



Autism Society of Alabama

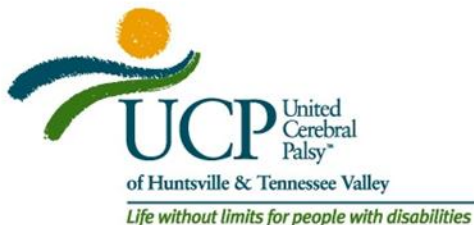
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Statewide Autism Needs Assessment

Key Findings June 2008

Conducted by the Alabama Autism Collaborative Group



*The Autism and Behavioral
Health Center of Alabama*



MITCHELL'S PLACE
unlocking potential

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Overview

House Joint Resolution 23, sponsored by House Representative Cam Ward and Lt. Governor Jim Folsom, created The Alabama Autism Task Force (AATF). The Task Force is charged with recommending ways to improve the condition of individuals with Autism Spectrum Disorders (ASD) in Alabama. Upon creation, Task Force members recognized the need for a source of statewide data to guide their work. 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), consisting of individuals affected by ASD as well as those with other expertise in ASD and in conducting needs assessments, was awarded the grant to begin the Alabama Autism Needs Assessment in September 2007. This report represents key findings of the statewide needs assessment which concluded in May 2008.

In addition to fulfilling the original charge from the ACDD, this document also offers information to all individuals with an interest in ASD, including parents, professionals, and legislators. This summary should be relevant for each of the seven Task Force Subcommittees of Systems of Care, Diagnosis and Screening, Interventions-Birth to Five, Interventions-Six to Twenty-one, Interventions-Adults, Healthcare/Medical Services, and Financial Impact. An Executive Summary of the complete results as well as the full report, including excerpts from the various data sources used, is available from the AACG.

Data Used

A mixed methods approach which incorporated a literature review, quantitative and qualitative data sources was utilized in this needs assessment. Initially, a literature review was conducted to determine current best practices regarding ASD. Concurrently, seven community forums on ASD were held during fall 2007 and spring 2008. 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.

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 in the survey data. For example, only 26% of survey respondents reported incomes of \$40,000 or less and respondents reported the average age of the individual with ASD in their family was 10.4 years. However, survey respondents represented 141 different zip codes in 102 different cities and towns across the state and about one-third of respondents identified themselves as being a member of an ethnic minority group.

Eighteen individuals selected as key informants (e.g., directors of public and private agencies and clinics) responded to eight questions regarding their perceptions of the service system for individuals with ASD across the life span. Focus group (n = 6) members were asked a series of 10 questions designed to elicit directed discussion of availability, accessibility, and effectiveness of existing services and systems. Additionally, provider comments were solicited through 171 online and written surveys.

For this summary, key findings and recommendations were identified in each category and verbatim quotations are included to illustrate the nature of respondents' written comments.

Key Findings

Autism Spectrum Disorders (Autism, Asperger Syndrome, and Pervasive Developmental Disorder) involve impairments in communication and social skills and a restricted range of activities and interests. ASD is a lifelong neurobiological disorder that occurs in all racial and ethnic groups and across all economic backgrounds. Approximately 40-60% of individuals with ASD also have an intellectual disability. The Centers for Disease Control and Prevention (CDC) considers ASD to be an “urgent health problem.” National estimates are that ASD occurs in 1 out of every 150 individuals, suggesting that there may be 30,000 people with ASD in Alabama.

Systems of Care

These results begin 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.

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.”

RECOMMENDATIONS

Create a statewide network of University affiliated regional centers in partnership with public and private agencies.

The most effective programs nationally 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
 - Certification programs for professionals interested in specializing in ASD
 - Student practicum placements combined with service delivery to ensure ongoing quality of service
- Ongoing consultation with other agencies to ensure quality service provision following professional training
- Support for basic and intervention research to increase our understanding of these enigmatic disorders

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.

