

## **Report to Governor Bob Riley and the Alabama Legislature: Riley Ward Alabama Autism Support Act of 2009**

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### **Executive Summary**

This is the Annual Report to Governor Bob Riley and the Alabama Legislature required by Act#2009-295, the Riley Ward Alabama Autism Support Act of 2009. Act#2009-295 created the Alabama Interagency Autism Coordinating Council (AIACC). *The AIACC is charged with meeting the urgent and substantial need to develop and implement a statewide comprehensive, coordinated, multidisciplinary, interagency system of care for individuals with Autism Spectrum Disorder (ASD) and their families.*

The Report provides (a) a brief introduction to ASD, (b) legislative background, and (c) an overview of the activities directed at the implementation of the Riley Ward Alabama Autism Support Act. Driven by both a sense of urgency and a spirit of collaboration, the AIACC is focused on a Plan of Action intended to accelerate the pace and improve the coordination of comprehensive services for individuals with ASD and their families.

### **Introduction**

Autism Spectrum Disorder (ASD) is a group of complex neurological disorders typically present by 3 years of age and characterized by atypical development in socialization and communication. ASD is often accompanied by unusual behavior and interests. Three disorders are considered ASDs (a) autism, (b) pervasive developmental disorder-not otherwise specified (PDD-NOS) and (c) Asperger's disorder.

The term "spectrum disorder" is used to indicate that ASD characteristics range on a continuum from mild to significantly disabling. Some with ASD also have a range of medical conditions including motor and sensory impairments, seizure disorder, immunological and metabolic abnormalities, sleep problems, and

gastrointestinal symptoms, among others. *Adequately addressing the extensive challenges requires sophisticated educational and therapeutic interventions.*

At present, there is no known biological marker for autism. Scientists are studying the interaction between a number of genetic, neurological, and environmental factors in the search for causal answers. In the meantime, 1.5 million individuals in the United States are facing a lifetime of challenges associated with their ASD diagnoses.

The 2009 report from the Centers for Disease Control (CDC) and Prevention states *1% or 1 in every 110 children in the United States has an ASD diagnosis.* This national statistic reflects a 57% increase in 4 years and underscores the need to regard ASD as an urgent public health concern. Even more alarming is that over the same 4 year period, the ASD rates in Alabama increased by 82%. Consider the following fact. *Approximately 640 of the Alabama babies who were born in 2009 will be diagnosed with an ASD.*

Although ASDs are typically thought of as childhood disorders, societal and economic costs extend well into adulthood. With *lifetime incremental costs for an individual with ASD reaching 3.2 million dollars*, the cost to families and our economy is staggering.

*Although the cost of lifetime ASD care can be reduced by 2/3 with early diagnosis and intervention, Alabama lags behind the curve in realizing this benefit.* According to the 2009 CDC Report, the median age for an ASD diagnosis in Alabama is 51 months of age. This is a reality that must change if Alabama is to realize the benefits associated with early diagnosis and critical early intervention services.

Adding to the long-term concern is that a majority of adults with ASD struggle with ongoing and mostly unmet needs for employment, housing, services, and supports. The 2009 Current State of Services for Adults with Autism (Organization for Autism Research) reported (a) *74% of working-aged adults with ASD are unemployed, but would like to work;* and (b) *84% of adults with ASD still live with their families.* Compounding these stressors, families of a child with ASD lose income, often as a result of one parent leaving the workforce to care for and meet the special health and educational needs of the child. *The cost of ASD to society is currently estimated by the Department of Health and Human Services at \$35-\$90 billion annually.*

Unfortunately, the need for ASD services continues to far exceed the available resources, leaving a generation of individuals with ASD and their families in programmatic, financial, and personal crisis. *It is imperative that increased resources, commensurate with the public health need, be devoted to the identified urgent and substantial need.* Absent the concerted effort on behalf of all stakeholders (i.e., parents, professionals, employers, and society at large), the societal and economic costs can only be expected to increase substantially.

## Background

### *2007*

House Joint Resolution 23, sponsored by House Representative Cam Ward and Lt. Governor Jim Folsom, Jr., on March 8, 2007 created the Alabama Autism Task Force (AATF). The AATF was comprised of advocates, state officials, educators, physicians, and members of the academic community and charged with recommending ways to improve the treatment of ASD in Alabama. The AATF held its first meeting on June 17, 2007 and immediately recognized the need for a source of statewide data to guide their recommendations.

Grant funding from the Alabama Council for Developmental Disabilities was awarded in September 2007 to the (a) Alabama Autism Collaborative Group (AACG) to conduct a Statewide Autism Needs Assessment and (b) University of South Alabama (USA) to conduct a Statewide Autism Awareness Assessment.

### *2008*

Reports from the AACG Statewide Autism Needs Assessment and the USA Statewide Autism Awareness Assessment then guided the AATF in the development of recommendations to improve treatment of ASD in Alabama.

House Joint Resolution 3, sponsored by House Representative Cam Ward on May 27, 2008 created the Alabama Interagency Autism Coordinating Council (AIACC). The AIACC held its first meeting on October 29, 2008.

### *2009*

The AATF Recommendation Report was submitted to Governor Bob Riley and the Legislature in January 2009. After completion of the Report, the AATF was dissolved.

