

# ALABAMA INTERAGENCY AUTISM COORDINATING COUNCIL



2012

Annual Report

*Autism Spectrum Disorder is a developmental disability that causes substantial impairments in social interaction and communication and the presence of unusual behaviors and interests. Many people with ASD have unusual ways of learning, paying attention, and reacting to different sensations. The thinking and learning abilities of people with ASD can vary from gifted to severely challenged. ASD begins before the age of 3 and lasts throughout the life of a person with the disorder. (Act 2009-295)*

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

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# Foreword: Autism in Alabama

The Alabama Interagency Autism Coordinating Council (AIACC) 2012 *Annual Report* provides updates on progress toward achieving goals set out in our State Plan, which is based on recommendations from the Alabama Autism Task Force's (AATF) 2009 findings.

The most recent autism prevalence rate released by the CDC's Autism and Developmental Disabilities (ADDM) Monitoring Network, 1 in 88 children are identified as having an Autism Spectrum Disorder (ASD). The prevalence rate increases even more when describing the male population – 1 in 54 boys are identified as having an ASD. That is five times the rate of ASD in girls.<sup>1</sup>

When applying these statistics to population estimates from the U.S. Census Bureau, there are as many as 54,800 Alabamians affected by ASD.<sup>2</sup> The number of children under the age of 18 affected by ASD may be as many as 12,900. The number of adults 18 years of age and older may be as many as 41,900.

Supports and services provided to those with ASD allow for greater gains through early identification and treatment, increased opportunities for employment, and a reduced need for as intensive of supports later in life (thereby reducing the associated costs for services). Thoughtful and intentional planning for this population is necessary – for the health and quality of life for Alabamians with ASD and their families, as well as for our state as a whole.

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<sup>1</sup> CDC's Autism and Developmental Disabilities Monitoring (ADDM) Network, [http://www.cdc.gov/NCBDDD/autism/states/ADDM\\_fact\\_sheet\\_2012.pdf](http://www.cdc.gov/NCBDDD/autism/states/ADDM_fact_sheet_2012.pdf)

<sup>2</sup> U.S. Census Bureau: State and County QuickFacts, <http://quickfacts.census.gov/qfd/states/01000.html>

# About the AIACC

## HISTORY

### Alabama Autism Task Force

On March 20, 2007, State Representative Cam Ward and Lt. Governor Jim Folsom, Jr. announced the formation of the Alabama Autism Task Force (AATF). House Joint Resolution 23 was passed by the Alabama Legislature on March 8, 2007 and signed into law by Governor Bob Riley shortly afterwards. The AATF reviewed the state's response to the increased incidence of ASD.

The AATF was comprised of advocates, state officials, educators, physicians, and members of the academic community to recommend ways to improve the treatment of autism in Alabama. Representative Ward and Lt. Governor Folsom served as Chairmen for the AATF, which held its first meeting on June 17, 2008. The final meeting of the AATF was held on January 22, 2009.

The AATF was composed of 27 appointed members and a number of volunteers, and was organized into the following Subcommittees: Diagnosis and Early Screening, Intervention Services (0-5), Intervention Services (6-21), Intervention Services (Adult), Health Care, Ad Hoc (Regional Center Development), Systems of Care, and Financial Impact.

Each Subcommittee reviewed data gathered through the Alabama Autism Needs Assessment, which was conducted in conjunction with the AATF's activities. Recommendations were given based on current identified needs and available research.<sup>3</sup>

### Alabama Autism Collaborative Group

The Alabama Autism Collaborative Group (AACG) received a grant from the Alabama Council for Developmental Disabilities (ACDD) to conduct a statewide Autism Needs Assessment in order to guide the recommendations of the AATF. The AACG conducted a thorough literature review to determine current best practices, seven community and family forums, in person and online surveys of parents and service providers, and key informant interviews. The Needs Assessment was conducted between September 2007 through May 2008.<sup>4</sup>

### Alabama Interagency Autism Coordinating Council

The AIACC was created to carry out the work of the AATF once it dissolved in 2009. The AIACC, secured by the Alabama Autism Support Act of 2009 (Act #2009-295), is charged with meeting the urgent and substantial need to develop a statewide, comprehensive, coordinated, multidisciplinary, interagency system of care (SOC) for individuals with Autism Spectrum Disorder (ASD) and their families.<sup>5</sup>

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<sup>3</sup> *Alabama Autism Task Force: Final Report to the Governor and Legislature, January 2009*, [http://autism.alabama.gov/Documents/Autism\\_Task\\_Force\\_Final\\_Report.pdf](http://autism.alabama.gov/Documents/Autism_Task_Force_Final_Report.pdf)

<sup>4</sup> *Statewide Autism Needs Assessment: Final Report, June 2008*, Alabama Autism Collaborative Group, [http://autism.alabama.gov/Documents/Autism\\_Needs\\_%20Assessment\\_Full\\_Report.pdf](http://autism.alabama.gov/Documents/Autism_Needs_%20Assessment_Full_Report.pdf)

<sup>5</sup> *Alabama Autism Support Act (Act 2009-295)*, [http://autism.alabama.gov/Documents/Legislation/ACT\\_num\\_09-0295\\_HB0041.pdf](http://autism.alabama.gov/Documents/Legislation/ACT_num_09-0295_HB0041.pdf)

Recommendations from the AIACC are to be derived from scientifically based research and national recognized best practices. The AIACC is also to ensure interagency collaboration, public participation, and mutual sharing of information to facilitate policy decisions and the implementation of a plan for a comprehensive statewide system of care to individuals with ASD.

