local chapter was very active.
- There is none that I am aware of in Etowah County until tonight's forum! ***:)***
- (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 am least satisfied with the local family support system. I would love an opportunity to meet and speak with other families without being segregated by high and low functioning ability of my child. Respite is also a need to maintain my marriage!
- I need respite care or my mind and marriage are going to implode!
- My husband and I are separated and planning a divorce and ASD has played a part in it.

- 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!
- Yes, autism has influenced family relationships. In some cases, we have to exclude ourselves from some functions because other children in the family cause our child to revert and/or backslide.
- Is there counseling for family members that does not cost a fortune?
- There are no sources (of family support) that I am aware of. *One of the biggest things I am hopeful for is some kind of summer program -- What I envision is a good program for the ASD child -- "a summer camp" per se, but then also sessions that would be fun and teach the siblings about autism and ways to deal with the sibling, parental support sessions would be wonderful, as well.
- Students with ASD need meaningful programs in which to participate during the summer.
- Need community support for families. Need a book, like the "Yellow Pages" for health services, OT/PT, social/behavior, mental, speech, etc.
- 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!

Healthcare Subcommittee

Thirteen forum participants submitted handwritten notes related to health insurance coverage, diagnostics, and access to specialists to treat their family member with ASD. Most (11) families decried the lack of financial assistance to pay for needed behavioral instruction, mental health services, physical and occupational therapy. Verbatim comments:

- In-home waivers are greatly needed. More $ for help!!
- I need financial support and treatments that consist of biomedical treatment and special diets and therapy to meet their needs and improve their life.
- Limited money from state school systems, insurance companies (is a service barrier). Location of care is, too. Limited availability for many kids for "spots" in places like Mitchell's place, Glenwood, etc.
- YES, autism is a financial strain! BCBS will only pay 50% on psychological services and meds. Our insurance requires us to pay in full and be reimbursed, later. Until he qualified for SSI, we were close to bankruptcy.
- Yes, almost nothing is covered by insurance and treatment is very expensive. (2 similar comments)
- The recommendation from the clinical diagnosis is for 25-35 hours each week of direct appropriate instruction for the child. It is often not possible for a family to provide this (themselves) or to hire support people.
- Cost of out-of-pocket expenses. (There is) lack of service options.
- All aids, learning materials, special school supplies, etc., come out-of-pocket. It gets expensive, fast!

- Yes, paying for autism care is a strain -- you can sometimes negotiate with insurance companies.
- Of course, ASD affects the (family) relationships, and of course it is a financial strain. I think one thing that would be helpful for parents is advice on how best to spend their funds -- what are the most important therapies etc., i.e., if you have $X to spend, here is where you should spend it.

Two respondents suggested needed healthcare services for those with autism:

- (We) need a diet plan and a medical plan and a better teacher on ASD.
- We need to push for ID cards for people affected with ASD, so the disability can be known in an emergency situation.

Intervention Subcommittee

Ten forum participants wrote concerns about behavioral, biomedical, and traditional (OT, PT, speech language pathology) therapies. Two identified specific interventions perceived to benefit children and youth with autism. Verbatim comments:

- Play project (floor time therapy) thru puzzle pieces is available in my area.
- (I) participated in *Partners in Policy Making*, which was a great help and taught me a lot about advocacy (statement of a 1998-program graduate).

Eight respondents submitted handwritten notes identifying lack of access to interventions due to distance from service providers, limited number of providers within a school system or agency, and long wait lists.

- I need community resources that would allow some development of social skills and even social friendships with friends of like abilities as well as vocational support services that start early in teens.
- Metro West area is pretty much disconnected from services and it is difficult to get people to join support in the area due to a lack of knowledge about ASD and available services.
- We don't have many services in our area. There are services available at school, but still there are not enough hours. They need more hours of speech and OT and there needs to be more programs available like music enrichment programs, sports and recreation that can teach them how to participate in many sports activities.
- (We need) more one-on-one social interaction programs; more options for this area (of services).
- Sensory integration is not included in OT for our school system.
- Waiting list for after-school services way too long!! What happens to kids who will probably never work? (transition services)
- (There are) no after-school help or community supports in Walker County or other rural areas! We were evaluated at Glenwood and placed on a 7-year waiting list.
- Alabama needs more people familiar with RDI (Relationship Development Intervention).

Training and Education Subcommittee

Five family members who attended autism community forums identified family education about autism as a needed supportive service, particularly for siblings of children with ASD.

- (We need assistance for children to) relate to siblings who do not have disabilities, also getting relatives to understand ASD-child's behavior.
- (We need) to educate the siblings and to teach them to not be ashamed. That them what autism is.
- (We need a) means to help siblings understanding what is going on - brother is concerned about his little brother "failing" kindergarten.
- (We need to) support families through financial help, educating them on ASD, and educating the communities on this disorder. Schools need to educate the students on autism.
- Barriers to obtaining services are many times due to a lack of knowledge of parents and caregivers. We need more parental and public education.
- I've noted that most information regarding services (speech therapy, OT, etc.) travels by word-of-mouth. The doctors do not know who to refer to! (sic)

Healthcare/Medical Services

Family members, consumers, and providers anonymously submitted 44 handwritten notes related to the category of **medical services.** Comments were grouped by similarity and organized according to the five working subcommittees of the Alabama Autism Task Force (*Training and Education, Healthcare, Family Support, Systems of Care, & Intervention*). Family comments about medical services are presented in rank order, most to least identified as concerns.

Twenty-two comments related to health insurance coverage, diagnostics, and access to specialists. Eleven participants submitted written comments regarding interventions for ASD. Seven forum participants submitted written comments related to training and education of clinical professionals and other service providers. Verbatim quotations are included to illustrate the nature of respondents' written comments.

Healthcare Subcommittee

Community forum participants submitted 22 comments related to health insurance coverage, diagnostics, and access to specialists. Recurring themes are frustration about denial of insurance coverage, unexpected out-of-pocket costs for diagnosis and therapies, delay in receiving a diagnosis and referrals, and qualifications of professionals. Verbatim quotations:

- We have to pay for office visits ($100+) every 30 days just to get medicine refills! This is crazy!
- (We need) to have therapy covered by medical insurance. Insurance companies start paying for ABA, speech, OT and PT for our kids. My insurance company said that speech therapy would not be covered unless my child was diagnosed before age one year, yet most children are not talking before this age. Cost (is excessive); funding from medical insurance, school district or government grant to treat my child.

- I am not satisfied with the medical services because insurance does not cover most of these services. My children need to improve. Biomedical treatments can help improve the life and body of my child. He has so many medical problems that won't show up in regular testing that will show up in biomedical testing.
- Occupational, physical therapy, etc., are not easily obtained. We need consistent state-supported organized programs. Few individuals are qualified and available, and the cost is very high. (These specialists) may not be covered by insurance. If opt to do it, (we) pay for it personally.
- Pediatricians did not listen to our concerns when our child was younger. Professionals are not referring to EI.
- The main barriers to service are lack of trained specialists, lack of funding to support an integrated autism diagnostic and treatment clinic. Insurance cannot cover these costs and, unfortunately, very intensive treatment is required to help these children.
- We [need] help with the medical bills not covered by insurance or SSI.
- (It) took months to get a diagnosis. Used grandparents' savings, loans to pay for services.
- ABA, speech, and OT were paid with retirement, grandparents' savings, and loans.
- (We are) not paying for anything unless it is short-term. More treatment is better, but 'more' treatment costs when insurance doesn't pay.
- My question is why doesn't CRS (Children's Rehab Services) cover autism?
- (There is a) long wait for a referral from general pediatrician to developmental clinic, etc. Dental care has been a battle.
- (Parents) we have to go out of state. Sparks said to wait 8-10 months for evaluation; got in at Vanderbilt within four weeks. (We) had to pay for this, as well.
- ABA, speech, OT – specialists all privately sought and paid for with loans, retirement savings, etc.
- I begged the mental health provider covered by my insurance to see him because he was about to be thrown out of preschool. They weren't equipped to work with 4-5 year olds. The most helpful person there was not a psychologist or psychiatrist, but a social worker who got me on the road to diagnosis.
- 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.
- HMO did not pay for speech therapy during our child's preschool years. We had to pay for our own evaluation.
- (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.

- I would like the insurance companies (esp. Blue Cross) to pay for various therapies, services, etc.
- 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.
- What medical support exists for ASD, especially in southeastern Alabama?
- (The) service that made the most difference to my child is occupational therapy, which was paid for by us, because insurance would not pay.

Intervention Subcommittee

Eleven participants submitted written comments regarding interventions for ASD, including access to, and provision of developmentally appropriate and affordable therapies. Several families who attended the community forums mentioned difficulties obtaining physician diagnosis and referral to early intervention programs. Verbatim quotations:

- (We need) life skill therapy provided by some type of care facility which would offer interaction with peers in an ASD-friendly environment.
- (We) need funds from the state and federal dollars in the area of biomedical research and treatment and better planning for these kids.
- The service area I am least satisfied with is programming that is developmentally-appropriate for the Asperger/high-functioning autism child. There is little available for this group in terms of summer, vocational and after-school programming.
- (We require) insurance coverage for developmental instruction.
- (We) need early prevention with doctors that do (sic) medical and biomedical services and if kids started to show symptoms, then the doctor needs to try biomedical or stop giving vaccines to help kids.
- Treatments that have been most successful are behavioral/cognitive therapies, speech therapy, and OT. I know some families are driving to Tennessee for DAN doctors and alternative medicines that they are reading about on the Internet.
- We tried our son on Secretin therapy. Our son wasn't really communicating or anything. After the first dose, it seemed that he opened up and we went through one more treatment and it helped a little more.
- (One) problem is that medical staff are not familiar with autism. The most effective treatments are behavior therapy, a good special education department in our child's school, Glenwood adult services, and, at times, anti-anxiety drugs.
- (I have a) 10-year old boy with a social problem. We have not been able to find a service/counseling to help him. He also has ADHD, so he has a problem with impulsiveness.
- (We need a) resource book/pamphlet of healthcare providers in the state that are willing to expand their practice to include persons with special needs.

- (Which) service made the most difference? Occupational therapy, paid for by us, because insurance would not pay. (We also depend upon a) full-time grandmother to help.

Training and Education Subcommittee

Seven forum participants submitted written comments related to training and education of clinical professionals and other service providers, including concerns about professional preparation about diagnosing and managing ASD. Selected quotations:

- What doctors understand autism? What treatments are out there and how do you get it paid for?
- (We) should train doctors about autism.
- Pediatricians have little knowledge of ASD and options for treatment.
- Problem: Medical staff not familiar with autism.
- Provide these service providers with appropriate information, Re: autism.
- Doctors need to be educated, now. I'm talking about local pediatricians. Our doctor questions the validity of my son's diagnosis. Looking back, I can see the signs that were obvious and were reported to the doctor on a regular basis, and are on the checklist for autism. (*name*) Pediatrics didn't pick up on any of these things. They need more training there on what to look for in the high-functioning kids. They just say 'All kids develop at different rates and he'll grow out of this.' What is really causing the great increase in the numbers of autistic children?
- Why don't doctors want or believe it would be better for an autistic child to try a Casein-free / Gluten-free diet?

Family Support Subcommittee

Three participants commented on family support issues related to the category of medical services, including obtaining financial support for implementing home-based treatment and learning about outcomes of various therapies/treatments.

- Can we get financial support from the state? California pays moms to stay home and covers therapies and services.
- (We need) a web site/forum for parents to tell experiences they have had with various treatments and swap/sell supplements!
- (We received helpful) faith-based grief support from ONE FAITH MINISTRIES.

Systems of Care Subcommittee

Two participants wrote comments related to systems of medical care, including lengthy wait for referral to a specialist and limited collaboration among healthcare providers.

- Long wait from referral from general pediatrician to developmental clinic, etc. Dental care has been a battle.
- A barrier to receiving care is lack of collaboration of providers, universities, advocacy organization for parents.

Adult Services

Across the 7 general family forums, family members, consumers, and providers anonymously submitted 39 handwritten notes related to the category of **adult services.** Comments were grouped by similarity and organized according to the five working subcommittees of the Alabama Autism Task Force (*Training and Education, Healthcare, Family Support, Systems of Care, & Intervention*). Family comments about adult services are presented in rank order, most to least identified as concerns.

Eight forum participants described issues regarding systems of care for their family member with autism. Eight respondents identified training, education and healthcare barriers to adults with ASD receiving services. Verbatim quotations are included to illustrate the nature of respondents' written comments.

Systems of Care Subcommittee

Respondents identified transition services, including vocational rehabilitation, job training, and supported employment, assistance with activities of daily living (ADLs), social and communication skills, transportation, and housing assistance within the theme of services needed for adults with ASD. Eight comments reflect concerns about continuum of systems of care, beginning with early intervention through adulthood. Selected quotations:

- We need increased community awareness/education (about ASD).
- (I wish for my adult family member) to develop lifelong skills and manage living as independently as possible.
- Transition services in the school system aren't being provided. The IEP's only require that a statement be written about my child's post-school outcome with no annual goals written to address his unique needs. Why is there a lack of focus on the transition needs of children with disabilities?
- We agree that early diagnosis and early intervention is important to children -- but there are some people who will need lifelong support despite early identification and intervention. There needs to be more residential services.
- What services are available to ASD/teens as they prepare for adulthood? Will they transition to an independent or group living situation? (will they be) employable?
- We desperately need sheltered workshops without a 5-year waiting list. Transportation, teaching job skills, teaching self-help skills, (arranging) safe living arrangements when I (caregiver) die; need schools to help us get help and direction BEFORE graduation.
- Job coaches who help (ASD and other developmentally disabled) adults find and keep supported employment need to be paid better and we would get better job coaches.
- Educating employers on how to make employment successful for autistic people.

Training and Education and Healthcare Subcommittees

Eight respondents identified several barriers to adults with ASD receiving services related to training, education and healthcare. Barriers included limited knowledge among families and professionals about available community services; difficulties obtaining referrals to service providers, especially for those with multiple

needs/diagnoses; limited funds to pay for services not provided by agencies or reimbursed by health insurance; and strict rules restricting services by diagnosis, e.g., mental retardation. Selected quotations:

- I don't know what's available or how to plan for my child's future - HELP!
- The (state) system for referral is confusing to families. It would be helpful if there were a linkage to help families negotiate the system. For adults, referrals are not made until it is a critical situation – (instead, we) need 1 to 2 years of planning.
- My son, 18 years old, is 'multi needs'. How do I work to get all his needs addressed? He has autism, mental retardation (third grade or so, mentally) and bipolar disorder.
- Adult autistics are in desperate need of supportive services in the state of Alabama: job placement and housing…(name) Rehabilitation Center needs qualified specialist in autism disorders on their staff. They do not understand what the most appropriate job placement or setting should be for the autistic person.
- (There are) no services for teens. No one (professional) wants them; the pediatrician says that he is too big to see them and there (are) not many doctors who understand their autism. My son is hard to test to get approval for services he needs.
- All adults with Asperger's or high-functioning autism need an inclusion for education and employment placement…our vocational rehab center in (*name*) has not helped my son find a good job and job setting with a mentor to help my son achieve employment longevity and success. The case worker…has dropped the ball, so to speak. Also, my son is very mad at Vocational Rehabilitation for not helping him. I would appreciate any help in this matter.
- There are no funding mechanisms for long-term vocational services for adults with autism. The Medicaid waiver has to be expanded to include individuals with developmental disabilities, not just mental retardation.
- As a pediatrician, it is hard to advise parents as they are leaving my practice, and the public school system, where to turn for help. I am hoping/assuming that the school system and/or the specialists they are seeing are doing a better job than I am in advising them where to go/what to do.

