Alabama Autism Awareness Assessment

A report to the

Autism Legislative Task Force

Prepared by the

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Overview

In 2007 the Alabama Legislature authorized a Task Force to review the states response to the increase in the rate of Pervasive Developmental Disorders (PDD) commonly referred to as Autism or Autism Spectrum Disorders (ASD). To assist the task force the Alabama Council for Developmental Disabilities commissioned studies. The first is being conducted by the Alabama Autism Collaborative Group working with the University of Alabama at Birmingham. The second was a state wide poll of the general population conducted by the University of South Alabama, College of Education and the USA Polling Group.

This report presents the findings of the statewide random sample telephone poll conducted between January 21st and February 7th 2008. A total of 746 surveys were completed, the confidence interval is plus or minus 3%. In the sample there were 4 individuals who identified themselves as having autism and an additional 119 individuals who reported that someone close to them had been diagnosed with Autism. This report describes the gender, age, income, marital status, number of children in the home, education, and racial composition of the sample.

The 43 question survey documented the opinions of the general population of Alabama with regard to several areas related to ASD. The common term Autism was used in the questionnaire. The survey addressed general knowledge of ASD, attitudes toward individuals with autism and their families, educational issues, adult care issues and the willingness to encourage the government to provide more support.

Where appropriate the report relates the findings to the preliminary recommendations of the Autism Task Force. Because the survey instrument was constructed prior to the development of the preliminary recommendations it does not address all of the Task Force recommendations. This narrative is a summary rather than an extensive report of findings. Some figures and tables are included as part of the narrative to highlight specific findings, the remainder are included at the end of this report.

Survey Methodology

Telephone interviews were conducted at USA Polling Group facilities by employees of the Polling Group. Standard random-digit dialing procedures were used to draw a sample of Alabama households. Participation within households was randomized using most recent birthday criteria, and respondents were screened to insure that they were over 18. As needed, follow-up appointments were scheduled for individuals unable to complete the interview at the time of the original call. A total of 746 interviews were conducted from January 21 to February 7, 2008. This yielded a sub-sample of 605 people who claimed to know at least a little about autism. Most of the questions in the survey were asked of this subgroup. Sampling error for the full sample is +/- 3.6% at the 95% confidence level. Sampling error for the subgroup who knew at least a little about autism is +/- 4.1% at the 95% confidence level.

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Respondent characteristics

The average age of the respondent was 52 years. Fifty seven percent of the sample were female, 43% were male. The greater number of females occurred because women were more likely to respond that they knew something about autism. An analysis of variance determined there were not significant differences in age, marital status, and education, number of children or income between genders. Figure 1 lists educational levels and Figure 2 marital status. Sixty eight percent reported that they did not currently have children in the home. Figure 3 summarizes income categories.

Figure 1: How much education do you have?

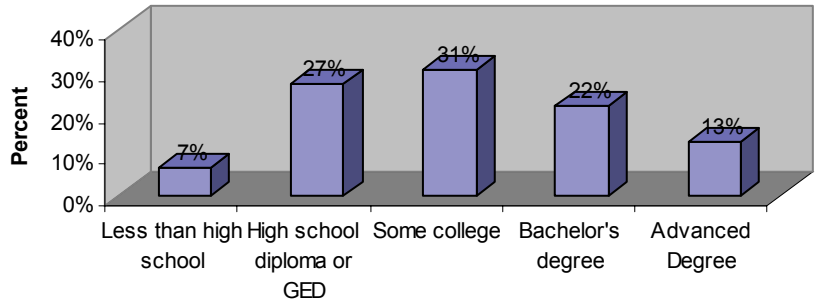


Figure 2: What is your marital status?