The AATF Recommendation Report offered recommendations for (a) diagnosis and early screening, (b) intervention services from birth through adulthood, (c) healthcare, (d) regional center development, (e) systems of care, and (f) financial impact. The recommendations focused on meeting the state needs through regional autism centers. In addition, the AATF recommended (a) an Alabama Interagency Autism Coordinating Council (AIACC) be established and (b) the creation of a State Autism Coordinator position.

Act#2009-295, the Riley Ward Alabama Autism Support Act of 2009 was signed into law on April 23, 2009 by Governor Bob Riley securing the Alabama Interagency Autism Coordinating Council. In addition, Act#2009-592 was signed on May 7, 2009 to provide for the establishment of regional autism centers.

In 2008, the Alabama Legislature appropriated \$80,000 for the AIACC. This line item was reduced slightly in 2009 due to proration. The AIACC will seek to have the legislature continue this appropriation in the upcoming fiscal year.

### **Act#2009-295 Activities**

Section 5 of Act#2009-295 defines the duties and authority of the Council.

#### **(1) Lead Agency**

The AIACC was responsible for making a recommendation regarding the designation of a lead agency to the Governor. The Department of Mental Health (DMH) was recommended by the AIACC to serve as lead agency in October 2008. Governor Riley accepted the recommendation and then designated DMH as the lead agency for the AIACC. Section 6 of the Act stipulates that the lead agency shall be responsible for the general administration, supervision, and monitoring of all council activities.

#### **(2) (3) Roles, Responsibilities, and Rules**

The AIACC was responsible for defining the roles and responsibilities of participating agencies and adopting rules for the internal operations of the AIACC. The AIACC Bylaws committee led the process and the AIACC Bylaws were passed on October 26<sup>th</sup> 2009 (Appendix A).

#### **(4) Recommendations**

The AIACC is responsible for recommending to the Governor the appointment of additional members to serve on the Council as deemed necessary and appropriate.

Governor Riley accepted all recommendations for appointments to the AIACC (Appendix B).

The composition of the AIACC includes:

1. Three adults with ASD, appointed by the Governor;
2. Three parents or guardians of a child with ASD, appointed by the Governor;
3. Five service providers, appointed by the Governor;
4. One member of the Senate, appointed by the President of the Senate;
5. One member of the House of Representatives, appointed by the Speaker of the House;
6. The chief executive officer, or his or her designee, from
  - Department of Children's Affairs.
  - Institute for Deaf and Blind.
  - Department of Education.
  - Department of Human Resources.

- Department of Insurance.
- Department of Mental Health.
- Department of Public Health.
- Department of Rehabilitation Services.
- Medicaid Agency.
- University Center of Excellence in Developmental Disabilities Education, Research, and Service.
- Autism Society of Alabama.
- Council on Developmental Disabilities.
- Academy of Pediatrics- Alabama Chapter.

## **(5) Long-term Plan**

The AIACC was charged with developing a long-term plan, to be reviewed annually, for a comprehensive statewide system of care, which, to the extent practical, is derived from scientifically based research and nationally recognized best practices.

Dr. Caroline Gomez was hired as Alabama's first Autism Coordinator on September 1, 2009 to assist the AIACC in meeting the requirements of Act#2009-295, the Riley Ward Alabama Autism Support Act of 2009.

A Plan of Action for meeting the requirements was presented to the AIACC by Dr. Gomez at the October 26<sup>th</sup> 2009 meeting (Appendix C). The Plan is divided into four steps with a number of efforts designated in each step. Step one of the Plan of Action will be focused on in 2010.

Interest Surveys were sent on November 9, 2009 to individuals throughout Alabama who had shown an interest in Alabama's autism community personally and/or professionally. The Survey introduction asked the recipients to consider offering their time and expertise in meeting the urgent and substantial need to develop and implement a statewide comprehensive, coordinated, multidisciplinary, interagency system of care for individuals with autism spectrum disorder and their families.

The 128 Interest Survey responses assisted in identifying interested committee/workgroup members. The interest Survey was specific to step one of the comprehensive Plan of Action.

Step one involves three committees (i.e., Strategic Planning, Special Projects, and Standards of Practice) and 14 work groups. The Strategic Planning committee is chaired by Dr. Bama Hager and charged with operationalizing the AATF recommendations and defining the parameters for regional autism centers.

The Special Projects committee is chaired by Melanie Jones. The committee consists of five work groups addressing (a) developmental surveillance and early autism screening, (b) family supports, (c) information dissemination (e.g., web-site), (d) community services (e.g., emergency first responder training), and (e) autism awareness. Special Project efforts have already begun with the AIACC web-site (i.e., [autism.alabama.gov](http://autism.alabama.gov)) which will be launched in January 2010.

The Standards of Practice committee is chaired by Alice Widgeon. The committee will initially focus on (a) regional autism center standards of practice, (b) guidelines for implementation of standards of practice, and (c) monitoring procedures. The committee consists of eight work groups each addressing specific facets of regional autism centers (a) diagnostic clinic, (b) family services, (c) services for birth through age 5, (d) services for ages 6 to 21 years, (e) transition services, (f) adult services, and (g) professional preparation and training. In addition a Legislative Agenda work group was formed.

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