Family Support and Interventions Subcommittees

Three respondents wrote about desires for their adult family member with ASD to receive ongoing services in support of independence, develop healthy peer relationships, and feel like a valuable member of society. Selected quotations:

- There's a need for an autistic adult support group - for each other.
- (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.
- Will there be something in place for parents with kids that are not adults yet? To help (make the) transition easier to adulthood.

Finally, three respondents identified available/helpful services for adults with ASD: Alabama Vocational Rehabilitation, Horizons School, Inc., and Gadsden State Community College supportive services.

In order to solicit additional information about the issues and concerns for adults with ASD, a community forum was held targeting adults with Asperger's or High-Functioning Autism. Thirty-two individuals with ASD attended this forum. A summary of that forum follows.

Appendix C

Community Forum for Post-high school Adults with High-Functioning Autism and Asperger's Syndrome

Method

A community forum for adults with autism spectrum disorders was held in spring of 2008 at The University of Alabama. The forum was promoted by distributing fliers by email and mail to service providers and individuals throughout the state who were likely to interact with adults with ASD. A total of 32 citizens (25 males, 7 females) from across the state participated in the forum. Of the participants who provided information regarding their home community, there were six individuals from Tuscaloosa and three from Montgomery. Twenty-two of the individuals present reported that they were involved with a specific support service for individuals with developmental disabilities or ASD (i.e., Glenwood, Triumph, Autism Asperger Syndrome Consulting Group). Many noted hearing about the forum from their service providers.

Facilitators for this forum included two academic clinicians with professional experience with adults with ASD. Several graduate student assistants were present to assist with data collection and organization of the forum. In addition, members from the Autism Society of Alabama and several other ASD professionals were present at the beginning of the forum. The forum started with an unstructured thirty-minute greeting and welcome reception during which the participants (and other individuals who attended the focus group that paralleled the forum, including parents and professionals) served themselves food, browsed informational tables, and spoke with one another. Following the reception, the forum was closed to individuals who were not participating (i.e., who were not adults with ASD). As with previous forums, facilitators used a script to introduce the Alabama Autism Collaborative Group, present the purpose of the forum and uses of data, identify source of funding, and guide discussion across settings. Forum participants had multiple opportunities to share their opinions and experiences aloud within the group and confidentially in writing.

Investigators adapted materials used at previous forums to develop questions to guide group discussion relevant to adults with ASD. The categories of questions included **diagnosis, school-based services, adult services, medical treatments,** and **other support**. Each of these categories and sample questions were presented on a screen at the front of the room as they were discussed to provide structure and visual supports for the participants. Sample questions included: a) What educational services do you think helped you the most?, b) Describe your experiences with employment support programs for individuals with ASD in your community, c) What types of medical treatments do you think have been the most successful for you as a person with ASD?, and d) What are the sources of support for you and your family in your community? Participants were encouraged to provide verbal responses as desired and were also encouraged to submit additional anonymous comments to facilitators and assistants using post-it notes provided at the beginning of each forum.

Investigators reviewed the main emphasis of verbal responses and each written comment submitted during the forum and at least two investigators coded and grouped these comments by category. Comments were grouped by similarity but were also generally organized according to their relevance to the topic areas covered in the forum. Thus, comments from the forum were grouped into five categories: *Diagnosis, School-Based Services, Adult Services, Medical Services,* and *Other Support*. Results below represent verbal and written responses from participants attending the forum.

Percentages represent numbers from those who responded to the facilitator comments/questions.

Results

Diagnosis

When asked to share their (participant) experiences about receiving a diagnosis, 12 of the 32 participants (38%) indicated they had initially received an incorrect diagnosis. Other participants noted they "knew something was wrong" and "it took a long time" to receive a diagnosis. Several participants reported feeling relieved upon receiving a diagnosis because they finally had an explanation for their differences. The majority of adults attending the forum had received their diagnosis from doctors or therapists. Some participants shared their frustrations at having been improperly diagnosed. One participant said, "There must be properly trained mental health specialists who can recognize behaviors of Asperger's and explore how that behavior affects the person, and assist the person in finding alternate, workable solutions." Family was ranked as the second largest category from which the adults received help or information. Additional categories included the internet, television, and educational videos. Sources for information on the internet and television were WebMD, Wikipedia, and *Autism is a World* (CNN, 2004).

School-Based Services

Sixteen participants attending the forum (50%) obtained a regular education diploma. Others had received a GED (4), were home-schooled (1), or received an occupational diploma (1). The adults listed "modified" curricula, including resource classes and modified physical education classes, as the educational services most beneficial during school years. Additional services and resources that were helpful included social skills courses, personal aides, smaller classes, individual attention, gradual change, and people who showed an understanding of the disorder. When asked what services and supports schools should provide, participants mentioned "better social skills training in schools for students with ASD" and "more teacher training and political correctness." Another participant noted that "A number of very bright high school students are dropping out of school due to their [special education teachers] lack of education in this area." The majority of those attending replied "no" to the question: "Do you feel you got the help needed to do well in school?" None reported having participated in their IEP meetings. Of the transition from high school to college, one participant noted "it was hard to go from getting notes in high school to not having that in college - I didn't even know I could ask."

Sources from which participants felt they received most of their help with social skills were church, Glenwood, Triumph, Horizons School, Alabama School of Fine Arts, and Autism Asperger Syndrome Consulting Group. Other types of school services that participants would have most wanted include counselors, teacher training, and social-skills training for students with ASD. Individuals noted that transitions are difficult and that gradual transitions are better when changing classes or grades.

Adult Services

Almost one-half of the adults attending the forum (15) have a job. A large percentage (41%) also lives independently and had attended college (41%). Of the students who have attended college, one commented, "Schools don't do a lot of accommodations outside the classroom; like they give you a note-taker, but you still need reminders on deadlines. It would be nice to get extra support, even from peers." Participants gave a variety of comments when asked to describe their experiences getting or keeping a job. One participant noted that "the problem in job searching is a lack of awareness (about ASD)." Most responses indicated that disclosure of disability had a negative effect on the participant's job situation. For example: "Disclosing my disability hurt me in getting a promotion," or "…I've been respected without disclosing my diagnosis. I'm treated differently when I choose to disclose my diagnosis." One respondent each stated disclosure helped, s/he has not disclosed, or s/he quit the job.

Vocational Rehabilitation, Triumph, and parents were listed as resources that helped participants get the right services needed. One participant stated, "Vocation Rehabilitation helped with social skills and Triumph helped me get a job." Another attendee stated, "My parents helped the most. They always had the best advice. If it wasn't for them, I wouldn't be where I am now."

Some respondents noted having difficulty making friends. One participant said:

> "Until I graduated high school I had friends in drama and other things. Upon leaving high school…I have a desire for friends and significant others and I am very depressed. How do I do this now? There are no opportunities like in high school. It is hard to meet people."

When asked whether services individuals with ASD should be ASD-specific or could it serve broader groups, one participant responded by stating a need for adult support groups "where adults can talk about specific problems to each other, help each other learn new ways of interacting, and share insights on the NT (neurotypical) world." Other responses from participants included statements referring to the need for a specific Asperger syndrome program and programs to address problems such as stuttering, panic attacks, and or rocking.

Medical Treatments

Several participants stated that even with insurance, they have significant out of pocket expenses for ASD services. One participant stated "I have insurance, but there are no psychologists trained in ASD in my network. I have to pay a $2,000 deductible and a high rate per session to see an out-of-network psychologist." Other comments were: "We need to teach/train people in med school about Asperser's syndrome and autism" and "Doctors don't know about ASD."

Other Support

Other information that participants wanted legislators to know included the fact that 12 (38%) rely on public transportation. Additionally, the transition from high school was difficult. It was difficult for those with ASD to meet people and make friends. When asked for final comments, one participant noted that "Asperger's doesn't define

everything." Another participant wanted others to know "Don't let your ASD diagnosis get to you. Accept your diagnosis and learn to live with it."

Appendix D

Results from the Surveys on Autism Spectrum Disorders

Method

Survey Development and Content

The Alabama Autism Collaborative Group members constructed a set of survey questions designed to gather information about available and needed services and supports from Alabama residents who had family members with ASD. As with the forum questions, investigators developed sets of questions in six service categories to parallel those categories used to report on the review of professional literature. The categories include *diagnosis, early intervention, school-based services, adult services, medical services,* and *family support*. Also included in the survey were a set of demographic items, a set of questions about the characteristics and abilities of the family member with ASD, and a section on pre-school services.

Survey Formats and Dissemination

Surveys were made available in both an online and paper (scannable) format. The online version of the survey was disseminated through various service organizations and agencies, such as United Cerebral Palsy and Autism Society of Alabama through their web site. Many agency representatives disseminated information about the availability of the survey through their email lists and LISTSERVs. The scannable version was offered to attendees at the Early Intervention Conference and Expo in Birmingham, as well as at four of the seven family forums held around the state. Following the forums, scannable surveys were also provided to at least 10 agencies and clinics for use with their clients. At the end of the survey, respondents were given an opportunity to provide additional comments.

Informed Consent

What is the Alabama Autism Collaborative Group?
The Group consists of clinicians, educators, and researchers from UAB and UA, members of the Autism Society of Alabama, parents, and agency professionals. Group members collaborate to identify the needs of those with Autism Spectrum Disorders (ASD) and their families with support provided by the Alabama Council for Developmental Disabilities.

Why was I invited to complete this survey?
State Representative Cam Ward and Lt. Governor Jim Folsom created the Alabama Autism Task Force, which is composed of elected officials, educators, physicians, and researchers. Task Force members will recommend improvements to diagnose and treat Autism Spectrum Disorders (ASD). Your experiences are important to share as we develop recommendations.

Informed Consent
TITLE OF RESEARCH: Alabama Autism Needs Assessment (Parent Survey)
INVESTIGATORS: Drs. Beverly Mulvihill, Russell Kirby, Elizabeth Griffith, Laura Klinger, Brian F. Geiger, Marcia R. O'Neal, & Karen B. Dahle

SPONSOR: Alabama Council for Developmental Disabilities

Explanation of Procedures: You are invited to complete a survey to discuss programs and services for family members with autism and related disorders. The information you provide will be used by the Alabama Autism Task Force and researchers at the Universities of Alabama and Alabama at Birmingham to summarize program strengths and issue recommendations for improvement in supports and services. The survey will take about 10 minutes. Read this form

before deciding whether to participate. There is no obligation to complete any or all of the information on this form. Your personal identity will not be revealed to others.

Risks and Discomforts: There may be mild psychological risks or discomforts that might occur because of your participation in this survey. If there are any specific questions you do not wish to answer, please skip them and move on to the next question.

Benefits: You may not personally benefit from your participation in this research; however, your participation will be helpful to indicate areas of program strength and needed improvements for people with autism.

Alternatives: You may decline participation at no penalty.

Confidentiality: All information provided will remain confidential to the extent of the law. The UAB Institutional Review Board (IRB) and the sponsor, the Alabama Council for Developmental Disabilities, may review the research records for auditing purposes.

Withdrawal without Prejudice: You are free to withdraw your consent and to discontinue participation in this survey at any time. You will not be offered any special consideration if you take part in this research.

Cost of Participation: There will be no cost to you to participate in the research.

Payment for Participation in Research: There is no payment for participation in this survey.

Questions: Call Dr. Beverly Mulvihill at 205-975-7942 if you have any questions about the research. If you have questions about your rights as a research participant, contact Ms. Sheila Moore, Director of the UAB Office of the Institutional Review Board for Human Use (IRB). Ms. Moore may be reached between the hours of 8:00 a.m. and 5:00 p.m. CT, Monday through Friday, at (205) 934-3789 or 1-800-822-8816. Press the option for an operator/attendant and ask for extension 4-3789.

Legal Rights: You are not waiving any of your legal rights by signing this consent form.

Results

The results of 270 completed surveys have been analyzed to date. Of the 270 respondents, 128 had attended one of the seven forums. Results are highlighted on the following pages. Detailed tables of descriptive statistics follow.

Demographics

Survey respondents represented 141 different zip codes in 102 different cities across the state.

Survey responses indicated the following demographic results:

Ethnicity:

66.7% were white non-Hispanic, 14.8% were white Hispanic

9.5% were black non-Hispanic, 6.1% were black Hispanic

Marital Status:

77.9% were married, 11.6% were divorced

Number of family members with ASD:

74.5% had one family member with ASD, 21.3% had two

Number of family members with ASD in the home:

76.5% had one family member with ASD living with them, 14.8% had two

Support networks:

46.4% have support networks with ASD in their community

66.7% with support groups in their community participate in support groups

Characteristics of family member with ASD

Gender of family member with ASD:

81.3% are male

Age of family member with ASD:

Mean age = 10.4 years, median age = 8.0 years, range = 4 months to 60 years

Living arrangement of family member with ASD:

89.5% live at home

Communication skills of family member with ASD:

Language Ability

Age 0-5 years: 50.5% are nonverbal or use simple sounds or single words

Age 6-10 years: 23.3% are nonverbal or use simple sounds or single words

Age > 10 years:28.0% are nonverbal or use simple sounds or single words

Conversations with others

Age 0-5 years: 54.5% rarely or never engage others in conversation

Age 6-10 years:31.5% rarely or never engage others in conversation

Age > 10 years:34.4% rarely or never engage others in conversation

Communication Aids

Age 0-5 years: 32.3% use picture exchange/picture symbols, 28.1% use sign language

Age 6-10 years: 28.2% use picture exchange/picture symbols, 12.7% use sign language

Age > 10 years: 21.7% use picture exchange/picture symbols, 7.6% use sign language

Daily living skills:

Feeding

Age 0-5 years: 30.9% require assistance, 2.1% do not have the skill yet
Age 6-10 years: 8.3% require assistance, 0.0% do not have the skill yet
Age > 10 years: 5.3% require assistance, 1.1% do not have the skill yet

Dressing

Age 0-5 years: 58.8% require assistance, 22.7% do not have the skill yet
Age 6-10 years: 47.2% require assistance, 0.0% do not have the skill yet
Age > 10 years: 23.4% require assistance, 3.2% do not have the skill yet

Bathing

Age 0-5 years: 60.6% require assistance, 27.8% do not have the skill yet
Age 6-10 years: 66.7% require assistance, 5.4% do not have the skill yet
Age > 10 years: 30.1% require assistance, 7.5% do not have the skill yet

Toileting

Age 0-5 years: 27.8% require assistance, 48.5% do not have the skill yet
Age 6-10 years: 26.4% require assistance, 11.1% do not have the skill yet
Age > 10 years: 16.3% require assistance, 3.3% do not have the skill yet

Cooking

Age 6-10 years: 16.7% require assistance, 80.6% do not have the skill yet
Age > 10 years: 38.3% require assistance, 43.6% do not have the skill yet

Managing Money

Age 6-10 years: 13.7% require assistance, 86.3% do not have the skill yet
Age > 10 years: 27.7% require assistance, 63.8% do not have the skill yet

Transportation (driving/riding a bus)