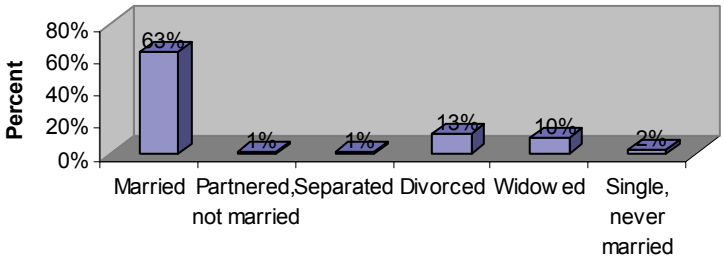
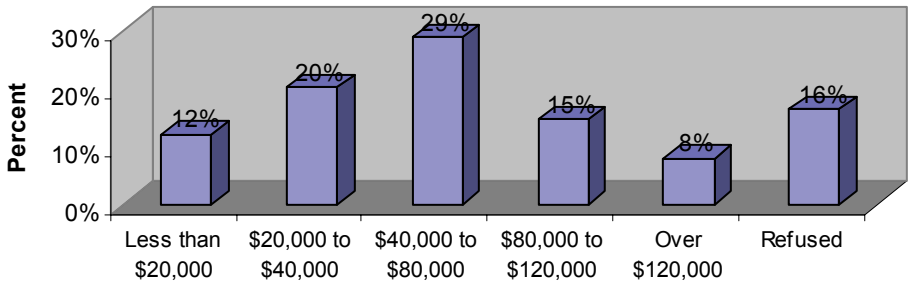


Figure 3: The category that includes your household's total income last year before taxes.



Survey Results

Knowledge of autism

The first item in the survey sought to ascertain the extent of knowledge of autism within the population of Alabama. Over 80% of those surveyed responded that they had at least a little knowledge of autism (see Figure 4). The other respondents reported that they knew nothing at all or did not respond to this question. It appears that recent media attention has successfully raised the level of awareness of the populace. The group who identified themselves as knowing nothing about autism was not asked any of the more specific follow up questions. This left 605 respondents for the remainder of the survey.

Almost 80% of the respondents considered autism as a medium or major problem (Figure 5). Respondents recognized the need for assistance for parents and the value of support as a means for families to remain intact.

Figure 4: How much would you say you know about Autism?

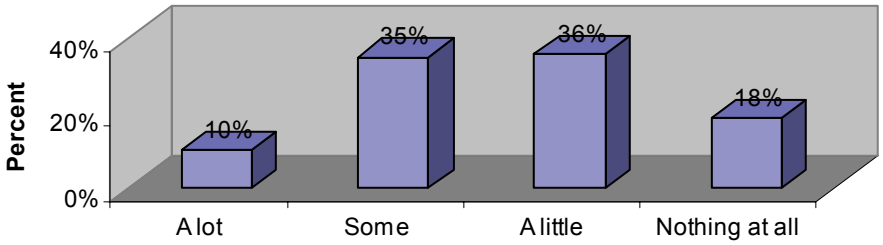
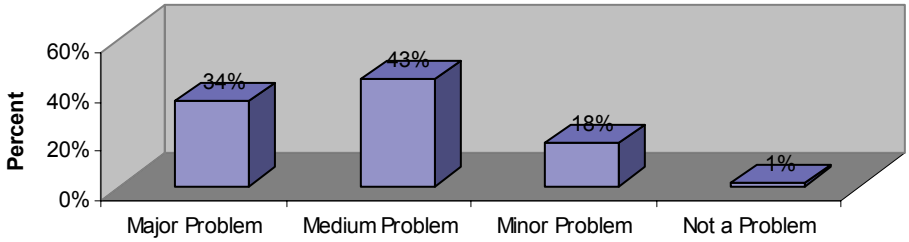


Figure 5 : How Big of A Problem is Autism For Society Generally?



Similarly the Task Force identified parent's need for assistance as an important issue that must be addressed. Almost 85% of the sample realized that parents of children with autism require support (Figure 6) and that the family should be the primary provider of supports (Figure 7).

Figure 6: Parents of children with autism cannot be expected to provide all necessary services by themselves.