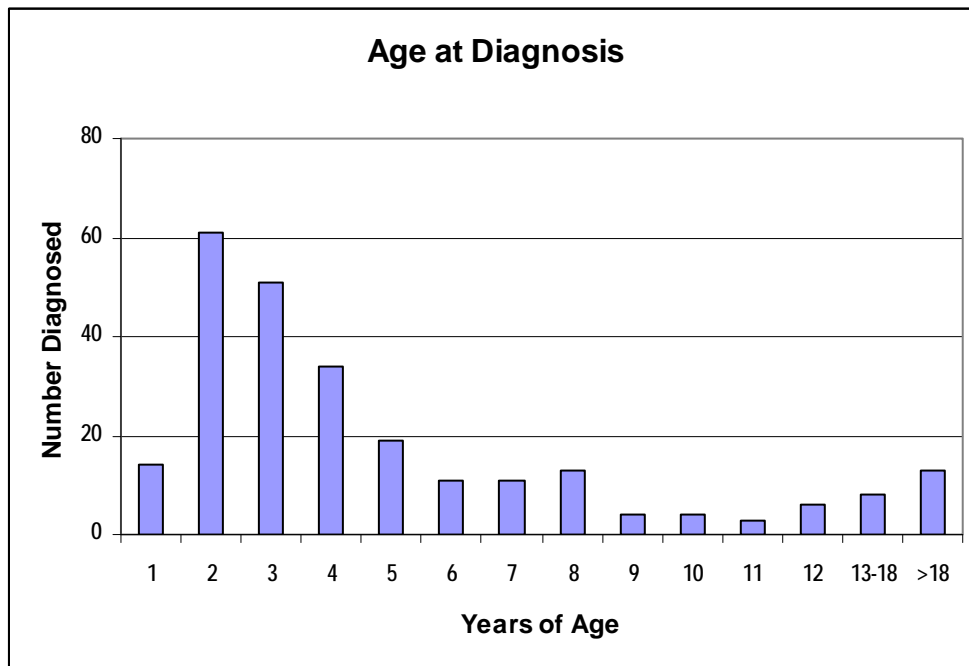
Screening and Diagnosis

Early diagnosis of ASD is critical. Intensive early intervention services before 3 ½ years of age leads to a significantly better outcome than intervention that begins in kindergarten. While parents are typically concerned by 18 months, children are often not evaluated until after their third birthday. In Alabama, more than 50% of survey respondents reported their family member was diagnosed *after* the age of three. Needs assessment respondents strongly supported national recommendations for early and continuous screening for developmental concerns and comprehensive, interdisciplinary evaluations. Parents report experiencing long waits for these 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."



RECOMMENDATIONS

**Use a broad based developmental screener that includes early social and communication symptoms associated with autism and other developmental disabilities.
--Create a brochure/document to be distributed through pediatrician offices.**

Develop a system of regional interdisciplinary diagnostic evaluation clinics with diagnostic expertise across the lifespan.

Interventions and Education

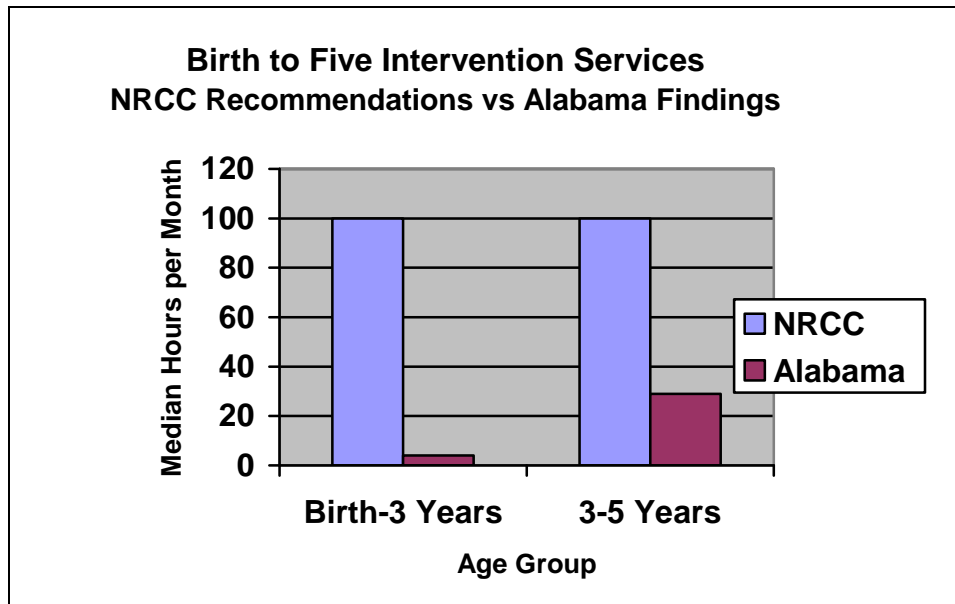
There is no “one size fits all” intervention approach; however, there are empirically validated key elements that increase the efficacy of programs. It is essential that programs be tailored to each person’s developmental (age and cognitive ability) needs throughout the lifespan. Access to evidence-based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