Age 6-10 years: 12.5% require assistance, 84.7% do not have the skill yet
Age > 10 years: 13.8% require assistance, 67.0% do not have the skill yet

Diagnosis

Number of service providers before diagnosis:

Mean = 3.19, median = 2.0, range = 0 to 25; 49.7% had 3 or more

Length of time (months) between first concern and diagnosis:

Mean = 36.83 months, median = 16.00 months, range = 0 to 528 months

Age at diagnosis:

Mean = 5.96 years, median = 3.00 years, range = 3.67 to 58 years

Accurate diagnosis:

79.5% said “Yes”

Diagnosed in Alabama:

23.0% said “No”

Professional offering diagnosis:

Physician (56.0%), Psychologist (28.6%), School Professional (4.6%)

Early Intervention Services

Received services:
8.5% currently receiving, 59.6% previously received, 29.2% never received
Months from diagnosis to first treatment:
Mean = 4.41 months, Median = 1.00 months, Range = 0 to162 months
Therapies received:
Speech Therapy = 86.5%, Occupational Therapy = 66.7%, Social Skills = 38.0%, Behavioral Therapy/ABA = 35.5%, Physical Therapy = 31.0%, Parenting Skills = 21.1%, Nutritional Counseling = 18.0%, Mental Health Counseling = 12.9%
Hours per month of services:
Mean = 20.20 hours, Median = 4.00 months, Range = 0 to288 hours (6.7% get 100 hours or more per month)
Training to provide therapy at home
42.7% said "Yes"

Pre-school Services
Received services:
19.4% currently receiving, 52.8% previously received, 25.4% never received
Therapies received:
Speech Therapy = 81.9%, Occupational Therapy = 64.6%, Pre-school = 66.7%, Social Skills = 38.6%, Behavioral Therapy/ABA = 33.5%, Physical Therapy = 28.6%, Parenting Skills = 19.7%, Nutritional Counseling = 15.2%, Mental Health Counseling = 11.9%
Hours per month of services:
Mean = 48.53 hours, Median = 29.00 months, Range = 0 to 210 hours (21.8% get 100 hours or more per month)
Training to provide therapy at home
42.1% said "Yes"

Services Through Public Schools
Received services:
55.5% currently receiving, 18.9% previously received, 22.7% never received
School system provided needed resources:
40.0% said "Yes" and 47.4% said "No"
Therapies received:
Speech Therapy = 73.6%, Occupational Therapy = 57.8%, Social Skills = 42.9%, Recreation/Exercise Therapy = 29.2%, Behavioral Therapy/ABA = 28.1%, Physical Therapy = 17.5%, Job Training/Coaching = 9.8%, Parenting Skills = 7.7%, Nutritional Counseling = 4.9%, Mental Health Counseling = 9.2%
Needs met by school:
Academic: 50.2% = very or somewhat effective
Behavioral: 44.3% = very or somewhat effective
Communication: 48.0% = very or somewhat effective
Social: 36.3% = very or somewhat effective
IEP meetings include discussion of services after high school
12.9% said "Yes"
27.3% of age 11 and older said "Yes"

Services for Adults

How much supervision does/will family member need as an adult:
none = 3.5%, occasional = 18.7%, frequent = 18.1%, continuous = 29.2%, don't know = 30.4%

Long-term care plans:
14.2% said "Yes" and 76.0% said "No"

On a waiting list for residential services:
3.5% said "Yes

Family member 21 or older:
13.3% said "Yes"

Therapies received:
Speech Therapy = 15.6%, Occupational Therapy = 18.8%, Job Training/Coaching = 27.3%, Social Skills = 27.3%, Nutritional Counseling = 15.2%, Mental Health Counseling = 33.3%, Physical Therapy = 6.3%, Recreational/Exercise Therapy=12.5%, Family Respite = 6.3%

Hours engaged in activities:
Adult Day Care: Mean = 5.22
Employed: Mean = 5.09
College: Mean = 2.66
Sheltered Workshop: Mean = 1.03
Social Activities with Friends: Mean = 4.38
Volunteer Activities: Mean = 2.15

Healthcare/Medical Services

Medications prescribed:
83.0% (224) reported one or more medications
Most often prescribed: Risperdal (35.3%), Adderall (22.8%), Clonodine (19.6%), Ritalin/Metadate (19.2%), Zoloft (17.0%), Concerta (14.7%)
Of the 224 who reported medications, those reporting one med = 54.5%, two meds = 17.0%, three meds = 12.5%, four or more meds = 16.1%

Alternative treatments tried:
52.6% (142) reported trying one or more alternative treatments
Most tried: Vitamin Supplements (71.1%), Dietary Changes (47.2%), GFCF Diet (28.2%), Dietary Supplements (16.9%), Chelation (10.6%)
Of the 142 who reported trying treatments, those reporting one treatment = 39.4%, two treatments = 30.3%, three treatments = 12.7%, four or more treatments = 17.6%

Other conditions diagnosed:
53.3% (144) reported other conditions diagnosed
Most often: ADD/ADHD (48.6%), Seizures (22.2%), OCD (18.8%), Anxiety (25.0%)
of the 144 who reported other conditions, those reporting one condition = 50.0%, two conditions = 22.9%, three conditions = 10.4%, four or more conditions = 16.7%

Insurance:
Employer-provided (67.2%), Medicaid (27.7%)

Services covered:
No services (18.6%), Some services (57.8%), All services (11.8%)

Detail Tables of Results

Please Tell Us about Yourself.

What is your ethnicity?

Response	Hispanic		Not Hispanic		Total	
	n	%	n	%	n	%
Asian	1	0.4%	0	0.0%	1	0.4%
Black	16	6.1%	25	9.5%	41	15.5%
White	39	14.8%	176	66.7%	215	81.4%
Other	2	0.8%	5	1.9%	7	2.7%
Total	58	22.0%	206	78.0%	264	100.0%

What is your marital status?

Response	Frequency	Percentage
Single	20	7.5%
Married	208	77.9%
Separated	4	1.5%
Divorced	31	11.6%
Widowed	3	1.1%
Other	1	0.4%
Total	267	100.0%

In what range is your family income?

Response	Frequency	Percentage
$20,000 or less	24	9.6%
$20,001 - $40,000	41	16.3%
$40,001 - $60,000	48	19.1%
$60,001 - $80,000	42	16.7%
More than $80,000	96	38.2%
Total	251	100.0%

How many members of your family (your siblings, children, parents) have been diagnosed with Autism Spectrum Disorder (ASD)?

Response	Frequency	Percentage
0	5	1.9%
1	199	74.5%
2	57	21.3%
3	5	1.9%
4	0	0.0%
5	1	0.4%
Total	267	100.0%

(One answer of “11" was not included because it was deemed a highly unlikely response.)

How many family members with ASD live with you?

Response	Frequency	Percentage
0	20	7.6%
1	202	76.5%
2	39	14.8%
3	3	1.1%
Total	264	100.0%

Are there formal support networks for ASD in your community?

Response	Frequency	Percentage
Yes	124	46.4%
No	82	30.7%
Don’t Know	61	22.8%
Total	267	100.0%

Do you participate in any of these support groups? (Results are for those who said "Yes" above.)

Response	Frequency	Percentage
Yes	82	66.7%
No	41	33.3%
Not Applicable	0	0.0%
Total	123	100.0%

Please Tell Us about Your Family Member Diagnosed with ASD

Please select the gender of your family member diagnosed with ASD.

Response	Frequency	Percentage
Male	218	81.3%
Female	50	18.7%
Total	268	100.0%

Please enter the age, in years, of your family member diagnosed with ASD.

N	Mean	Standard Deviation	Median	Minimum	Maximum
265	10.35	8.88	8.00	0.33	60.00

Where does your family member with ASD live? (Select one response.)

Response	Frequency	Percentage
At home	238	89.5%
In foster care	0	0.0%
In residential placement	10	3.8%
At college	5	1.9%
In his/her own apartment or home	6	2.3%
With another family member	2	0.8%
Other	5	1.9%
Total	266	100.0%

What is the language ability of your family member with ASD?

Response	All Respondents		Family Member Age 0-5 years		Family Member Age 6-10 years		Family Member Age >10 years	
	n	%	n	%	n	%	n	%
Nonverbal	36	13.5%	21	21.6%	6	8.2%	8	8.6%
Makes simple sounds*	17	6.4%	12	12.4%	3	4.1%	2	2.2%
Uses single words	41	15.4%	16	16.5%	8	11.0%	16	17.2%
Speaks short sentences	99	37.1%	35	36.1%	24	32.9%	39	41.9%
Speaks complex sentences	74	27.7%	13	13.4%	32	43.8%	28	30.1%
Total	267	100.0%	97	100.0%	73	100.0%	93	100.0%

*This option was available only on the online version of the survey.

Does your family member with ASD engage others in conversation?

Response	All Respondents		Family Member Age 0-5 years		Family Member Age 6-10 years		Family Member Age >10 years	
	n	%	n	%	n	%	n	%
Usually	80	30.1%	20	20.8%	23	31.5%	36	38.7%
Sometimes	79	29.7%	24	25.0%	27	37.0%	25	26.9%
Rarely	52	19.5%	20	20.8%	11	15.1%	21	22.6%
Never	55	20.7%	32	33.3%	12	16.4%	11	11.8%
Total	266	100.0%	96	100.0%	73	100.0%	93	100.0%

Does your family member with ASD use any of the following to help him/her communicate? (Select all that apply. If no assistance is needed, select None.)
All respondents

Response	Frequency	Percentage of Responses	Percentage of Respondents
Picture Exchange/Picture Symbols	72	23.3%	27.4%
Talking Device	7	2.3%	2.7%
Sign Language	43	13.9%	16.4%
None	165	53.4%	62.7%
Other	22	7.1%	8.4%
Total	309	100.0%	117.5%

A total of 263 respondents selected one or more responses to this item. A total of 224 selected one response, 32 selected two responses, and 7 selected three responses. The percentages in the last column represent the percentage of the 263 participants who selected each item.
Among the 22 participants selecting "Other", 7 indicated the use of gestures or pointing, 6 indicated some speech was present, 2 indicated some form of therapy (discrete trials, ST, OT), and 1 each indicated the use of an Alpha Writer at school, a spellboard, a hearing aid, and typing.

Respondents with family member age 0-5 years

Response	Frequency	Percentage of Responses	Percentage of Respondents
Picture Exchange/Picture Symbols	31	26.7%	32.3%
Talking Device	2	1.7%	2.1%
Sign Language	27	23.3%	28.1%
None	51	44.0%	53.1%
Other	5	4.3%	5.2%
Total	116	100.0%	120.8%

A total of 96 respondents selected one or more responses to this item. A total of 77 selected one response, 18 selected two responses, and one selected three responses. The percentages in the last column represent the percentage of the 96 participants who selected each item.

Respondents with family member age 6-10 years

Response	Frequency	Percentage of Responses	Percentage of Respondents
Picture Exchange/Picture Symbols	20	24.1%	28.2%
Talking Device	1	1.2%	1.4%
Sign Language	9	10.8%	12.7%
None	44	53.0%	62.0%
Other	9	10.8%	12.7%
Total	83	100.0%	116.9%

A total of 71 respondents selected one or more responses to this item. A total of 62 selected one response, 6 selected two responses, and 3 selected three responses. The percentages in the last column represent the percentage of the 71 participants who selected each item.

Respondents with family member age > 10 years

Response	Frequency	Percentage of Responses	Percentage of Respondents
Picture Exchange/Picture Symbols	20	19.0%	21.7%
Talking Device	4	3.8%	4.3%
Sign Language	7	6.7%	7.6%
None	67	63.8%	72.8%
Other	7	6.7%	7.6%
Total	105	100.0%	114.1%

A total of 92 respondents selected one or more responses to this item. A total of 82 selected one response, 7 selected two responses, and 3 selected three responses. The percentages in the last column represent the percentage of the 92 participants who selected each item.

For each of the following activities, please indicate how well your family member with ASD is able to perform the activity.

All respondents

Response	Total	Independently		With Help or Support		Does Not Have This Skill Yet	
		n	%	n	%	n	%
Feeding	267	222	83.1%	41	15.4%	4	1.5%
Dressing	267	127	47.6%	114	42.7%	26	9.7%
Bathing	266	92	34.6%	135	50.8%	39	14.7%
Toileting	265	145	54.7%	61	23.0%	59	22.3%
Cooking	266	21	7.9%	53	19.9%	192	72.2%
Managing Money	266	8	3.0%	38	14.3%	220	82.7%
Transporting Him/Herself (driving, riding a bus)	266	23	8.6%	26	9.8%	217	81.6%

Respondents with family member age 0-5 years

Response	Total	Independently		With Help or Support		Does Not Have This Skill Yet	
		n	%	n	%	n	%
Feeding	97	65	67.0%	30	30.9%	2	2.1%
Dressing	97	18	18.6%	57	58.8%	22	22.7%
Bathing	97	11	11.3%	59	60.8%	27	27.8%
Toileting	97	23	23.7%	27	27.8%	47	48.5%
Cooking	96	2	2.1%	3	3.1%	91	94.8%
Managing Money	95	0	0.0%	2	2.1%	93	97.9%
Transporting Him/Herself (driving, riding a bus)	96	3	3.1%	4	4.2%	89	92.7%

Respondents with family member age 6-10 years

Response	Total	Independently		With Help or Support		Does Not Have This Skill Yet	
		n	%	n	%	n	%
Feeding	72	66	91.7%	6	8.3%	0	0.0%
Dressing	72	38	52.8%	34	47.2%	0	0.0%
Bathing	72	20	27.8%	48	66.7%	4	5.6%
Toileting	72	45	62.5%	19	26.4%	8	11.1%
Cooking	72	2	2.8%	12	16.7%	58	80.6%
Managing Money	73	0	0.0%	10	13.7%	63	86.3%
Transporting Him/Herself (driving, riding a bus)	72	2	2.8%	9	12.5%	61	84.7%

Respondents with family member age > 10 years

Response	Total	Independently		With Help or Support		Does Not Have This Skill Yet	
		n	%	n	%	n	%
Feeding	94	88	93.6%	5	5.3%	1	1.1%
Dressing	94	69	73.4%	22	23.4%	3	3.2%
Bathing	93	58	62.4%	28	30.1%	7	7.5%
Toileting	92	74	80.4%	15	16.3%	3	3.3%
Cooking	94	17	18.1%	36	38.3%	41	43.6%
Managing Money	94	8	8.5%	26	27.7%	60	63.8%
Transporting Him/Herself (driving, riding a bus)	94	18	19.1%	13	13.8%	63	67.0%

Diagnosis

How many different service providers evaluated your family member with ASD before you were given a diagnosis of ASD?

N	Mean	Standard Deviation	Median	Minimum	Maximum
246	3.19	3.17	2.00	0	25

Response	Frequency	Percentage
Two or fewer	124	50.4%
Three	54	22.0%
Four	29	11.8%
Five	16	6.5%
Six	10	4.1%
Seven or more	13	5.3%
Total	246	100.0%

What is the length of time (number of months) between your first concern and receiving a diagnosis for your family member with ASD?

N	Mean	Standard Deviation	Median	Minimum	Maximum
244	36.83	67.89	16.00	0	528

At what age, in years, did your family member with ASD receive a diagnosis?

