

Alabama Autism Task Force Preliminary Recommendations

Having reviewed the findings to date from the Alabama Autism Collaborative Group (AACG), The Alabama Autism Task Force proposes the following changes to the Service Delivery Systems currently responsible for implementation of services to children and adults with autism spectrum disorders.

1. It has been determined that a **Coordinated System of Care** for persons living with autism needs to be developed in Alabama.

A system of care is seen as a coordinated network of community-based services and supports that are organized to meet the challenges of children, adolescents, and adults with Autism Spectrum Disorders (ASD) and their families to live full, productive lives in their homes, communities, educational, and employment settings throughout the lifespan. A new, coordinated system of care must be envisioned and created which ensures that individuals ASD receive timely and developmentally appropriate services that evolve from meaningful partnerships with individuals with autism, their families, public and private entities. Adequate services and supports should be provided regardless of age, race, intellectual testing or IQ scores, or physical or geographic location. Services should be individualized, evidence-based, build on the strengths of individuals, and developed in conjunction with the individual with ASD, the family and appropriate others.

To achieve this, we recommend:

- A. **Executive and Legislative Support that encompasses and continues the work of the Autism Task Force**, setting forth the appropriate authority, responsibilities, membership, accountability, funding and resources to develop, implement, and monitor a multi-year plan for a coordinated and comprehensive system of care for individuals with ASD. The appropriate authority may be a new agency, or given our limited resources, may be similar to other successful interagency models, such as the Governor's Interagency Council for Early Intervention, or the Multi-Needs Child model. Appropriate stakeholder involvement to include individuals with autism, parents, provider agencies, university systems and others should be assured.
- B. Federal funding opportunities must be explored and developed, including, but not limited to a **Medicaid Waiver for Persons with Autism** or Rehabilitation Option. New state match dollars should be appropriated to access federal participation rates. A new Autism Specific Medicaid Waiver would not be dependent on co-morbidity.
- C. A **Director of Autism Services should be employed and should report to the designated authority or interagency council** and its designated members. This individual should coordinate the planning and development of a comprehensive and coordinated system of care. The Director should be an advocate, collaborator

and problem solver who can bring many parties together to resolve issues and service needs.

- D. **The State of Alabama should encourage Universities to play a leadership role in research and as a source for training** and state of art practice and education. Universities should foster collaboration among all parties with the goal of advancing research and best practice.
- E. **Regional centers for autism and related disabilities should be established and funded** to provide services to families and to be an integral part of a comprehensive system of care. The Regional Centers should foster collaboration of families, advocacy groups, and providers. Regional centers should provide year round training opportunities for all interested parties, should support the work of Community Integration Specialists and Case Managers. Multidisciplinary staff will have expertise in all areas related to autism. Technical assistance and consultation offered by the centers should not supplant other responsibilities of state and local agencies. The centers should be operationally and fiscally independent however, basic service delivery should be consistent across centers. Each center should coordinate services within and between state and local agencies and school districts but should not duplicate services provided by those agencies or school districts. Each center should have a constituency board. An annual conference should be held, to promote statewide planning and coordination.
- F. **Comprehensive Case Management Services** should be provided by Case Managers that are trained to work with individuals with autism. The case managers should work across all service entities and state agencies to ensure that the needs of the individual are met throughout their life span. Case loads should be reasonable and divided regionally.
- G. A **workforce development task team should be appointed** to further pursue strategies and plans to address the critical shortage of professionals and para professionals that are needed to implement an appropriate system of care as well as the training needs of existing personnel.
- H. **Best practice standards should be developed** and appropriate certification or accreditation for service providers and personnel must be a part of a comprehensive plan.
- I. Independent Advocacy is a critical part of moving any system forward. **An advocacy group should play a critical role in providing community awareness and should be funded** to insure that the needs of individuals with autism and their families are represented.

Findings reported by the AACG indicate that Alabama is behind the national average when it comes to its ability to screen and diagnose children at an early age. Early identification of children with autism is the prerequisite for providing early intervention services. In 2007, the American Academy of Pediatrics recommended practitioners administer an autism specific screening test at 18 and 24 months.

- 2. 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.

To achieve this, we recommend:

- A. **Awarding grants to advocacy groups** that raise professional awareness.
- B. **Rewarding practitioners who routinely provide developmental screening,** penalizing those that do not.
- C. **Using public health practitioners to conduct autism screenings** in non-medical settings.
- D. Educating physicians about routine developmental screening as part of a **one hour mandatory CME course on autism** for license renewal.

AACG findings also indicate a lack of trained diagnosticians and found that parents experience long delays when trying to obtain a diagnosis for their child.

- 3. **Regional centers** (described in recommendation 1) **providing multidisciplinary evaluations, diagnoses, treatment, and training** should be identified so that referrals can be made to these clinics.

To achieve this, we recommend:

- A. Establishing regional centers that are University affiliated and inclusive of established private providers.
- B. Hiring a State Coordinator for Autism Services (see recommendation 1) to work with public and private providers to provide a long term plan for autism services.
- C. Increasing reimbursement for providers in clinic settings that use the multidisciplinary model to encourage the growth of this practice.

The AACG investigated best practices in terms of intervention, across the lifespan. Key elements were identified. The intensity of evidence based interventions is linked to outcomes. Early Intervention and Preschool services are vital to a child's success.

- 4. Enhancement of Early Intervention services.

To achieve this, we recommend:

- A. **Early Intervention should provide feedback** regarding their assessments, treatments and progress **to referring physicians.**
- B. Early Intervention should include both center based and home based services. Center based services should be provided with typically developing children.