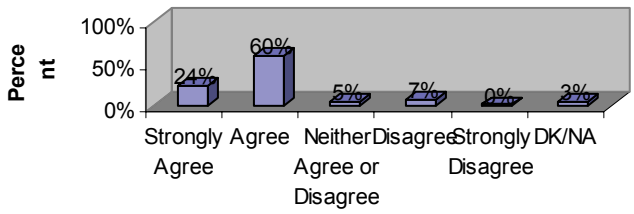
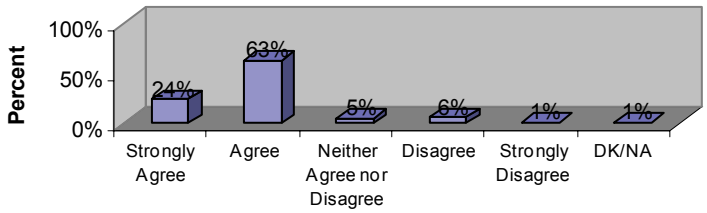


Figure 7: Most people with autism should be cared for by their immediate family, as much as possible.



Role of the government

The majority of respondents felt that the government was spending too little on services for persons with autism. Less than 1% of the sample (6 persons) felt that the government was spending too much money. We asked respondents to rate the level of importance of service areas that represent the need for lifelong supports to assist individuals and families. These results are presented in Table 6. These areas coincide with the recommendation of the Legislative Task force that "…determined that a **Coordinated System of Care** for persons living with autism needs to be developed in Alabama."

Each area was overwhelmingly rated as important. As you can see money for research was strongly recommended. The respondents rated need for research and protective services as most important. Somewhat less important was the need to provide support for housing and residential care, although 92% rated this area as somewhat or very important.

Table 1 Areas of Service Needs

	Very Important	Somewhat Important	Not Very Important	Not Important At All	DK/ NA
Centers where people with autism can learn job skills.	66%	29%	1%	1%	2%
Additional support for schools to educate and train people with autism.	70%	26%	1%	1%	3%
Assurance of access to quality health care services.	72%	26%	1%	0%	1%
Protection services to prevent abuse of people with autism.	81%	17%	1%	1%	1%
Support for housing and residential care for people with autism.	48%	44%	3%	1%	4%
Research to learn about the causes and treatment of autism.	83%	16%	0%	0%	0%

Education

The Task force has several recommendations concerning education. As a general population survey we could not address some of those more technical issues, such as applied behavior analysis. In general the respondents felt that schools should provide the services needed by students with autism and that these services should begin as early in the life of the child as possible.

Regarding the provision of educational services in inclusive classrooms the responses were nearly evenly divided. Equal numbers agreed and disagreed with this service delivery strategy. This result reflects an ongoing debate among special education professionals pertaining to the right to participate as a full member of the school community and the possible need for seperation for some forms of intensive instruction. It is interesting to note that the population of Alabama models this, as yet unresolved, impasse.

Special education within the public schools is charged with providing individualized, intensive, and highly technical services. Students receiving services range from those with high incidence disabilities preparing for postsecondary education to those with more challenging needs who learn the most basic life skills to prepare for independent community living. In Alabama, teachers hold a Collaborative Teacher certificate that qualifies them to serve students with learning disabilities, emotional and behavioral disorders, mental retardation, and multiple disabilities. This credential does not necessarily reflect the level of specialization necessary to serve students with the most challenging needs. Teachers are not now required to receive specialized training in autism or other developmental disabilities in order to serve this population. To further exacerbate this service gap, many students with developmental disabilities require a multidisciplinary service package. Schools are not now able to readily provide the level of occupational therapy, physical therapy, nursing, and behavioral services necessary to effectively implement such educational plans.

Figure 8: It is important to start services for children with autism as early as possible.