N	Mean	Standard Deviation	Median	Minimum	Maximum
253	5.96	7.36	3.00	3.67	58

Do you believe you received an accurate diagnosis for your family member with ASD?

Response	Frequency	Percentage
Yes	206	79.5%
No	13	5.0%
Don’t Know	40	15.4%
Total	259	100.0%

Was your family member with ASD diagnosed in Alabama?

Response	Frequency	Percentage
Yes	197	77.0%
No	59	23.0%
Don't Know	0	0.0%
Total	256	100.0%

What type of professional provided the diagnosis for your family member with ASD?

Response	Frequency	Percentage
Physician (pediatrician/neurologist/psychiatrist)	135	56.0%
Psychologist	69	28.6%
School Professional	11	4.6%
Other	26	10.8%
Total	241	100.0%

A total of 43 respondents (33 of whom selected "Other") wrote in a response. Write-in responses included Glenwood (8), Sparks (7), and neuropsychologist or neurologist (5). Other write-in responses appearing one to three times included multi-disciplinary or collaborative team (3), self (3), school personnel (3), Monskay Clinic (2), Dr. Dossett (2), pediatrician (1), psychologist (1), autism specialist (1), clinician (1), DAN doctor (1), EI (1), nurse (1), and university professor(1).

Early Intervention Services

Does/did your family member with ASD receive early intervention services?

Response	Frequency	Percentage
Currently receives early intervention services	22	8.5%
Previously received early intervention services	155	59.6%
Never received early intervention services	76	29.2%
Don't know	7	2.7%
Total	260	100.0%

How many months after diagnosis did it take before you could begin therapy for your family member with ASD?

N	Mean	Standard Deviation	Median	Minimum	Maximum
134	4.41	15.11	1.00	0	162

Most (78%) of the 134 respondents whose answer could be quantified said they received therapy services within 3 months. Another 27 indicated they were receiving therapy before diagnosis.

Do/did you receive any of the following early intervention services for your family member with ASD?

Response	Total	Yes		No		Don't Know	
		n	%	n	%	n	%
Behavior therapy/ABA	186	66	35.5%	112	60.2%	8	4.3%
Mental health counseling	178	23	12.9%	151	84.8%	4	2.2%
Nutritional counseling	178	32	18.0%	143	80.3%	3	1.7%
Occupational therapy	192	128	66.7%	61	31.8%	3	1.6%
Parenting skills	185	39	21.1%	142	76.8%	4	2.2%
Physical therapy	187	58	31.0%	125	66.8%	4	2.1%
Social skills training	184	70	38.0%	108	58.7%	6	3.3%
Speech therapy	192	166	86.5%	25	13.0%	1	0.5%
Other	25	17	68.0%	8	32.0%	0	0.0%

Those choosing "Other" listed a variety of services including hearing, vision, behavior aid, ABA, music therapy, art therapy, play therapy, chelation, biofeedback, and sensory integration.

How many hours PER MONTH of specialized services (including special education pre-school and individual therapies) does/did your family member with ASD receive from a professional before 3 years of age? (Do not include hours in general day care.)

N	Mean	Standard Deviation	Median	Minimum	Maximum
195	20.29	40.44	4.00	0	288

Only 13 respondents reported having 100 hours or more per month of specialized services.

Do/did you receive training from a professional on how to provide therapy at home for your family member with ASD?

Response	Frequency	Percentage
Yes	85	42.7%
No	107	53.8%
Don't Know	7	3.5%
Total	199	100.0%

Pre-school Services

Does/did your family member with ASD receive pre-school services?

Response	Frequency	Percentage
Currently receives pre-school services	49	19.4%
Previously received pre-school services	133	52.8%
Never received pre-school services	64	25.4%
Don't know	6	2.4%
Total	252	100.0%

Do/did you receive any of the following pre-school services for your family member with ASD?

Response	Total	Yes		No		Don't Know	
		n	%	n	%	n	%
Behavior therapy/ABA	182	61	33.5%	115	63.2%	6	3.3%
Mental health counseling	177	21	11.9%	152	85.9%	4	2.3%
Nutritional counseling	178	27	15.2%	146	82.0%	5	2.8%
Occupational therapy	189	122	64.6%	65	34.4%	2	1.1%
Parenting skills	178	35	19.7%	140	78.7%	3	1.7%
Physical therapy	182	52	28.6%	124	68.1%	6	3.3%
Pre-school classroom attendance	186	124	66.7%	54	29.0%	8	4.3%
Social skills training	184	71	38.6%	103	56.0%	10	5.4%
Speech therapy	188	154	81.9%	31	16.5%	3	1.6%
Other	18	10	55.6%	7	38.9%	1	5.6%

Those choosing "Other" included swimming, music therapy, Fast Forward, AIT, behavior aid, ADHD, eating, and babysitting.

How many hours PER MONTH of specialized services (including special education pre-school and individual therapies) does/did your family member with ASD receive between ages 3 and 5 years? (Do not include hours in general day care.)

N	Mean	Standard Deviation	Median	Minimum	Maximum
174	48.53	49.99	29.00	0	210

A total of 38 respondents reported having 100 hours or more per month of specialized services.

Do/did you receive training from a professional on how to provide therapy at home for your family member with ASD who was 3, 4, or 5 years of age?

Response	Frequency	Percentage
Yes	83	42.1%
No	111	56.3%
Don't Know	3	1.5%
Total	197	100.0%

Services Through Public Schools

Does/did your family member with ASD receive services through public schools?

Response	Frequency	Percentage
Currently receives services through public school	132	55.5%
Previously received services through public school	45	18.9%
Never received services through public school	54	22.7%
Don't know	7	2.9%
Total	238	100.0%

Does/did your school system provide the resources necessary to support your family member with ASD?

Response	Frequency	Percentage
Yes	76	40.0%
No	90	47.4%
Don't Know	24	12.6%
Total	190	100.0%

Do/did you receive any of the following school-based services for your family member with ASD?

Response	Total	Yes		No		Don't Know	
		n	%	N	%	N	%
Behavior therapy/ABA	185	52	28.1%	124	67.0%	9	4.9%
Job training/coaching	184	18	9.8%	156	84.8%	10	5.4%
Mental health counseling	184	17	9.2%	157	85.3%	10	5.4%
Nutritional counseling	182	9	4.9%	165	90.7%	8	4.4%
Occupational therapy	192	111	57.8%	72	37.5%	9	4.7%
Parenting skills	181	14	7.7%	160	88.4%	7	3.9%
Physical therapy	189	33	17.5%	146	77.2%	10	5.3%
Recreation/exercise therapy	185	54	29.2%	119	64.3%	12	6.5%
Social skills training	189	81	42.9%	96	50.8%	12	6.3%
Speech therapy	193	142	73.6%	43	22.3%	8	4.1%
Other	24	17	70.8%	6	25.0%	1	4.2%

Several (5) respondents choosing "Other" mentioned IEPs or special education services. One each identified Learning Tree, pragmatic language, and classroom aid. Several simply indicated that services they received were inadequate.

How effective is/was your school at meeting the following needs of your family member with ASD?

Response	Total	Very Effective		Somewhat Effective		Somewhat Ineffective		Very Ineffective		Don't Know	
		n	%	n	%	n	%	n	%	n	%
Academic needs	195	26	13.3%	72	36.9%	32	16.4%	52	26.7%	13	6.7%
Behavioral needs	194	20	10.3%	66	34.0%	33	17.0%	64	33.0%	11	5.7%
Communication needs	194	25	12.9%	68	35.1%	41	21.1%	49	25.3%	11	5.7%
Social needs	196	17	8.7%	54	27.6%	52	26.5%	62	31.6%	11	5.6%

During IEP meetings, does/did anyone discuss services after high school for your family member with ASD?

Response	Frequency	Percentage
Yes	25	12.9%
No	158	81.4%
Don't Know	11	5.7%
Total	194	100.0%

Services for Adults

How much supervision does your family member with ASD need as an adult? If your family member with ASD is not yet an adult, how much supervision do you think he or she will need as an adult?

Response	Frequency	Percentage
No supervision	6	3.5%
Occasional supervision	32	18.7%
Frequent supervision	31	18.1%
Continuous supervision	50	29.2%
Don't know/unsure	52	30.4%
Other	0	0.0%
Total	171	100.0%

Does your family have long-term care plans for your family member with ASD?

Response	Frequency	Percentage
Yes	26	14.2%
No	139	76.0%
Don't Know	18	9.8%
Total	183	100.0%

Are you on a waiting list for residential services for your family member with ASD?

Response	Frequency	Percentage
Yes	6	3.5%
No	155	90.1%
Don't Know	11	6.4%
Total	172	100.0%

Is your family member with ASD an adult (21 years or older)?

Response	Frequency	Percentage
Yes	29	13.3%
No	189	86.7%
Total	218	100.0%

Do you receive any of the following services for your family member with ASD who is an adult?

Response	Total	Yes		No		Don't Know	
		n	%	N	%	N	%
Family respite	32	2	6.3%	28	87.5%	2	6.3%
Job training/coaching	33	9	27.3%	21	63.6%	3	9.1%
Mental health counseling	33	11	33.3%	20	60.6%	2	6.1%
Nutritional counseling	33	5	15.2%	25	75.8%	3	9.1%
Occupational therapy	32	6	18.8%	24	75.0%	2	6.3%
Physical therapy	32	2	6.3%	26	81.3%	4	12.5%
Recreation/exercise therapy	32	4	12.5%	25	78.1%	3	9.4%
Social skills training	33	9	27.3%	21	63.6%	3	9.1%
Speech therapy	32	5	15.6%	24	75.0%	3	9.4%
Other	4	1	25.0%	2	50.0%	1	25.0%

How many hours per week is your family member with ASD engaged in each of the following activities? (If none, enter a zero.)

Activity	N	Mean	Standard Deviation	Median	Minimum	Maximum
Adult Day Care	32	5.22	12.33	0.00	0.00	40.00
Employed	32	5.09	11.24	0.00	0.00	40.00
College/post-secondary school	29	2.66	5.51	0.00	0.00	29.00
Sheltered workshop	29	1.03	5.57	0.00	0.00	30.00
Social activities with friends	30	4.38	6.02	.25	0.00	20.00
Volunteer activities	31	2.15	4.47	0.00	0.00	16.00

Health Care/Medical Services

What medications have been prescribed to treat your family member with ASD? (Select all that apply. If none, select *None*.)
A total of 224 respondents identified one or more medications.

Response	Frequency	Percentage of Responses	Percentage of Respondents
Abilify	23	4.4%	10.3%
Adderall	51	9.7%	22.8%
Clonidine	44	8.3%	19.6%
Concerta	33	6.3%	14.7%
Focalin	18	3.4%	8.0%
Prozac	26	4.9%	11.6%
Risperdal	79	15.0%	35.3%
Ritalin/Metadate	43	8.2%	19.2%
Seroquel	24	4.6%	10.7%
Zoloft	38	7.2%	17.0%
None	82	15.6%	36.6%
Other	66	12.5%	29.5%
Total	527	100.0%	235.3%

A total of 224 respondents selected one or more responses to this item. A total of 122 selected one response, 38 selected two responses, 28 selected three responses, and 36 selected four or more responses. The percentages in the last column represent the percentage of the 224 participants who selected each item. Among those choosing "Other" medications, the most frequently listed medications were Lexapro (9), Straterra (8), Depacote (6), Zyprexa (6), Celexia (4), Tenex (4), Paxil (4), Topamax (3), Nystatin (3), dietary supplements (3), Lamictal (3), GI medications (2), Aricept (2), Luvox (2), Remeron (2), Spironolactone (2), Lorazepam (2), and other unnamed medications (4). Other medications mentioned once included Amantadine, Anaframil, Anapril, Ativan, B12,Catapress, Clonapin, Cyvanse, Datrona, Diacepam, Diflucan, Effexor, Godon, Haldol, Keppra, Librium, Lithium Melatonin, Mellaril, Metaclopremide, Mirtazapine, Oxytoetion, Tegretol, Trazodone, Vancomycin, Vyvanse, and Wellbutrin.

What alternative medical treatments have you used for your family member with ASD? (For example, dietary changes, vitamin supplements, chelation.) If none, write *None*.
A total of 142 respondents offered from one to six alternatives they had tried.

Response	Frequency	Percentage of Responses	Percentage of Respondents
Vitamin Supplements	101	31.7%	71.1%
Dietary Changes	67	21.0%	47.2%
GFCF Diet	40	12.5%	28.2%
Dietary Supplements	24	7.5%	16.9%
Chelation	15	4.7%	10.6%
Medication	8	2.5%	5.6%
Auditory Integration	6	1.9%	4.2%
Yeast	6	1.9%	4.2%
Hyperbaric	5	1.6%	3.5%
Sensory Integration	5	1.6%	3.5%
ABA	5	1.6%	3.5%
Enzymes	4	1.3%	2.8%
Secretion	4	1.3%	2.8%
DAN	3	0.9%	2.1%
Biomedical Intervention	2	0.6%	1.4%
Biofeedback	2	0.6%	1.4%
Chiropractor	2	0.6%	1.4%
Probiotics	2	0.6%	1.4%
Homeopathic	2	0.6%	1.4%
Other	16	5.0%	11.3%
Total	319	100.0%	224.6%

A total of 142 respondents provided one or more responses to this item. A total of 56 provided one response, 43 provided two responses, 18 provided three responses, and 25 provided four or more responses. The percentages in the last column represent the percentage of the 142 participants who selected each item. Included in the "Other" category are responses given only once: massage, exercise, social skills, IGG, votamine, DHEA, elderberry, glutathione cream, IV seratonin, music therapy, sauna, therapeutic listening, brush therapy, weight therapy, IVIG, and DMG.

What other conditions have been diagnosed for your family member with ASD? (For example, seizures, anxiety, ADHD, etc.) If none, write *None*.
A total of 144 respondents offered from one to six responses to this item.

Response	Frequency	Percentage of Responses	Percentage of Respondents
ADD/ADHD	70	23.8%	48.6%
Seizures	32	10.9%	22.2%
OCD	27	9.2%	18.8%
Anxiety/Phobias/Panic Attacks	36	12.2%	25.0%
Apraxia/Dyspraxia/Language Delay/Speech Delay	9	3.1%	6.3%
Asthma	9	3.1%	6.3%
Sensory Disorder/Sensory Integration Disorder	8	2.7%	5.6%
Depression	8	2.7%	5.6%
ODD	7	2.4%	4.9%
Tourette's/Tics	7	2.4%	4.9%
Mental Retardation	6	2.0%	4.2%
Allergies	5	1.7%	3.5%
Bipolar Disorder/Personality Disorder	5	1.7%	3.5%
Asperger's	4	1.4%	2.8%
Gastrointestinal Disorders	4	1.4%	2.8%
Developmental Delay	3	1.0%	2.1%
Blind/Visual Impairment	2	0.7%	1.4%
Central Auditory Processing Disorder	2	0.7%	1.4%
Diabetes	2	0.7%	1.4%
Down's Syndrome	2	0.7%	1.4%
Eczema	2	0.7%	1.4%
Hearing Loss/Deafness	2	0.7%	1.4%
Hypertension	2	0.7%	1.4%
Psychosis	2	0.7%	1.4%
SPD	2	0.7%	1.4%

Other	36	12.2%	25.0%
Total	294	100.0%	204.2%

A total of 144 respondents provided one or more responses to this item. A total of 72 provided one response, 33 provided two responses, 15 provided three responses, and 24 provided four or more responses. The percentages in the last column represent the percentage of the 144 participants who selected each item. Included in the “Other” category are responses given only once: autoimunine disorder, Behavior Disorder - NOS, Bifid Uvula, Trigger Thumb, C.P.-lower extremities, Celiac Disease, chromosome abnormality (partial trisomy 18), chronic constipation, congenital cranio-facial malformation, craniosynostosis 2ndary to hydrocephalus, cyclical vomitting, difficulty with composition, dystonia, encephalopathy, Fragile X syndrome, hand flapping/pacing, Hydrocephalus (congenital), learning disabilities, low attention, low muscle tone, Migralepsy, none except for side effects from some of her prescription drugs, Pancreatic Lipase Deficiency, Partial Trisomy 18, Pathologically Introverted, Post traumatic stress disorder, RAD, rages, Reflux (just diagnosed), respiratory issues, schizencephaly, scoliosis, septo-optic dysplasia/absence of corpus callosum - bilateral open lip, Sleep Apnea, Staring Spells or "optic seizures", Tactile defensiveness, yeast-DAN doctor is helping

Has your family member with ASD received care from the following?*

Response	Total	Yes		No		Don't Know	
		n	%	N	%	N	%
Psychologist	57	30	52.6%	24	42.1%	3	5.3%
Psychiatrist (MD)	67	40	59.7%	25	37.3%	2	3.0%

*This item was asked only on the scannable form of the survey.