- 5. Enhancement of Preschool programs

- A. **Preschool programs** providing services to children with autism **should provide a minimum of 25 hours a week of combined educational instruction** and individual instruction. These services should be provided **year round.**
- B. Preschool teachers providing services to children with autism should be encouraged to be certified in early childhood special education.

6. School systems should provide funding for independent evaluations by qualified examiners outside of the school system.
7. Provide funding of in-home Applied Behavioral Analysis programs thru Medicaid Waivers and Private Insurance.
8. **Funding a state awareness campaign** to educate the public regarding the early warning signs or “red flags” of autism and to educate Alabamians about Autism Spectrum Disorders.

To achieve this, we recommend:

- A. The implementation of on ongoing law enforcement training would be beneficial.
- B. ID cards for individuals with autism and their families would be useful.

School based services for early childhood and school aged children are imperative. School aged students continue to need evidence based interventions that are delivered intensely and throughout the calendar year. There is no Federal or State Law that mandates the amount/time of special education services required for a child with any disability.

9. All teachers who instruct children with autism should have training in applied behavior analysis.

To achieve this, we recommend:

- A. Pre-service undergraduate and graduate special education teacher training programs should have courses in Applied Behavior Analysis.
- B. Providing 5 day training workshops in Applied Behavior Analysis during the summer.
- C. Providing funding for regionally based University affiliated training programs.
- D. Making paraprofessional training available in Community Colleges.

10. The state should develop a licensure for school based Behavioral Analysts and make them available to each school system.

11. A **review of the current teacher training** should be a priority.

Consideration should be given to the training needs indicated and the established and regional training centers should design training after a careful review of the findings.

The need for immediate technical assistance by existing teachers should not be overlooked and monies should be allocated for this purpose.

To achieve this, we recommend:

- A. A review of the education curriculum offered in State 4 year colleges for both general and special education teachers. The survey should assess teacher understanding of autism, foundations of applied behavioral analysis and behavior

- modification principals, understanding the functions of behavior, and knowledge of the evidence based teaching strategies known to work for persons with autism.
- B. Development of a teacher training protocol given the findings of the teacher training survey.
 - C. Offering teacher training regionally.

12. **A fund should be established to support evidence-based training of paraprofessionals and teachers.**

To achieve this, we recommend:

- A. Funding for the payment of substitute teachers
- B. Funding for other expenses related to teacher and paraprofessional training

Autism is a lifelong disability. The AACG found clear, pressing and significant needs for those aging out of high school and for adults living ASD.

13. The Alabama Autism Task Force recommends the **establishment of a continuum of residential options specific to individuals with ASD**, accessible in each region of the state.

To achieve this, we recommend:

Establishing an Autism Specific Waiver (as seen in recommendation 1-2) with provision for payment for the supports listed below.

- A. In home services, for those that would like to continue living in their family homes.
- B. Companion services, for those that do not require 24/7 care but do need assistance with some aspects of daily living.
- C. Out of Home Residential Placements, small 3 to 4 bed group homes/apartments with tailored supports.

14. Establishing certification standards for autism specific residential providers.

15. Consideration should be given to the establishment of “transition homes.” These homes could also be used for respite.

16. Pilot programs should be established for state of the art job training.

To achieve this, we recommend:

- A. The training program should be funded at a level that would provide intensive support for the participant (long-term job coaching and job preparation). The focus of the training should be on competitive employment.
- B. A summer job corps should be established for teens with ASD for the development of job skills.

17. College and university preparation and supports for individuals with ASD.

To achieve this, we recommend:

- A. Creation and statewide acceptance of a confidentiality release for college bound students for ASD.
- B. Transition programs should be established at State Universities.

Few mainstream medical professionals have ASD specific training. Although most in Alabama are insured by public or private insurance, coverage of needed services is very limited. 24 states to date have some sort of inclusion of services for ASD mandated by state law.

- 18. In order to ensure appropriate and equitable coverage for Autism Spectrum Disorders by private health plans and insurers, we recommend that **health insurance policies that include benefits for neurological disorders provide equivalent benefits to individuals with ASD**. We recommend that the evaluation and treatment be covered by public and private health insurance providers.
- 19. **In state documents, Autism Spectrum Disorders should be conceptualized as a non static neurobiological disorder with psychiatric co-morbidity** instead of an exclusively psychiatric or behavioral disorder.
- 20. **Enhance statewide access to appropriate diagnostic tests** for Autism Spectrum Disorders. Such tests include thorough neurodevelopmental assessments using standardized diagnostic tools. In addition, we recommend the state assist pediatricians statewide in implementing the American Academy of Pediatrics recommendation of screening children for ASD at 18 months and 2 years of age. This recommendation includes **ensuring appropriate insurance coverage for these activities**.
- 21. **Enhance the availability of evidence based treatments for ASD** across the state once diagnosis has been established. This treatment should be individualized and include but not limited to behavioral therapy, speech therapy, occupational therapy, and psychopharmacological treatment. These therapies should be available from trained professionals in ASD or supervised by trained professionals including certified behavior therapists, board certified speech language pathologists, board certified occupational therapists, licensed psychologists and medical doctors, including Neurologists and Psychiatrists, or nurse practitioners.

Families affected by autism are under extreme stress. The AACG found that education is vital to a family's ability to navigate the existing systems and to access needed services.

- 22. Families need a coordinated service delivery mechanism that extends thought out the lifespan.
To achieve this, we recommend:
 - A. **Developing services for our expanding teen/adult/senior populations** regardless of functioning level.

- B. **Allocating funds to the development of a web based directory of state and local services** working in conjunction with the established Statewide Advocacy organization.