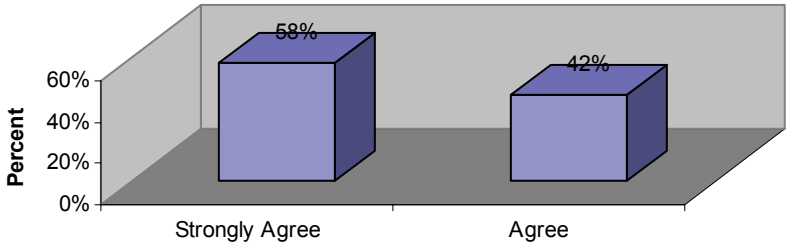
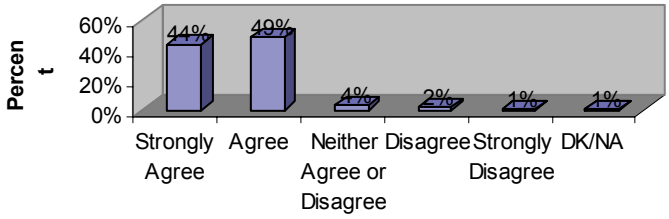


Figure 9: . It is important for public schools to provide the educational services that children with autism need.



Employment

Our educational system must prepare students with autism and other developmental disabilities to be productive citizens within their communities. Because autism is a spectrum disorder, a continuum of career and vocational training, and employment opportunities must be made available with the ultimate goal being full time competitive employment. Many individuals with autism are productive in today's society. Allocating resources that target job skills are an investment that promotes independence and productivity and may ultimately save the state over the lifespan of an individual. The continuum must also include part time employment, and sheltered employment.

The task force recommends a coordination of services. Alabama serves adults with disabilities primarily through two state agencies, the Department of Mental Health Mental Retardation (DMHMR), and Alabama Department Rehabilitation Services (ADRS). As the name implies DMHMR criteria is mental health and mental retardation. There are many individuals with developmental disabilities like autism, cerebral palsy, and spina bifida, who have significant needs, but are neither mentally ill nor mentally retarded. ADRS is equally limited in its mandate.

Figure 9: With the right training, most people with autism could be productive citizens.

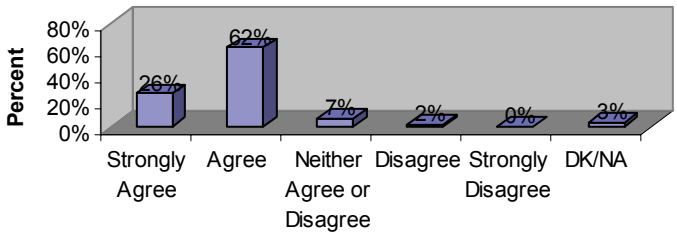


Figure 10: I have a lot of respect for companies that employ people with autism.

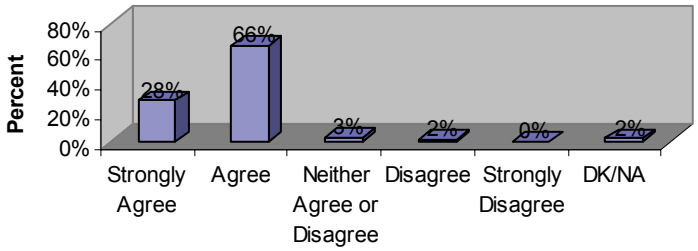
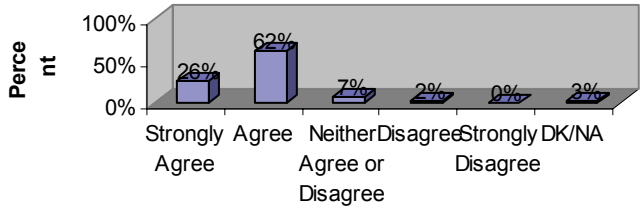


Figure 11: If children with autism do not receive appropriate services, they are more likely to become burdens as adults.



Community Living

Respondents agreed that individuals with autism should be part of their community. In constructing the questionnaire we were careful not to use terminology that would bias the responses toward inclusive community supports. To accomplish this we asked questions about an individual's ability to live a "normal" life, make their own decisions, and be involved in the community.

Figure 12: Most people with autism can learn to live normal lives.

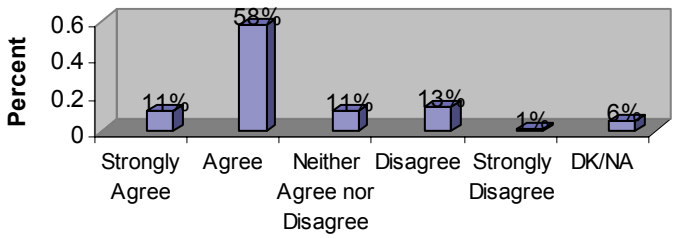


Figure 13: People with autism look different from typical people.