What type of health insurance do you have for your family member with ASD? (Select all that apply. If you do not have health insurance for your family member with ASD, select *None*.)

Response	Frequency	Percentage of Responses	Percentage of Respondents
All KIDS	8	3.0%	3.4%
Employer-provided insurance plan	158	58.5%	67.2%
Medicaid	65	24.1%	27.7%
None	3	1.1%	1.3%
Other	36	13.3%	15.3%
Total	270	100.0%	114.9%

A total of 235 respondents selected one or more responses to this item. A total of 204 selected one response, 27 selected two responses, and 4 selected three responses. The percentages in the last column represent the percentage of the 235 participants who selected each item.
A total of 36 respondents wrote in a response to "Other" Insurance. Of these, 17 indicated BCBS, 6 indicated Tri-care, 5 indicated Medicare, 2 indicated Medicaid, and 7 gave a variety of other responses. One respondent did not provide an "Other" insurance type.

Does your health insurance cover services needed for your family member with ASD?

Response	Frequency	Percentage
No services are covered	44	18.6%
Some services are covered	137	57.8%
All services are covered	28	11.8%
Not Applicable	2	0.8%
Don't know/unsure	26	11.0%
Total	237	100.0%

Would you like to provide any additional comments about services you have received for your family member diagnosed with ASD?

It is apparent that the school system would like to ignore my child's intelligence and just baby-sit him. I am supplementing his treatments with insurance and personal payment of OT and Speech. The amount of OT is completely inadequate for sensory integration and other OT teaching (shoe tying etc). It is 1 hour every other week (maybe even in a group. I have an OT that sees him twice weekly with the sensory input - and she has been seeing him for almost 3 years. Fabulous progress has been made because of her work. The school system supplies speech therapy 1 a week in a group for 30 minutes. The ST is ambitious, young and enthusiastic. Her goals are appropriate and ambitious - the group setting is good for my son, as he doesn't want to speak when in groups with the regular classroom teacher. The Special Ed teacher, seems nice, but I am unsure of her capability to teach autistic children, especially ones that are bright. At this point, I am reserving judgment, but I am not impressed and I do not think
Neither ABA nor OT is 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.
Alabama is deficient in available services, and job training is non-existent.
All teachers and aides should be aware and trained as to what autism is and how to deal with it. ABA therapy should be taught too. I feel my child is just being passed on through school. She cannot do the work that they are giving her A+ grades on.
As a parent I find it exhausting to stay a step ahead of educational issues at his elementary school.
Basically, they threw their hands up on the air because they didn't know what to do with him, didn't care. 1 teacher let him watch Barney videos all day at school. The special education services in our school system SUCK. I finally had to sue the school system and he is now attending The Learning Tree in Tallassee, a school for children with autism, where he is FINALLY getting the support, services, therapy - that he needs.
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.
Because of Autism my child is no longer alive.
Because of the no child left behind act, children are not allowed to learn in there own way or at their own pace.
Because he is higher functioning, services have been a little easier to accomplish for our son. However, easier to accomplish is still a far cry from easy.
Burkett should not be the only option for special needs children in the Gardendale area.
... attended Brewer Porch Children's Center Preschool class. It was very good for him. He now attends a regular classroom with an aide, but is doing pretty well. Mainstreaming has been great for him socially.
Diagnostic services have extremely long wait list at a critical age range for starting therapy. Services at well qualified clinics typically cannot be waited for (it would have been 6 months later to even get into Sparks Clinic -- and then would have cost us $1,800 out of pocket). Instead, our family was referred to Children's Behavioral Health, and the psychologist was "educated" by us on autism. She performed the standard basic rating scales, took our compilation of why we believed autism was what we were dealing with -- and substantiated that conclusion. It was QUITE discomforting to know that if we were less educated (both parents have Masters degrees) or less self aware of our child's situation -- even the doctor would probably have missed the mark or taken her time reaching the mark.
Didn't know I had autism until my child was diagnosed and I began to read about it.
Early Intervention was great but not enough hours per month. We needed more. The eclipse program at public school is great but he is requiring more one-on-one assistance due to behavioral issues arising within the classroom setting. He needs more one on one speech, OT and behavioral therapy (ABA)/Counseling on how to handle his frustrations.
Early Intervention services were pathetic. Agency was not interested in autistic children; was more centered on children with cerebral palsy. Although I complained and begged, my child definitely did NOT receive needed services from time of diagnosis up until Kindergarten at public school. This was even in

addition to having employer sponsored insurance coverage.
... is very smart, but slightly lower functioning than his older brother. We tried and tried to get assistance with ABA therapy including a mediated IEP. This is the therapy that worked with our kids and we have had to eat the cost of the therapist and programs, and I have had to become the primary therapist for both my kids.
Even though services are provided in the school system, often they are not adequate to the needs of the child. Either poorly trained staff or not enough time available to meet the needs of the child.
Glenwood provides Classroom Observations in which one of their representatives comes into the school and observes teaching methods and gives input as to how these methods can be modified for the benefit of my ASD child.
Haven't received any.
He currently does not have an IEP and does not qualify for Special Ed. services so no services are provided thru the public school.
Her Dr. said she needed behavioral therapy-school system refused. I searched for over a year and found 1 at ins. expense, also receives speech therapy @ ins. expense. The special needs' services of our county & city are GROSSLY LACKING in services.
I fought for services and private paid for 2 years at Mitchell's Place. It was worth it. My son is doing great. Thanks for asking.
I found it humorous that you asked if my school had counseled ME about therapies. I definitely had to teach the teachers. I do not fault them that they didn't know how to help a child with autism, but I did fault them that they wouldn't listen to me. I had read more books, magazines, done research, had my own ABA teaching in my own home at my own expense, but they did not listen to me. Almost all of my child's progress was because of the work we did at home. Ironically, my daughter's education was coming along fine and she was learning until I put her in school. Then progress stopped and constraint frustration with the schools began. It was horrible. We now home school. I am so appreciative of the work being done now to get some services in our schools but I fear they will come only as my daughter is aging out of the schools system. PLEASE address in your work the children who are on the crest of this wave of autism. Thank you.
I have not received any other services that I know that I am entitled to like respite care along with a trained behavior aid.
I have extensively been in search for services with no luck.
I currently receive no services and have quit my job because I missed so much work due to having pick this child up and there is no after school programs in my area. My family cannot handle this child and will not keep them while I work. Their father and I are divorced. I have physical custody.
I had to threaten to sue Early Intervention to get some ABA therapy as he was only rcvd 2 hours/week of speech and OT therapy. I think Early Intervention should be forced to advise parents what they are legally required to provide their children. BC B/S Insurance needs to step up and cover ABA as well as increase amount of speech and OT visits allowed coverage throughout the year. It's not like my son just doesn't need speech and OT the last quarter of the year once their max limit is completed! I'm very happy with the resource program that is offered my son at Farley Elem.; however the school system (Huntsville City Schools) still has no behavioral therapists on staff to help provide the teachers with behavioral plans for the students.
I do not feel that the tri-county area offers enough services for my child. My son's pediatrician and psychologist have both recommended that we move to Auburn. I know someone who lives in Montana and her son receives 40 hours per month of free therapy.
I think parenting classes should be made available to parents of children at all ages, new classes for each stage they are entering. The parents just feel lost with no answers.
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.
It is EXTREMELY difficult being a parent of an autistic individual in THIS state because all of the support groups in this state are so fanatical (i.e. blame vaccinations, stick your kid in a hyperbaric chamber, take

wheat and dairy away from your kid, blame the government and then expect them to support you financially). We just want to find support that is RESEARCHED based--not quick-fix, fanatical based--and it would appear that we find that at Vanderbilt in Tennessee, but NOT in this state. We will love and nurture our son with autism, but we're not taking away wheat and dairy or blaming vaccinations when those haven't been scientifically and medically proven. We don't know if it is ignorance or hype that promotes these thoughts in this state, but we frankly can't wait to move. Rather than lobbying for bill makers to take wheat and dairy off of school lunch trays, we need to embrace our children and nurture and love them.
Lack of services or placement for individuals 18 years and above. These kids fall through the gap.
More ideas or groups to be formed in our area.
most physicians do not know how to test a child with asd, other test are needed that will not show up through traditional testing. some EEG can't be done because the child will not keep the wires on or cap on. More technology are needed to help better testing for children under the asd spectrum.
my child needs OT three times/wk. all he gets now is an evaluation, per request, and ideas for the teachers/aides. I want the OT to see him.
My two sons have been suffering over the years with Autism (ASD). Lack of services in our state has caused a tremendous amount of stress on our family. Having to fight for services has been overwhelming. When my sons were diagnosed with ASD no one knew much about this disorder. Doctors did not know how to treat them medically. They didn't have information, so leaving them without the proper treatment they had to go without treatment and therapy that could have improved their lives. There needs to be more Autism Specialists recruited to this state to help ASD children.
My son has received very little help from Early Intervention. He needs at least 2 hours a week of Speech Therapy and qualified for 1 hour per month from EI. He needs at least 1 hour a week of OT and qualified for 1 hour per month from EI. He needs 30-40 hours per week of ABA therapy and that is not provided at all from EI. I am very frightened at the prospect of him attending the preschool in my district as their services are far from adequate for any child with ASD. 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. It is time for a change, it is time these children get the help they so desperately need and deserve.
My daughter was not diagnosed with autism until the age of 12 years old. It was very hard to make that call because her blindness played a big roll in sameness between her blindness and autism. No one could really pinpoint it until she was older. Doctors hated dealing with her because she was a handful. Very aggressive. But she has come a long way. The Learning Tree has helped her so much. Pat Murphrey is wonderful. Very dedicated to those children. They have helped my daughter so much. You cannot fill these papers out too good without explaining things that have taken place over the years. It is very hard to pinpoint hours, months, days.
My first child has been at Churchill Academy, a private school for children with learning disabilities for 4 years because the public school system does not care about these children, does not care if they succeed, improve, get better - it's just a job to them. Churchill costs a lot of money, but there is no where else I can put him and he has thrived there. Sad that I my tax dollars are paying for mediocre schools, poor personnel.
My child has not had a professional who understands AAC devices and therefore - a $4000 device is used minimally and really - there is no support. T.A.S.C. in Huntsville has been the only real support and provider of critical information so that at least at home - communication is successful. However, the school system is reluctant and won't pay the fees for the training to support my child's communication in the educational setting. Now that my child is 15, we are tired. The battle isn't worth fighting. The school system has too many excuses and poorly prepared teachers.
My son goes to Mitchell's Place and receives wonderful care there.
My children are on opposite ends of the spectrum. I feel that we could have received more services for my second son but did receive more than most. Still not enough...

My concern now is whether there will be services for my child in 3 years when she is mainstreamed into the 'real world' and out of high school. Huntsville currently has a 6 year waiting list, which is simply unbelievable. This state has a lot of work to do....and quickly!! My daughter is of the age where nothing has been there for her. No early intervention, etc. I need this state to be there for her when she becomes an adult.
My son is quite high functioning, but he still requires help in some areas. I work full time and he can't drive and it would be wonderful if there were some type of transportation service available that would enable him to travel to work and to school without him having to rely on others. He would feel so much better being able to do some of the things that other teenagers and young adults do.
My daughter is on a waiting list for a wavier. to cover the cost of ABA services. That school or insurance WON"T cover. I mainly won't ABA covered but have applied for other services as well.
need more info about what is appropriate for a child with high functioning autism. also need more info about services past high school.
Needs social skills/job preparation training. Alabama Department of rehabilitation Services has been of no help.
No, looking for any services available, I am really concerned about the future and the lack of services available. It is even difficult to go to church because of no services. I am also interested in year round school services and a more appropriate program for children with severe autism spectrum disorders.
Not much is available in the area without having to drive to Birmingham. I have had extreme difficulty getting extended school year services for him.
Number and type of medications have greatly affected his personality. I do realize that they may be needed to control his behavior. Due to aggressive behavior, he was placed in residential school at age 10.
Our state and school system are greatly lacking in support for our kids diagnosed with ASD.
Our son is 36 years old. He never received early intervention services. He attended special education public school from 5 years to 15 years, and then was placed in residential school/home setting at Glenwood in Birmingham after spending some time at Bryce for behavior problems. We got very little support from our town or community. He now resides in a group home (The Learning Tree). His diagnosis was made after he had started school, although we knew from reading books, etc., that he was autistic.
Our oldest child has a diagnosis of Asperger Syndrome and has always been very verbal and fairly independent. However, our youngest child of nine years old who has a diagnosis of High Functioning Autism is quite different. He is in the general education room at school with a resource teacher in the classroom at times. This was accomplished only after MUCH insistence on our part and bringing in our child's psychologist and an Autism consultant. His resource teacher's training is in speech and hearing impairment. She does not have much of a background in autism. We feel the staff in general is much need of training in how to teach children on the autism spectrum. In an ideal situation, there would be an autism specialist at least within the system to provide guidance and service training.
Our initial school system, Anniston City Schools, is woefully limited on their ability to provide services and support for mildly autistic children. They tend to hide behind No Child Left Behind, and focus more on making sure our child takes and passes state tests so that funding for general education can continue to flow. Our new school system, Calhoun County Schools, has a self contained autism unit and provides varying services to a broad spectrum of children. Our child is in a regular education classroom with the exception of a 1-hour pull out to address his ASD needs. All staff members in the school seem to be aware of children with special needs and they all work collectively to ensure those children that need extra support get what they need to help them grow and learn.
Overall, my impression of what is being done medically and, especially, academically to benefit children with ASD in Alabama is exceptionally poor. Alabama is my home state and I love it, but when it comes to what is being accomplished for the good of children with ASD, and their families, I am disappointed to say that Alabama leaves a lot to be desired.
Public Schools are not equipped to handle children with ASD. All they could provide was Speech Therapy and Special Education Services. The teachers are not trained to handle children with ASD and they have