Interventions in Early Childhood (Birth to Five)

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?”

“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!”



*NRCC = National Research Council Committee on Educational Interventions for Children with Autism

RECOMMENDATIONS

Increase the number of hours of early childhood intervention that involve the key elements of effective intervention.

Educate families and other caregivers to understand that intervention can occur in many arenas, such as 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 and the adult is trained in evidence-based methods of intervention.

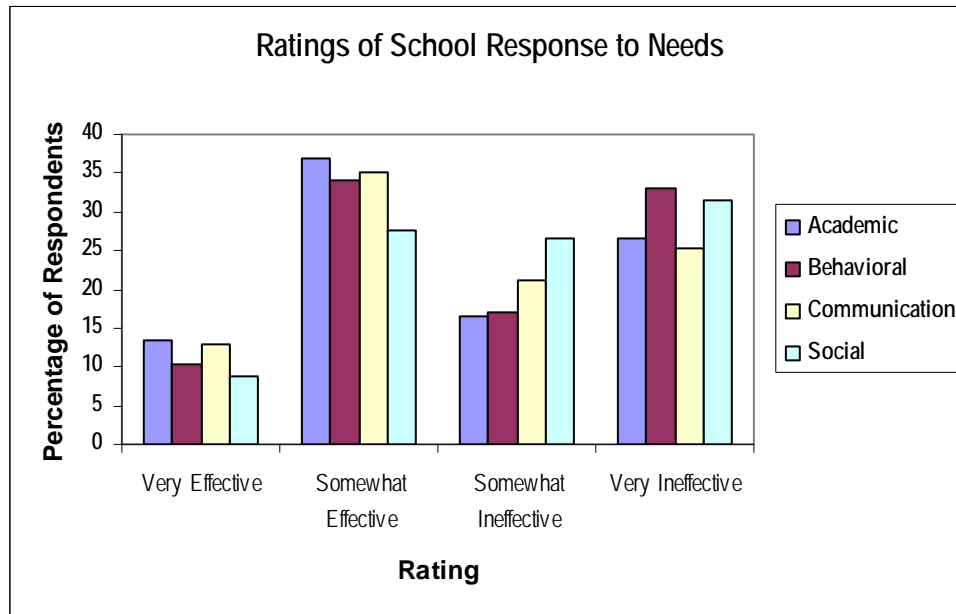
School-Based Services

Students with ASD present challenges for educators that are different from many other students served by special education or general education. National recommendations are for educators and support personnel to be familiar with theory and research concerning best practices for children with ASD. Unfortunately, there is a deficit in the number of special educators available, especially those with ASD-specific training.

Selected Quotations

“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 school system supplies speech therapy once a week in a group for 30 minutes. ... 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. ...”

“Even though services are provided in the school system, often they are not adequate to the needs of the child. (Due to) either poorly trained staff or not enough time available to meet the needs of the child.”



RECOMMENDATIONS

Provide training, supervision, and on-going consultation regarding techniques of intervention that have been validated empirically.

With the growing incidence rate of ASD, there is a parallel need for increased pre-service training leading to well-trained ASD professionals entering the workforce.

Interventions for Adults (Post High School)

Many adults with ASD will require continued treatment to build social and communication skills to support successful employment and independent living. Interventions need to be tailored to the specific and different needs of adults with ASD. A total of 29 survey respondents were caregivers of individuals with ASD who were 21 years of age or older. For nearly 60% of these adults with ASD, their caregivers reported that they will require frequent (23.1%) or continuous (30.8%) supervision. 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. A total of 32 adults with ASD participated in a community forum. They echoed their parents concerns, noting difficulties obtaining jobs and developing friendships.