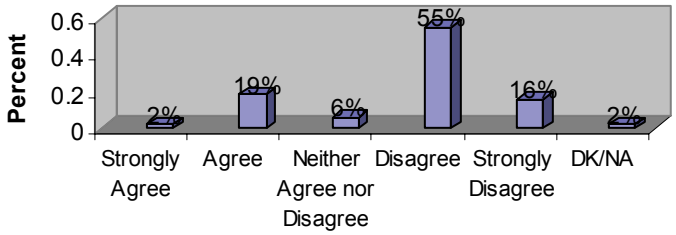


Figure 14: People with autism should be encouraged to get out and be involved in the community.

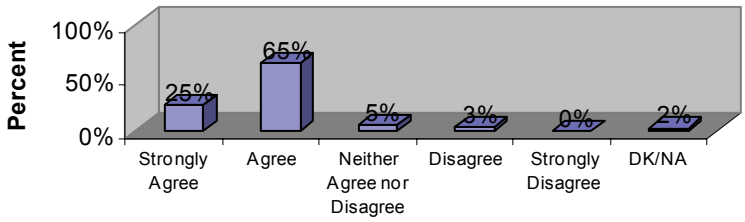
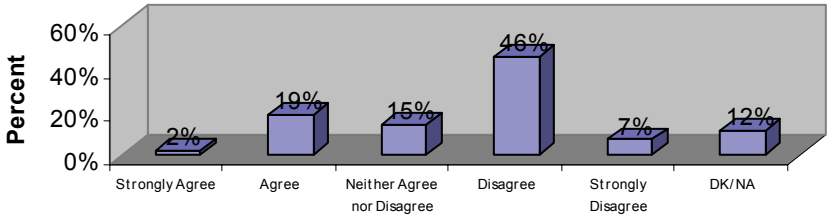


Figure 16: Most people with autism are not capable of making regular daily decisions.



Respondents with a personal connection

As noted earlier we have included the other findings from the study as an appendix. This study was designed to complement the needs assessment undertaken by the Autism Collaborative Group. That study's primary focus was to gather information from families and stakeholders directly involved in supporting individuals with autism in Alabama. The next section describes the results from a subset of the survey. These data are based on responses from persons who responded that they either had autism or knew someone with autism. Almost 20% of those surveyed responded affirmatively to this item. This result mirrors the national prevalence statistics. The responses from this group are summarized in the next section. Most notable is that 1 in 5 Alabamians know someone with autism.

"The Alabama Autism Task Force recommends all health care providers who provide primary care to young children **provide universal screening for developmental delays/ disabilities and conduct autism specific screening** as recommended by the American Academy of Pediatrics." This recommendation is strongly supported by respondents aware of who provided the first diagnosis.

Forty seven respondents reported that they were involved in the care of an individual with autism. Seventy Five percent of this group reported that a medical provider made the diagnosis; for 50% it was a family doctor or pediatrician. Age of diagnosis nationally is about three years of age. This group, when we include only those diagnosed prior to age 12, reports average age as over four years of age, one year older than the national average.

In regard to preschool programs, of the 31 respondents who knew someone identified prior to age six, four reported the individual had been in an inclusive preschool, nine reported a special preschool and the remaining 18 no preschool program attendance.

For school age services, three reported inclusive public school programs, 15 reported special education in public schools, two reported private school placements, and two reported the student was home-schooled. Since we did not obtain a current age for the individual being described we do not know if the remaining individuals did not receive special education services or were still in preschool.

When we asked this group "Did you, or do you, bear any of the costs of care and treatment for this person?" Twenty two responded affirmatively, eight (36%) reported it a major burden, nine (41%) a minor burden and five (22%) not a burden. With regard to the effectiveness, 16 respondents reported services to be either very effective or somewhat effective. Two reported they were not effective and 4 did not know or did not answer.