too many children in the classroom.
Requiring insurance companies to not exclude proven therapies for ASD on policies should be legislated as other states have done. Additionally after school care for children with ASD and other disabilities is desperately needed. Currently children loose this school sponsored care after age 12. Traditional dare care settings are often not appropriate for ASD adolescents.
Services are inadequate, often unavailable, expensive - mostly not covered by insurance, and not well advertised.
Since my son was 3 years old I begged doctors to help me with his unusual behavior and moods and it took 10 years and moving to Alabama for the diagnosis of Asperger's and now we are dealing with it is a little late for intervention.
Speech Therapy and Sensory Integration prior to starting public school.
Sure.
Sure.
The services provided through the elementary school years was very good. However, it seems with middle school, there are needs that are not being met (study skills, how to organize, etc.). Our child is not a behavior problem at school, therefore, he is not "on the radar" at school. However, once he gets home, he is extremely anxious and high strung and upset about school work in general. Because the teachers do not see this behavior at school, our requests for services related to organization, study skills and PRACTICAL social skills training is met with much resistance.
The positive comments about services apply only to the current school my son attends, Oscar Adams Elementary School in East Gadsden, AL. Before that, he attended two schools in the same district and two schools in Georgia. While many of his needs were not taken seriously because he excels academically and only has and IEP for consultation/as needed services, the staff at Oscar Adams has been very cooperative about accommodating certain things like telling him to go to the toliet after meals (he has encopresis) and ignoring abberant but nondisruptive behavior in the classroom.
The Early Intervention team in Florida dropped the ball in terms of diagnosis. I started noticing things when my son was 4 months old. I am a professional social worker, and worked with children most of my career. They disregarded my concerns as being just a nervous mother.
The school system has not been helpful. Only got services after contacting ADAP but school still has negative attitude and I am scared they will kick my child out of school.
The Huntsville Rehabilitation Center as well as the Public School System in Huntsville are in need of qualified professionals who understand and can provide the appropriate education and training for people with Autism. The adult Autism population in the state is in desperate need of qualified support services that specialize in the disorder. There are not presently any support services in Huntsville that understand how to provide services for the adult autism population. The Alabama Dept. of Rehabilitation needs qualified professionals who understand the disorder as well. In total I have not been happy with the quality of services provided to my son. There is in general a basic ignorance and lack of understanding of this disorder by service providers in the state. This needs to be addressed by the Governor and the Legislature. Qualified support services must be provided for these people.
The school system is very disappointing. You are trying to do what is best for your child, but the schools won't work with you.
THE SERVICES WE RECIEVE FOR OUR SON IS NOT GOOD ENOUGH FOR HIM BECAUSE WE DONT HAVE SERVICES FOR AUTISTIC CHIJDREN IN OUR TOWN SPECIALLY UNDER 5 YEARS AND THE NOMBERS OF THE AUTISTIC KIDS ARE INCREASING AND WE NEED HELP IN THIS AREA BECAUSE THE CLOSEST SPECIALIZED ONE IS 1 HOUR DRIVING AND WE NEED SPECIALIZED PLACES FOR AUTISM HER . THANK YOU.
THE SCHOOL DISTRICT IS TERRIBLY UNPREPARED FOR INCLUSION OF CHILDREN WITH SPECIAL NEEDS. DESPITE THE LAWS IN PLACE PARENTS ARE FORCED TO SPEND HOURS AND HOURS DOING RESEARCH AND TRAINING TEACHERS, FIGHTING TO IMPLEMENT SERVICES THAT ARE SO NEEDED BY OUR CHILDREN.
There are no transition services available for our adolescents anf young adults. With their diverse skills & weaknesses these services are critical for them to become valuable citizens in our communities.

There should be stricter rules regarding pre-school children and insurance companies.
There wasn't enough early intervention provided. If I had not fought to get my son in Goodwill Easter Seals before the age of 3, he wouldn't be as far as he is. We provided as much of our income as we could for outside ABA services and therapies and couldn't continue. There needs to be more, more services for our children.
There are not a lot of service providers. If son does receive services it is under a different diagnosis. I am surprised that Autism is not covered for Children's Rehabilitation Service.
traditional services received did not help him the most improvements were from some changes in diet and some biomedical treatment, but these services are not covered by Medicaid.
Very hard to get any adult help for high functioning Asperger's, almost impossible.
Vocational Rehabilitation Services (August 1996-January 1997). First experiment with medications. Spiraled down hill for 9 years on and off medication. Mental Health (ACT team) multiple medication several commitments to Hospital Mental Ward and Mental Health facilities. Lack of knowledge or limited knowledge of ASD by health care.
We appreciate the help we have received. Everyone has been wonderful, but we feel a little lost when it comes to doing everything we can for our son. We know that there are lots of things you can do for autism, but are unsure what steps we need to take. We live in a very small town and feel there's just not enough services for autism. We are concerned that we may need to move to a larger city to give him the best chance for the treatment he needs.
We are currently receiving services through a private school and are not receiving any services through the school system.
We have found it very difficult getting the proper evaluations to aide in getting the proper interventions in place for our son. We had concerns since he was eighteen months. Pediatricians here in Alabama (and we changed several times) told us that "He's a boy.". We wasted a lot of time and continue to have difficulties finding the proper resources for a four year old. The school system has been extremely difficult to navigate.
We had to take our school system, St. Clair Co, to mediation in order to get the proper services for our son. They paid for him to go to Mitchell's Place for K-5 (which was a wonderful experience)but currently is in first grade in the school system where we have had numerous problems. They have even suspended him from school in which has resulted in getting the school board and our lawyer involved AGAIN. They simply do not understand ASD.
We are currently in a school with a great teacher and principal. Because my son's autism is so severe, the time the teacher is spending on the Alternate Assessment (which is exposing him to academics, NOT helping him develop "developmentally") coupled with the very limited (15-20 min)/day of ABA he is receiving and the more limited speech and OT, he is making little to no meaningful progress. Just another note that my son's autism began as very mild and he did make progress during the intensive intervention we did during the preschool years. He suffered a horrible regression and is now very severe.
We received 12 weeks of intensive behavioral therapy out of state. Our BC/BS covered 100%.
We do private ST & OT in addition to school services. It has been difficult to find quality therapists with experience in various modalities. Those speech therapists that are qualified seem to have long waiting lists. We have also done music therapy in the past.
When you make $48,000 per year and your out of pocket medical expenses are $24 to 26,000 per year it makes it difficult to pay for housing, food, and other basic needs. But when you apply for Medicaid or All-Kids your application is rejected before its really looked at in-depth, because your income exceeds limits for the program. PLEASE do something to help families with ASD kids afford proper care for them. I know of many more families in the same financial crunch that we're in, and that's just the truly medically necessary care, NOT the things like ABA that I'd like to get for my kids.
Yes, you fail to ask WHO is paying for these services. For the vast majortiy of Johanna's life, we have paid for training and support (Lovass, auditory training, tutoring, Kirkman vitamins, etc.). VOC rehab has been inneffectual, even though we have a very capable young adult (reads, writes, math skills, computer skills, social and athletic skills, etc.) She is "too fast" for alot of special services, but "not fast enough" to keep up with mainstream society. She "falls between the cracks". We were even told by "professionals"

to discontinue some of our teaching /tutoring / OT /other therapies so she would "fail" and the system could then serve her better. She is currently volunteering in a library and in an office setting. Please contact me with any quesiotns. Thank you, Dr Stef Eisen (xxx-xxx-xxxx).
Although I make 48,ooo dollars a year, when I spend 28,000 of it on items/services directly related to my 2 children with ASD, I really make 20,000 and should get Medicaid for my kids, but I don't!!! And it stinks!!!
Just to clarify about insurance - health issues are covered, but if a doctor indicates that our son's diagnosis is autism, even if it's for a cold, it comes back NOT COVERED!
Please help!
Public Schools need to be more educated about Autism. Educators I hae encountered have no idea how to teach autistic children (admittantly). It frustrating to me as a parent to have to educate them every year on how to educate my daughter. It is exasperating. I am a mother of six and we own our own business. Why can't they take the time to educate themselves about their students? Mine is not the only autistic child to ever walk through their doors and she won't be their last. If I ran my business like that...not knowing the needs of my client...I might be out of business. It is not my job to teach them about autism. Sorry for the rant!
She is still not in public school so we are in the preliminaries dealing with services. I am worried that our Public System will not be able to meet her needs. She only receives speech therapy and there is so much more out there that could help her. It's very frustrating!
there is a serious need for AFTER SCHOOL Care for childern still in school, while parents work. There is a need for ABA therapy In Montgomery,AL- Insurance Company's such as BLue Cross BLue Sheild of AL need to cover cost ABA services and other services related to AUTISM. Currently only FEW MENTAL HEALTH services are covered at 80 % and other are not even covered at all. We also pay a lot on suppliments and vitamins. Please Help!
We have been to specialists from here to CA. Have had all types of testing done. Bottom line . . . "Where are the services for ADULTS with Autism. Everyone is all of a sudden children - early intervention - (I said this 20 years ago!). There is an extreme need for our adult children -- besides sitting in day care making beds! Would you want your children doing this for their career? Presently, there is this huge influx on Autism and "early intervention." Please focus on our kids that have never been a focus and are forgotten by "early intervention." We need jobs and programs that are appropriate! Not a waiting list for residential baby sitting!
We are very unhappy with the school my son is currently in. We would like to relocate him to a school out of our district (the school he is at now is out of our district too), which would be more condusive to a positive learning environment! The school he is in now (and school board)is not supporting us in this decision. He is FAILING and we do not feel that they are doing everything they can do to help him succeed!
We have to private pay for ABA therapy which is desparately needed for a good portion of children with ASD and it is very expensive!
When Travis was diagnosed there was not a "qualified teacher or classroom" for him. It has taken us a LONG 5 years now to get the program that we now have. Now...his IEP's take about 4 or 5 hours and we go over EVERYTHING!!!
will never send my child back to Burkett center. People with children with autisim living in jeff. county should be careful and be aware of how awful they can treat and do your child and get away with!
yes!!!
I have always had my son in necessary therapies and have had a hard time finding good resources in alabama dothan area
ABA therapy is not covered nore is any other type of therapy. Early intervention only comes 1 time a month and I still have to pay for speech therapy. All programs are full and no waiting list and heis only 2 years old
schools need more training teadhers should be better prepeared, smaller classrooms, more forthcoming discussions instead of hiding necessary information pretaining to my child
what really helped my child was a greenspan floortime therapy. also meeting with an experienced person

weekly to discuss my individula child
I wish that insurance would cover more programs I wish we had a school that was especially for children with ASD
IN MY AREA HERE THER IS NO SERVICES FOR KIDS WITH AUTISM SPICIALLY UNDER FIVE YEARS OLD
Nephew live in MI , MI Public has much better understanding/services for kids on the ASD
the Shelby County Schools have not hired teachers for the last 2 years who seem to know how to teach young children w/ASD
the school system is supposed to provide education with typically fxning peers, however, classroom only has special needs kids; my child is picking up more autistic traits, so i'm cutting back & using daycare
There are no services provided in the town where we live. Some services are available in Birmingham,(Mitchell's Place) But the ones that my son would greatly benefit from are not covered by his medicaid. The school where he attends provides service for multi needs children, not for children with autism. If AUTISM had been recognized early on in my son he would have received early interventions that would have better prepared him for the future. But his doctor was not equipped with the right tools & knowledge to diagnose it. Please help JOSEPH to get the help he needs to improve his quality of life
I think it is essential for the state of Alabama to recognize the growing needs for children with autism. This children and their families require an extraordinary amount of support both physically and emotionally. Also I think pediatricians should be made aware to recognize the symptoms of autisms. In my case I knew my son was having developmental problems; I addressed this with my pediatrician, but she was not familar with the signs of autism. Fortunely I was able to get involved with Alabama Early Intervention. He was two years old when he started and he has helped him tremendously. Additionally, I think their should be support organizations in every county to address the needs of autistic children. He should part of the mental health or the health department. Their these department should have skilled autism educators who offer information and treatment options. I still have not had any one to explain gluten and casin free diets and I would like to know more about the diet. Also more information on allerg
THERE IS NOT A SUITABLE CLASS FOR MY DAUGHTER, REGULAR CLASS TOO HARD AND MD CLASS TO LOW FUNCTIONING
I knew at age 2 something was wrong - clinical results indicated delay but declined services until age 3 (I feel it was downplayed as they did not suggest we be proactive but "wait and see") AUM Speech and Hearing Clinic was caring, compassionate, and dedicated when she reached three YO. The public school system has proved to be the opposite. The first year of school we were unprepared, uninformed and trusting. However, after being told our child was "borderline MR", yet being denied special services because she "didn't qualify", we sold our home and moved. A new city and school system made things better with each passing year, until 7th grade. The most disheartening fact is knowing that, six years later, regardless of the IEP's, test results, pediatric neurological diagnosis, etc., we will continually be forced to demand the services to which she is entitled be provided. Transition to JH has been extremely difficult. Much of the first five weeks I camped out in the office demanding answers as to why th
Our pediatrician was not trained to diagnos ASD. Therefore, early intervention was never an option, as we did not know the warning signs for Autism. After his 3-year well check-up, our pediatrician referred us to early intervention. At that time, our insurance did not pay for speech therapy; despite the fact he did not qualify for early intervention and public school services were not available to us. Private pay speech therapy was very expensive. Our son was evaluated three times before a diagnosis was made. This was also very expensive. We also did occupational therapy for sesory integration. This was/is not an option through our public school system even though the benefit are experienced in the classroom. We have spent countless hours educating ourselves from the internet/reading and networking with professional and other parents. We have had our IEPs violated, with little or no concern from the public school system. We have witnessed/experienced services interrupted without any concern from th
Prayer Ministry and church
we have been doing private ABA therapy since my son was 2 1/2 with speech and OT, early intervention was terrible and just started with the city schools, just OK
public school system needs more resources for school-aged children with autism. Preferably a school

This child does not receive any additional services beyond special education placement in public school
Alabama is WAY BEHIND. We moved here from Texas where we recieved early intervention, preschool services and multiple services through public school. We moved to Alabama and basically have been told that because my child is high functioning and not causing a problem in class that we don't need services and that they wont provide them. We've seen speech gains lost because the school wont provide speech therapy, my son miraculously just passes the school-given testing by a couple points and then they deny all services. After 3 years of speech therapy in texas preschools and clear speach, Alabama denied speech therapy, 1 year later i'm having to ask my own son to draw or write what he's saying because the schools have done NOTHING to maintain our gains. Same with Occupational--teachers complain about his writing but SPED says he doesnt need OT services, now he's declining even further. I have to go outside and pay for testing to contradict the crappy testing given in schools and wow! we always have very differen
Public schools don't want to help
We were told to do things for our first child, but received no help providing the treatment and the most helpful intervention, ABA we had to pursue do and pay for and still do totally out of pocket neither the ins. co nor the school system help
Once the diagnosis was obtained, Early Intervention was absolutley wonderful. Unfortunately, we tapped out our private insurance on physical therapy, occupational therapy and speech therapy before we even found out about Early Intervention. It was during one of his final physical therapy appointments when he was 2 1/2 that a physical therapy student asked if we had heard of Early Intervention. Not a single doctor had ever mentioned it and his regular daycare provider had never heard of it. If there is one problem with the system, it is that Early Intervention is not publicized enough. I know that the information is not out there because of our personal situation, but also through my profession. I am an employee with the public school system and I see children all the time who come into kindergarten with severe problems who have never had services and who would certainly qualify. My second problem comes with the public school system. He is not receiving services that will prepare him for life. The system is
My child was 2 when we contacted Alabama Early Intervention due to his lack of speech. He was diagnosed with a speech delay and sensory integration disorder. He began to receive speech and occupational therapy for this. We did take him to a neurologist in Atlanta who did not seem to think there was anything wrong with him except for the speech delay. After he turned 3 and still had not improved much and was receiving services from the school system, we took him back and the neurologist suggested ... be tested for an auditory processing disorder. I want to say that each time we went to this particular doctor, she never once tried to explain what was possibly going on with our child. All she said was he was not autistic but had autistic behaviors that most children all have at that age. With the recommendation for him to be tested for the auditory processing disorder, the Head Start he was attending was able to have someone come in and evaluate .... It is at this time we were given the diagnosis of au

Appendix E

Questions Used for Key Informant Interviews

Alabama Autism Needs Assessment
Key Informant/Follow-up Questions

1. What is your role or relationship with individuals with Autism Spectrum Disorders (ASD) in Alabama?

2. How do you define Autism Spectrum Disorders?

3. What do you believe are the three greatest strengths or resources of the current system of care for individuals with ASD in Alabama?