Selected Quotations

“...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)

RECOMMENDATIONS

Create coordinated system of intervention and support.

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.

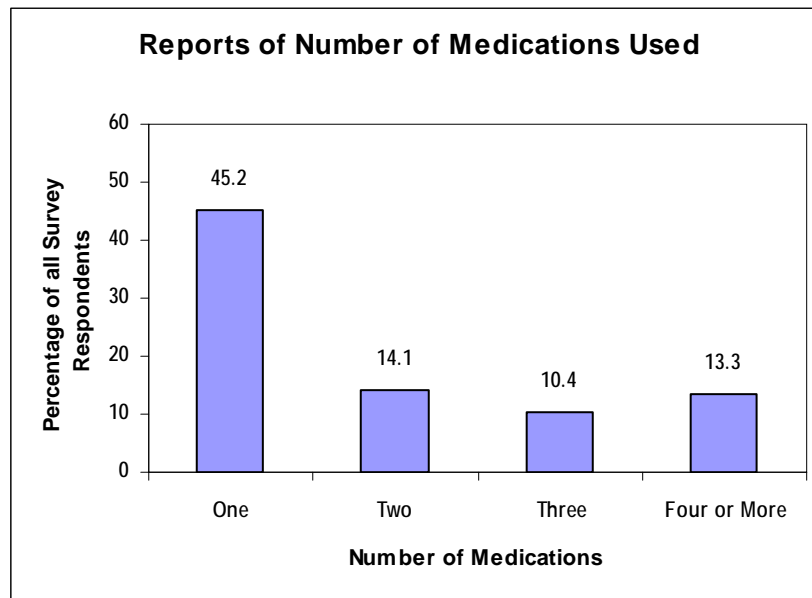
Train individuals providing adult support services on empirically intervention techniques.

Health Care/Medical Services

Families look to their medical providers for guidance. Among the survey respondents, the average age of the family member with ASD was 10.4 years. Eighty-three percent of the respondents reported to have taken one or more prescription medication. Many of the medications were used to treat behavioral symptoms of autism. Fifty-three percent of the respondents report trying one or more alternative treatments.

Selected Quotations

“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.”



RECOMMENDATIONS

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.

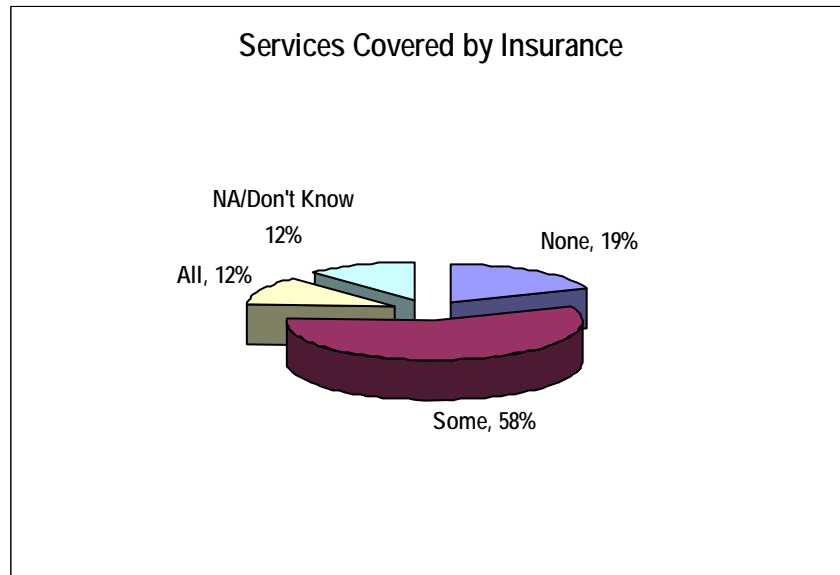
Financial

The financial implications of ASD in 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. Insurance is not adequate for the needs of most individuals with ASD resulting in a significant financial burden for families seeking intervention services for their family member with ASD.

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.”



RECOMMENDATIONS

Permanently allocate state resources to ASD efforts.

Increase providers' reimbursement for services.

Work with insurance companies to expand coverage types and amounts.