

January 21, 2008

Systems of Care

In attendance: Jennifer Sellers, Lee Yount, Kim Hill, Jennifer Muller, Beverly Marson, Linda Haines, Alice Widgeon.

The committee worked to develop the preliminary recommendations to be presented to the Full Task Force on Wednesday, January 23rd in Birmingham.

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.

The Systems of Care Subcommittee met on seven occasions to determine what systems needs exist in Alabama so that citizens with ASD can be better served. Within this meeting structure and timeframe, the committee reviewed existing systems, studied national approaches and reviewed models of service used for various disabilities. This intensive effort led to the identification of the following problems, which need to be addressed:

PROBLEMS AND NEEDS:

Individuals with autism do not receive the supports and services they need to reach their full potential at home, community and educational settings, and vocational pursuits.

1.) Existing systems of care are fragmented and limited in their services and supports for individuals with ASD; these existing systems may serve some individuals with autism and exclude others with autism due to statutory authority, eligibility criteria, age exclusions, waiting lists, policies, or other access barriers. Parents are often sent to numerous agencies that do not have “ownership” of the “problem” and often feel that they are a “hot potato” being passed around with no solutions or help being offered.

- Services provided through DMH/MR Medicaid Waivers and the Medicaid Rehabilitation Option are limited to statutorily authorized and/or targeted populations; have age restrictions, waiting lists, and limited provider capacity to serve specialized populations. Other state Home and Community Based Waivers, such as State of Alabama Independent Living Waiver (SAIL) and the Elderly and Disabled Waiver (E & D) contain similar access barriers. Even if a person with autism meets criteria for these waivers, the service configuration may not be designed to meet the needs of a person with autism.
- Services for older adolescents and adults through the Department of Rehabilitation are very limited and do not provide the scope or type of long term supports necessary for the majority of individuals with autism to be successful in a vocational or work related setting.
- A child with Asperger’s Syndrome, or a less severe form of autism, may “test out” academically in the school system and not qualify for special education services, but still not have functional use of academic, communication, or social skills.

2.) Individuals with autism and their families need supports and services from many different systems of care service agencies and organizations throughout the lifespan. However, in Alabama, these systems are not timely, are fragmented, may have duplicative services and lack other needed

services. Overall, the systems have not accomplished a seamless transition process from one system to the next that works well for individuals with ASD or their families.

- In Alabama, the average age of diagnosis is 5+ years. A lack of standardized screening (to include autism specific screeners) at 18 and 24 months hampers early diagnosis and treatment, both of which are demonstrated to produce effective outcomes for children in terms of accomplishment and school readiness, and have to have long-term cost savings. Waiting lists for comprehensive, multidisciplinary diagnostics may be 4 – 6 months.
- Alabama's Early Intervention System (AEIS) under the AL Department of Rehabilitation Services is the only system identified that is mandated, under the Individuals with Disabilities Education Act (IDEA, Part C), to serve infants and toddlers birth to three, with autism or other developmental delays and their families. The mandate for Head Start is that 10% of the children served are to be children with disabilities, inclusive of autism. Transition into public preschool special education (IDEA, Part B) from the above systems is problematic for children and families, with different eligibility criteria, uneven levels of services, and lack of service coordination (case management) to continue to help families navigate the various systems of care.
- The medical system of care for this population needs strengthening. There is a lack of trained medical personnel that are available and accessible to individuals with autism. This includes but is not limited to psychiatrists, dentists, and geriatric and other specialist.
- Transition from the public school system to systems of care for adults (adult services, independent or supported living arrangements, employment, or higher education) is very problematic and extremely limited in scope and capacity.
- Additional resources are needed throughout in order to provide the necessary level and intensity of evidence-based practices that are known to be effective with this population.

3.) Our existing systems of care, including the medical profession, early intervention and pre-school systems, service providers, public school systems and teachers, vocational and higher educational settings are not well-trained to address the needs of individuals with ASD. Education, recruitment, retention, training and personnel development should be addressed in the development of a supportive infrastructure.

- There is a lack of opportunity for coordination of services, collaborative work and training opportunities
- Although several Universities offer some services and training opportunities they often operate as silo's and services are not well integrated within the University and the community.
- While there are several national and federal funding opportunities available, the lack of a coordinated system of care prevents Alabama from competing for grants from many of the funding sources. This limits our capacity to develop services and pursue research.

4.) Other related systems and findings:

- *Parent, Sibling, Peer Support, ongoing Case Management, and Advocacy Organizations.* These are vital contributors to quality of life and rights and due process issues for those with autism and their families, but more are needed.
- *Private health insurance.* Coverage is often employer driven and thus limited in scope. Parity for mental health, inclusive of behavioral treatment needs, and physical health needs is needed. Incentives should be developed for early screenings.

- *Public health coverage:* May lack adequate resources to provide covered services or expand services.
- *Legal and justice systems.* There are a growing number of cases coming to the attention of the police, local family courts and within the judicial system. Law enforcement needs to be trained in dealing with individuals with autism and special needs. Some of the actions of individuals with autism are misunderstood and viewed as uncooperative or resistant due to their unique behaviors and arrest and charges may result which could have been resolved more appropriately.

In summary, as a result of the committee's work, it was found that Alabama citizens with ASD need the following:

- Early Screening and Diagnosis
- Service Coordination/Case Management
- Access to effective and evidence-based Treatments, Interventions, Individualized Services, and a Range of Supports throughout the Lifespan
- Protection, Advocacy, and Parent and Peer Support Groups
- Respite Care, Crisis Care and Related Crisis Services
- Access to meaningful work including long term supported employment
- Seamless transition processes and supports across systems throughout the life span

RECOMMENDATIONS:

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 independent 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:

- 1.) 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, based on 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.
- 2.) 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.
- 3.) A Director of Autism Services should be employed that reports to the designated authority or interagency council and its designated members, and coordinates 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.

- 4.) 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.–
- 5.) 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.
- 6.) 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.
- 7.) 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.
- 8.) Best practice standards should be developed and appropriate certification or accreditation for service providers and personnel must be a part of a comprehensive plan.
- 9.) 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.

- **But we can perhaps remember – even if only for a time – that those who live with us are our brothers, that they share with us the same short movement of life, that they seek – as we do – nothing but the chance to live out their lives in purpose and happiness, winning what satisfaction and fulfillment they can."**