4. What are the system's 3 most prominent weaknesses or needs?

5. What information is currently available for the population with ASD in Alabama?

6. What information is needed to identify and meet the needs for individuals with ASD in Alabama?

7. How can the needed information best be gathered?

8. What groups or individuals should be involved to best assess the needs for individuals with ASD in Alabama?

9. Other comments or issues that should be addressed in assessing the needs for individuals with ASD in Alabama?

Appendix F

Glossary of Terms

Acronyms & Abbreviations

Glossary of Terms

Adaptive skills	Skills needed for everyday life (bathing, dressing, etc.)
Ages and Stages Questionnaire	A screening tool for developmental delays in early childhood (birth to 5).
Alabama Autism Collaborative Group (AACG)	An interdisciplinary and inter-university collaboration with the responsibility of conducting the Alabama Autism Needs Assessment.
Alabama Council for Developmental Disabilities (ACDD)	A state advocacy organization with the mission to serve as an advocate for Alabama's citizens with developmental disabilities and their families; to empower them with the knowledge and opportunity to make informed choices and exercise control over their own lives; and to create a climate for positive social change to enable them to be respected, independent and productive integrated members of society.
Alternative medicine	Biomedical, supplemental, and dietary interventions
Applied Behavioral Analysis (ABA)	A method for changing behaviors and is based on principles of operant and respondent conditioning.
Asperger Syndrome	One of the three conditions considered a Pervasive Developmental Disorder and an Autism Spectrum Disorder. Social and behavioral impairments exist, usually with no social or cognitive delays.
Autism	One of the three conditions considered a Pervasive Developmental Disorder and an Autism Spectrum Disorder. Substantial impairment in social interaction and communication are present. Restricted range of interests and unusual behaviors may also be present.
Autism Program Quality Indicators (APQI)	Developed by the New York Autism Network; guide for self-review and quality improvement evaluation for schools and programs for students with ASD and evaluates various aspects of an individual's life
Autism Spectrum Disorders (ASD)	A group of neurobiological and developmental disorders that cause substantial impairments in social interaction and communication. Individuals affected by ASD often have restricted range of interests and unusual behaviors. ASDs can be detected as early as 18 months of age and last throughout a person's life. ASD occurs in all racial, ethnic, and social groups, and it is four times more likely to occur in males than females. ASDs include: Autistic Disorder, Pervasive Developmental Disorder-not otherwise specified, Asperger Syndrome, Childhood Disintegrative Disorder, and Rett's Syndrome.
Behavior modification	Can be used to decrease nonproductive behaviors and increase adaptive and positive behaviors. Behavior modification is not limited to ABA, but rather includes cognitive-behavioral strategies and pharmaceutical interventions (The Autism Encyclopedia, 2005)

Building Based Student Support Team (BBSST)	A school-based, problem solving team. Group members discuss issues related to specific needs of students' teachers and offer assistance in resolving problems. The team is composed of teachers, administrators, counselors and other individuals as needed, including, but not limited to, attendance officers and representatives from Nursing Services. Teachers receive support when confronting specific academic, social, and/or behavioral concerns regarding students.
Case management	A paid service that helps individuals and families coordinate and advocate within health care and resource systems.
Childhood Disintegrative Disorder	A Pervasive Developmental Disorder that resembles autism, but with an age of onset prior to 10 years (typically between 3-4 years)
Communication & Symbolic Behavior Scales Profile (CSBS)	A screening and evaluation tool that measures communicative competence of children with a functional communication age between 6 and 24 months. Administered by a trained professional.
Community/family forum	Data collection method consisting of guided discussion among volunteer participants, in this case, caregivers, family members, and individuals affected by autism.
Developmental Disability	The term developmental disability means a severe, chronic disability in an individual five years of age or older that: is attributable to a mental or physical impairment or a combination of mental and physical impairments, is manifested before the person attains age 22, is likely to continue indefinitely, results in substantial functional limitations in three or more of the following areas of major life activity: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, economic self-sufficiency, and reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated. In infants and young children: an individual from birth to age 9, inclusive, who has a substantial developmental delay or specific congenital or acquired condition, may be considered to have a developmental disability without meeting 3 or more of the criteria described in 1-5 above if the individual, without services and supports, has a high probability of meeting those criteria later in life.
Diagnostic Statistical Manual-IV-TR (DSM-IV-TR)	The American Psychiatric Association's manual of mental disorders
Disparity	Different or unequal
Effectiveness	Measure of how well something (e.g., a treatment) does what it is intended to do.
Epidemiology	Study of incidence, distribution, and contributing factors to a disease.

Focus group	A method of collecting data in which a small group (ideally 8-12 participants) participates in a guided discussion using a series of questions related to the topic being studied. In this project, providers, caregivers, family members, and individuals affected by autism participated in focus groups.
High-functioning Autism	A form of autism in which the individual has average range IQ.
Individualized Education Program (IEP)	A comprehensive document for students in public school systems written by a team of educational professionals and parents and that is reviewed at least annually. The document contains present levels of educational performance, future goals and benchmarks, special education services needed, dates, frequency, and duration of services.
Interdisciplinary	Two or more professional disciplines.
International Classification of Diseases -9 (ICD-9)	The World Health Organization's official system of assigning codes and procedures for medical use.
Key informant	An individual who contributes to data collection by providing special knowledge regarding a specific topic, in this case, Autism Spectrum Disorders.
Mental Retardation	Overall impairments in intellectual functioning and/or adaptive skills
Minority group	Black, Hispanic, or other, as used in this report
Pervasive Developmental Disorder, Not Otherwise Specified (PDD-NOS)	A general designation for a group of disorders that impact multiple areas of functioning. PDD-NOS includes Rett disorder, Childhood Disintegrative Disorder, Autism, Asperger Syndrome, and Pervasive Developmental Disorder-Not Otherwise Specified.
Respite	Care for an individual with the intent of providing temporary relief to the caregiver
Rett Syndrome	A Pervasive Developmental Disorder that is progressive and degenerative syndrome is similar to autism. It is reported to affect only girls.
Scientifically backed	
Transition	Process of changing settings (e.g., inside to outside) or events (e.g., circle time to playground) or stages of life (e.g., high school to adulthood).
Visual supports	Tools to augment communication and self-expression.

Acronyms and Abbreviations

Alabama Autism Collaborative Group	AACG
Alabama Autism Task Force	AATF
Alabama Council for Developmental Disabilities	ACDD
Alabama Department of Rehabilitation Services	ADRS
American Academy of Pediatrics	AAP
Applied Behavioral Analysis	ABA
Asperger Syndrome	AS
Association of University Centers on Disabilities	AUCD
Autism Program Quality Indicators	APQI
Autism Society of Alabama	ASA
Autism Spectrum Disorders	ASD
Building Based Student Support Team	BBSST
Carolina Living and Learning Center	CLLC
Center for Autism and Related Disabilities	CARD
Centers for Disease Control	CDC
Communication & Symbolic Behavior Scales Profile	CSBS
Department of Mental Health/Mental Retardation	DMH/MR
Diagnostic Statistical Manual	DSM
Early Intervention	EI
Early Periodic Screening, Diagnosis, and Treatment	EPSDT
Extended School Year	ESY
High-Functioning Autism	HFA
Indiana Resource Center for Autism	IRCA
Individualized Education Program	IEP
Individuals with Disabilities Education Act	IDEA
International Classification of Diseases	ICD
Learning Experiences: An Alternative Program for Preschoolers and Parents	LEAP
Lovaas/Discrete Trial Training	DTT
Mental retardation	MR
New York Autism Network	NYAN
Occupational therapy	OT
Office of Vocational and Educational Services for Individuals with Disabilities	VESID
Ohio Center for Autism and Low Incidence	OCALI
Pervasive Developmental Disorder, Not Otherwise Specified	PDD-NOS
Physical therapy	PT
Pivotal Response Training	PRT
Relationship-Development Intervention	RDI
Responsive-Teaching Curriculum	RT
Socio-economic status	SES
Treatment and Education of Autistic and Related Communication Handicapped Children	TEACCH
University Center for Excellence in Developmental Disabilities	UCEDD
University of Alabama	UA
University of Alabama at Birmingham	UAB
University of Alabama Autism College Transition and Support	UA-ACTS
Vocational Rehabilitation	VR
Young Autism Project	YAP

Appendix G

Questions Used in Focus Group Protocol

Alabama Autism Needs Assessment
Focus Group Protocol Questions

1. Autism Spectrum Disorders are a group of biologically based neurodevelopmental disorders characterized by impairments in socialization, communication and behavior. What is the first thing that comes to mind when you hear “Autism Spectrum Disorders”?

2. Think back to when you first became involved with or heard of Autism Spectrum Disorders. What were your first impressions?

3. How satisfied are you with the availability of services for individuals with Autism Spectrum Disorders in your area?

4. What are the barriers in trying to access services for individuals with Autism Spectrum Disorders?

5. What efforts should be taking place to improve the availability and accessibility of services and supports for children, youth, and adults with Autism Spectrum Disorders?

6. Who should be responsible for financing such efforts?

7. If you had a chance to give advice regarding what the Alabama Autism Task Force should recommend to the Governor and other decision makers, what would that advice be?

8. We wanted you to help us understand more about your experiences with supports and ser vices for individuals with Autism Spectrum Disorders and their families. We want to know how to improve availability and accessibility of these services. Is there anything that we missed?

9. Is there anything that you came wanting to say that you did not get a chance to say?

Appendix H

Summary from Key Informant Interview Responses

Definition and characteristics of Autism Spectrum Disorders

- Medical interpretation (ICD-9 codes)
- Psychological interpretation (DSM-IV-TR)
- Educational interpretation and eligibility (Alabama Administrative Code)
- Non-diagnosed individuals exhibit symptoms
- Neurological disorder
- Signs and symptoms are expressed in a variety of ways
- Group of illnesses with presenting developmental delays
- Can be confounded by mental retardation
- Specific diagnostic tools and clinical judgment are used to diagnose
- Sometimes referred to as a communication learning disability
- Lifelong
- May affect sensory system
- May have significant behaviors
- Pervasive Developmental Disorder
- Difficult to define broadly—different systems of care have different eligibility requirements and definitions for Autism Spectrum Disorders.

Strengths and Weaknesses

Comments regarding specific efforts towards public awareness and increasing statewide services were mentioned as strengths. Additionally, key informants listed specific examples of providers, both public and private, that provide services to individuals with Autism Spectrum Disorders:

> Autism Society of Alabama, Glenwood, Inc., , University of Alabama in Tuscaloosa, University of Alabama at Birmingham, the Alabama Autism Task Force, Mitchell's Place Auburn Autism Center, parent advocates, Early Intervention, Children's Rehabilitation Service, Easter Seals, national attention currently surrounding autism, individuals in state government that have relatives affected by autism and supportive of reforms,, public awareness, Alabama's University Center for Excellence in Developmental Disabilities, Education, Research, and Service (UCEDD) and MCH LEND Project at Sparks-Civitan Clinics, Department of Education, research being conducted at major universities in Alabama, respite care services, diagnostic services (public and private), Dossett Clinic, The Riley Center, The Learning Tree, The Little Tree, Family Voices, ChildFind, Children's Hospital

Key informants noted the geographic disparities that exist within our state when it comes to autism service provision in every major system of care in Alabama. They also identified weaknesses in quantity of services able to be provided by the relatively few autism service providers in the state. Other identified weaknesses include difficulties in obtaining: vocational services, employment, transition services, transportation services, services for adolescents and adults, mental healthcare services, supports for activities of daily living, and insurance reimbursement for therapeutic services. In addition, key informants reported that it is difficult for many individuals and families affected by Autism Spectrum Disorders to find advocates within respective systems of care, to

manage legal problems, and to support individuals as they complete school. It was also noted that the system of care is poor and fragmented in Alabama—eligibility requirements vary among systems of care, making it difficult to obtain a comprehensive and coordinated system of care.

Information Currently Available

Key informants reported that the Autism Society of Alabama provides information and referral services statewide. Individual service providers were reported to provide information on local services that may or may not be specific to Autism Spectrum Disorders. National resources (e.g., the American Academy of Pediatrics recent screening guidelines) were reported as other sources of information. It was noted that there is not enough information regarding Autism Spectrum Disorders available in Alabama.

Information Needed to Identify and Meet the Needs

Key informants noted that a coordinated effort and system of care is needed to identify and meet the needs of individuals affected by Autism Spectrum Disorders. They mentioned needed information regarding: training centers; comprehensive treatment centers; familiarity with early warning signs, diagnostic tools and EPSDT; knowledge of rights in public school system, transition services between systems of care, and treatment options for individuals with varying degrees of symptom severity.

Key informants also reported needing information regarding:

- Number of individuals in Alabama with an Autism Spectrum Disorders
- Cost per person for services (at different ages)
- Current available services through various systems of care (e.g., educational system)
- Extent of the urban and rural disparities regarding services
- Which interventions are scientifically proven to be effective at varying ages
- Outcomes for various interventions and services provided
- Number of individuals in hospitals, jails, and nursing homes affected with Autism Spectrum Disorders

Method for Gathering Needed Information

Key informants recommended funding a comprehensive system of care for individuals affected by Autism Spectrum Disorders to gather, distribute, and apply information. Data collection from the various systems of care (e.g., educational system, mental health system, rehabilitation system, insurance systems) was another recommended method of gathering information. Key informants suggested the inclusion of the Alabama Autism Collaboration Group, families, and clinicians in this endeavor. It was also suggested applying for grants to fund these projects.

Other comments:

- Insurance coverage needs to be examined.

- Information about autism needs to be included in programs of study at the undergraduate and graduate levels, especially in the programs for education, psychology, and medicine.
- More support and training should be given to primary care doctors regarding developmental assessments and medicine management, need to know how to use meds with this population.
- Look at other comprehensive systems of care as models for autism.
- We spend a large amount on residential care for this population.
- We need to look at the age of transition in the educational system in Alabama.
- Funding is essential.
- We need a Medicaid Waiver for ASD not only through mental retardation eligibility.
- Case management is critical. Service coordination weakens as the child ages.
- Individuals with ASD are isolated.
- We need to use evidence based interventions, that will help all kids not just those with autism.
- Look at common co-occurring conditions in individuals affected by ASD.

Appendix I

Summary from Focus Group Responses

Early Intervention Top Themes

1. **Increased education and training for service providers, communities, and families.**
2. **Address regional disparities by using regional centers to provide services (i.e. diagnostics, respite, parent education, service coordination, parent mentorship, technical assistance)**
3. **Improve collaboration among systems (Early Intervention & State Department of Education) for transition and planning purposes, and to help address eligibility differences for services in each system.**
4. **Need for increased funding.**
5. **Increased emphasis on long-term functionality.**

Early Intervention Summary Themes

- Difficulty getting accurate count of individuals with autism
- Difficult assessing eligibility—especially for Asperger's or High Functioning Autism since social functioning is most affected
- Qualification criteria for services is different depending on the system, making transition difficult
- Need for autism screeners
- Funds are being cut, but more money is needed to serve these individuals
- Families have typically just entered the EI system when it is time to transition into the school system
- Regional disparities
- Need to teach generalizing skills
- Childcare providers need support & training—how to work with children affected by ASD, how to access resources, how to communicate with parents if concerns arise
- Cost of in home service is high
- Time constraints on in-home visits and travel time
- Many children are multi-needs
- Many kids with autism are in residential centers at high cost to state per year (approx $200K per year)—some need 24/7 supervision to manage self-injurious behaviors, etc.
- need to put more money and specific trainings into EI
- Need consistent pre-K services available statewide
- Increased focus on long-term functionality
- EI is one of the only systems mandated to serve kids with Autism Spectrum Disorders
- Disinterest from other providers not mandated to serve kids with autism
- Developmental screenings will mean more referrals—do we have the capacity to serve this population in Alabama?
- Lifelong needs—cannot focus only and all of energy on front end
- Need to increase parent's capacity to care for kids
- Community issue—not localized to individual or family
- Need increased communication among service providers

- Families need personal contact for support, education, etc.
- Need standardized criteria for autism diagnosis
- Education on red flags and where to go for help
- Organizations to help fund education & training (ex: AAP)
- Need regional centers: diagnostics, respite, parent education, services/service coordination, parent mentorship, development/fundraising coordination, technical assistance
- Communication among service providers
- Focus on strengths of family, individual, community when planning services
- Loss of support system when gets into school system
- Parent mentors
- Public/private partnership for funding and service provision—collaboration
- Separate agencies and separate funding streams pose problems
- Emphasis on social interaction—through parent, family, community interactions—can be included in "therapy' hours
- Medical personnel need to have pre-service and university training
- Better involvement and partnership with school systems (development of IEP, transition, etc)
- Need way to tell schools the number if children transitioning out of EI system into the school district for planning purposes
- Need better checklist for EI evaluation process
- Procedures when recognizing early warnings signs of autism
- Insurance coverage
- Payment options for parent education (insurance, scholarships, entity that takes that responsibility)
- Support current and future research

Medical/Healthcare Top Themes

1. **Regional disparities are present. Need to create statewide coordinated and comprehensive system of care in order to bring uniformity to services provided. Provided through a state agency or department and state funded.**
2. **Need more service providers (child psychiatrists, medical professionals, case managers). Individuals are placed on wait lists for long periods of time.**
3. **Increased emphasis should be placed on education and training requirements of service providers of adult services (Vocational Rehabilitation, medical professionals, mental health professionals, etc.).**
4. **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 Autism Spectrum Disorders as a diagnosis. If an individual does qualify for the MR waiver, the wait list is enormous.**

5. **Increased funding to support providers who treat individuals with autism. Increased public and private insurance coverage of services is also needed. Increase capacity of providers who accept clients with Autism Spectrum Disorders. Loan and reimbursement programs at the university level may encourage additional practitioners to join the field.**

Medical/Healthcare Summary Themes

- Diagnosis has changed over the years (from developmentally delayed to Autism Spectrum Disorders)
- Behavior issues can be managed with appropriate training
- Length of wait lists (8-12 months) is a problem
- Not enough practitioners (psychologists, psychiatrists, etc) treating individuals with autism
- Referrals rates are high because few are willing to work with individuals with autism. Those providers have long waiting lists.
- Need more child psychiatrists around the state who are familiar with autism
- Regional disparities
- Better general knowledge of Autism Spectrum Disorders and medications, referral sources, appropriate evaluations
- Parent education
- Mental health centers don't treat autism
- Asperger population doesn't qualify for day programs because of mental retardation eligibility requirement
- Lack of adult providers (therefore adults stay with child psychiatrists and pediatricians).
- Nowhere to refer adults while they are on wait lists
- Needed services include: medical, psychiatry, dental, etc.
- Hospitals will not take individuals with autism—many have GI (like ulcerative colitis) and immune issues that need treatment
- Only one group of dentists takes MCD and will see individuals with ASD
- Veinapuncture is difficult—although it is necessary for many medical procedures, including checking lithium levels (necessary for medication management).
- Financial issues—private providers and too expensive and will not accept MCD
- Difficulty getting services through schools (e.g., speech)
- Schools will not tell parents they suspect autism because they will have to pay for services
- Stigma with autism (among general public and even service providers)
- Interventions are difficult, because there is no cure
- General practitioners/pediatricians avoid screening, even when given tools
- Refusal for doctors to tell families of red flags of autism
- Need to focus on level of functioning
- Need to attach money to serving this population
- Need to educate community and providers to help relieve stigma
- Need a track in pediatric psychiatry for Autism Spectrum Disorders, DD, or special education—like at Vanderbilt. Increase exposure to these disabilities while in school.

- Need better availability and accessibility of services
- Need more frequent services (EI)
- Many therapists work part time
- Recruit BCBAs
- Need services from birth until death
- Multi-needs issues
- Create state department to address issues (Autism Spectrum Disorders or DD) through DOE & DMH/MR. Centralized program funded through state
- Difficult waiver process
- Discrimination of mental health program—because they don't accept DD
- Need continuum of care
- Source of responsibility (for reimbursement; understanding of differentiations between education and medical systems)
- Training, funding, & recruitment into field
- Need community psychiatrists
- More services "housed under one roof" that work together to provide services to a catchment area of service
- Length of time in years of missed services because diagnosed late
- Need to spend money now, because cost will be lots later. Serving the population now (and early) will save approx $200K per person
- Need more/better insurance coverage for services
- Parents must act as service coordinators, because no one is able to help do this with them across the lifespan
- Modify national programs and programs in other states to develop a model of regional and statewide care in Alabama
- Whether it is autism or not, if the characteristics are present, these individuals do not receive services because no one knows what they need
- Need resource directory
- Need developmental screening resources
- Need to know what treatments families are trying. Some have not been scientifically proven, and some are being conducted without medical supervision. Many children are very young and going through some "experimental" or not scientifically validated therapies
- Issues with parents not vaccinating their children—can have broader implications

School-Based Services Top Themes

1. **Regional disparities exist. Regional centers would be helpful in providing resources, trainings, and advocacy information for parents and professionals.**
2. **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.**
3. **Transition services are poor statewide. Transitions services are required to start at age 16 or 'earlier if necessary.'**
4. **It is difficult to prove eligibility for services. The time for the IEP process and the BBSST is too lengthy. State regulations focus on required skills that**

some individuals with Autism Spectrum Disorders may not have yet acquired. Functional language and adaptive skills should be part of the IEP and education, not pushed out by state regulations.

5. **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.**

School-Based Summary Top Themes

- In school, should receive following services when deemed 'appropriate' through eligibility: resource teacher, self-contained classroom, pullout for speech (2-3 times per week), pullout for OT (include sensory integration); social groups; teacher training (including over summer) for regular & special education teachers; group therapy, PT
- Rural vs. urban & regional disparities
- Eligibility criteria and process is to meet and difficult to obtain
- Lack of training (regular education teachers, special education teachers, administrators)
- Problems with generalization can occur when individual works exclusively with a paraprofessional
- Everyone who works with child should be aware of behavior management plan
- Funding
- Healthcare issues—not enough nurse personnel and teachers uninformed of medications, side effects, and conditions
- Lack of summer programming/ESY
- BBSTE requirements difficult to follow and prove eligibility for services
- Large population of home-schooled children
- Lack of services for adolescent into adulthood (transition)
- Difficulty in middle school setting because of transitions between classes and added responsibilities
- Need better knowledge of true evidence-based practices and methods
- Provide services in trans-disciplinary approach (everyone learns same techniques and applies them across the board)—team approach for effective strategies
- Issues with the practicality of following state regulations when individual does not have prerequisite skills
- Acknowledgement and training for teaching/serving both high- and lower-functioning individuals
- Need in-classroom, hands-on training
- Undergraduate training for special education teachers on working with special education, dealing with MR, dealing with autism, etc.—not just at Master's level
- Special education law training for administrators
- Recognize behavior modification in general (chaining, shaping, positive and negative reinforcement, association, etc) rather than only ABA
- Need more awareness of resources in Alabama (ASA, ADAP)

- Need for ESY—in order to receive ESY, must show proof of regression (problems with data, teacher not feeling they are doing job, etc)
- Safety concerns for parents who do not have access to ESY
- Transition is poor statewide
- Only programs that are available are for individuals with MR (not always appropriate for persons with autism)
- Eligibility criteria for adult services is MR—many do not have MR, therefore, don't qualify for services. If you do have MR, there is a long waiting list that is years to get through.
- Different systems of care (EI to school, school to adulthood) that are fragmented
- Teaching needs to be on a functional scale (adaptive skills) starting in Pre-K; life skill planning
- Increased funding for adult services
- Training for providers of adult services
- Parent education and advocacy training
- Transition used to start at age 14, now it starts at 16 years. People don't follow "earlier if necessary" clause
- AAA standards are tedious, time consuming, and not always functional
- IEP needs to become more functional
- Collaborative degrees do not provide enough special education training
- Many kids with autism taking accelerated reader and ARI (Alabama Reading Initiative) tests do not have functional language skills (e.g., getting across the street safely)
- Need regional center for resources, guidelines, training
- Need autism advisor in SDOE
- Self-esteem is often low in individuals with autism
- Length of time it takes to get through an IEP before changes can be made is problematic
- Students must initiate disability services themselves at the college level—parents cannot. They need an advocate to help them.
- Recognition of autism is coming, but is still lacking
- Social needs
- Capitalize on strengths and interests of the individual
- Recognition of grief in parents
- Incorporation of parents into treatment plan (IEP)

<u>Adult Top Themes</u>

1. **Regional centers that offered skilled case management, community integration, and advocacy may help address the issue of regional disparities. Some families seek residential placements because they cannot support their child/adult child using existing community resources.**

2. **Services and structure ends upon high school graduation. Services that are available are based on a mental retardation diagnosis, which many individuals with Autism Spectrum Disorders do not have. Existing services are also offered inconsistently. Supports need to be lifelong and long term in employment, living, and social issues.**
3. **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 has been done in other states and may work in Alabama.**
4. **Education and training is needed for adult service providers—this includes Vocational Rehabilitation, medical providers, and emergency personnel.**
5. **Autism Spectrum Disorders vary widely in severity but all individuals on the spectrum face social isolation if not given the needed support.**

Adult Summary Themes

- No services after high school exit
- Cost of available services
- Parent as service coordinator
- Severity—many do not qualify for services. Some cannot be part of community concept because of severity while others can
- Most services are for MR. Individuals with High Functioning Autism/Asperger's don't qualify for, and neither do the lower functioning group
- Autism Spectrum Disorders shut out of services if not MR or DD
- Funding (why autism is not called developmental)
- MCD services available through only MR diagnosis
- Need more services (providers, monies, expertise)
- Georgia has a DD waiver that includes Autism Spectrum Disorders
- Need supports for daily living (for families and individuals)
- There are no public supports (only some from Glenwood and Vocational Rehabilitation)
- Need structure when out of school and throughout rest of life
- Many in justice system because lack of structure & support
- Mental health services don't treat autism
- Even if individual has received state of the art supports their entire life, they still need supports through adulthood—it is a lifelong disorder
- Rural vs. urban disparities (sometimes look for residential placement because an individual can get services outside of home better than in home because of location)
- Aggression issues
- Residential services that are available are for substance abuse or MR and are not appropriate for many with High Functioning Autism, Asperger's, or autism
- Strengthen referral system
- Need improved flow of information from agencies to families
- Start futures planning early (e.g., employment, living, activities of daily living, social)

- Regional centers for resources & help (e.g., skilled case management, community integration specialist, services, community advocate to work with legal system)
- Needs supports in college system
- Funding
- Job coaching (on-site)
- Variations in what Vocational Rehabilitation offers
- Knowledge and availability of funding (e.g., SSI)
- Need state wide database of resources
- Individuals with Autism Spectrum Disorders live approximately 50 years after their parents—they will age and need older adult services too
- Systems break down as an individual ages
- Community funding
- Train fire and police departments
- Line item budget like North Carolina
- Think of broader ideal
- Transportation, especially for higher functioning population & those in supportive employment
- Poor public transportation systems in Alabama
- Medical health issues—reimbursement/loans for those who work in autism or in region
- Psychiatric care—difficult finding practitioners that accept MCD; age faster if taking medication, medication management
- Dental health—even fillings can be major ordeal (e.g., doctors are not willing to sedate for procedure)—need to educate dentists
- Isolation of the individual and family
- Lack of education
- Need strength-based interventions/programs
- Disconnect exists between services
- Collaboration among agencies to provide support services (e.g., employment, living, etc.)
- Look at other states with self-determination experience (e.g., Wisconsin) and their systems
- Need more providers like Glenwood (more adult providers)
- Need more money available to serve adult population
- Can't afford private agency and public agencies don't serve the population
- Vocational Rehabilitation can contract private providers for limited number of sessions
- Need to use evaluation tools (e.g., WAIS (Wechsler Adult Intelligence Scale)) & look at the 14 subscales
- Need to look at social aspects of living
- Adult services are severely lacking outside the Birmingham/Jefferson County metro
- Need resource manual
- Classical autism is no longer the norm

- Need social skills groups that includes interactions with typically developing individuals
- Apprenticeships style of learning would be helpful
- Many individuals with ASD appear to be lazy, but they usually do not understand directions or are not able to complete the given task.
- Some adults are very intelligent, but cannot function (e.g., use stove, drive, get dressing, bathing, time management)
- Parents don't want to resort to a group home
- Huge responsibility on siblings
- Socialization will be a lifelong problem—even if they have gotten quality services since an early age.
- High requirement of 12 hours of classes to be enrolled in Vocational Rehabilitation and have supports in college
- Collaborative degrees receive minimal education for special education, especially autism
- Medical vs. psychological perspectives/modes of treatment
- Difficulty getting and maintaining employment because of social issues
- Need agency to address issue of autism—1 in 150 is a large population
- Currently no one in state government to help with advocacy or represent autism issue
- Difficulties in SDOE—high dropout rate for typically developing individuals—even worse situation for individuals with Autism Spectrum Disorders
- Individuals can be great workers with the right supports and understanding – could be great contributors and taxpayers with right supports
- Need long-term support for employment and living
- Safe living options at community college level; independence with support
- Kids sit at home on couch when they graduate because there are no activities for them afterward
- Elderly parents are caring for adult children with Autism Spectrum Disorders