The AIACC is to develop a long-term plan and steps toward creation and implementation of a comprehensive system of care. The plan is to address: identification barriers such as duplicative or fragmented policies which may require modification; the development of a coordinated program of services; a comprehensive fiscal review, analysis and recommendations for state spending on programs and services for ASD; and the identification of annual action steps toward implementation.

## MEMBERSHIP

The AIACC is composed of the following members:<sup>6</sup>

### **Governor appointed members include:**

Linda Bachus, A.S.F.A.  
\*Greg Carlson, A.C.A.  
Robert Tristan Dunn, A.S.E.A.  
Jerimie W. Goike, A.S.E.A.  
Bama Folsom Hager, Ph.D., A.S.F.A., Co-chair  
\*Doris Hill, Ph.D., A.C.A.  
\*Mitchell Lord, A.S.E.A.  
\*Sarah Ryan, Ph.D., A.C.A.  
Hanes Swingle, M.D., M.P.H., A.C.A.  
\*Todd Tomerlin, A.S.F.A.  
Kathy Welch, M.A., C.C.C./S.L.P., A.C.A.

**Senate Appointee:** Cam Ward, A.S.F.A., Chair

**House Appointee:** Becky Nordgren, A.C.A.

### **The chief executive officer or a representative from each of the following state agencies:**

Alabama Council on Developmental Disabilities  
Alabama Department of Children's Affairs  
Alabama Department of Education  
Alabama Department of Human Resources  
Alabama Department of Insurance  
Alabama Department of Mental Health<sup>7</sup>  
Alabama Department of Public Health  
Alabama Department of Rehabilitation Services  
Alabama Institute for Deaf and Blind  
Alabama Medicaid Agency  
American Academy of Pediatrics – Alabama Chapter  
Autism Society of Alabama

University Center of Excellence in Developmental Disabilities Education, Research, and Service

*\*New appointments as of October 2012*

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<sup>6</sup> Key: Autism Spectrum Expert Advisor (A.S.E.A.), Autism Spectrum Family Advisor (A.S.F.A.), Autism Community Advocate

<sup>7</sup> The Alabama Department of Mental Health is the lead agency for the AIACC.

# Year in Review

## LEGISLATIVE REVIEW

### Relevant Legislation

Senate Bill 283 requires health benefit plans to offer certain coverage for ASD in certain policies and contracts. Under contracts with employers of at least 51 employees, a health benefit plan shall offer coverage for screening, diagnosis, and treatment (prescribed by licensed physician or psychologist) of ASD for an insured nine years of age and younger. Screening, diagnosis, and treatment of ASD shall be offered inclusion in health insurance policies beginning in the following renewal period. A health benefit plan may not deny or refuse coverage on an individual solely because the individual is diagnosed with ASD. Coverage for behavioral therapy is subject to a \$36,000 maximum benefit per year.<sup>8</sup>

*The bill was enacted and is now part of the Alabama Code (Act 2012-298).*

### Budget

Total state dollars allocated to support the mission and recommendations of the AIACC in 2012 amounted to \$91,000. This came from both the State General Fund (\$36,316) and the Education Trust Fund (\$55,000). The 2013 budget is set to be approximately \$90,000.

## LONG TERM PLAN PROGRESS

The AIACC is continuing to “build the infrastructure” (Step 1 of 4 of the State Plan). Preparations for Steps 2-4 are being made; however, they can only occur when funding is available.

### Strategic Planning

The Strategic Planning Committee completed their work in May 2011. The work is incorporated into the proposed Long Term Plan. To view the Strategic Plan, visit:

[http://autism.alabama.gov/Documents/AIACC\\_Strategic\\_Plan.pdf](http://autism.alabama.gov/Documents/AIACC_Strategic_Plan.pdf).

### Standards of Practice

The **Diagnostic Clinics Workgroup** and the **Professional Preparation and Training** reports have been completed. All of the recommendations will go through a vetting process; however the Diagnostic Clinics report will be vetted first as a pilot. Recommendations by the other workgroups (**Birth – 5 Services, 6-21 Services, Transition Services, and Adult Services**) are nearing completion as well. It is anticipated that all Standards of Practice recommendations will be fully vetted by 2014. These recommendations may be viewed online upon review at [www.autism.alabama.gov](http://www.autism.alabama.gov).

Fred Biasini, Ph.D., Director of the University Center of Excellence in Developmental Disabilities Education, Research, and Service, became the new Standards of Practice chair as the previous chair stepped down upon her retirement. His valuable experience in systems of care development and implementation, developmental disabilities, clinical service delivery, healthcare structures, and education will help guide Standards of Practice development.

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<sup>8</sup> Excerpted from *Riley Ward Act* (Act 2012-298)

## Special Projects

The **Developmental Surveillance and Early Screening Workgroup** has made much progress. Products from the CDC State Systems “Act Early Alabama” grant (\$15,000) continue to be distributed and adapted for healthcare, early education, and parental use. Act Early Alabama information was shared with practice managers of Children’s of Alabama across the state, focusing on early signs of ASD. New partnerships with Alabama’s *Help Me Grow* program are being strengthened through joint grant application projects (although unfunded), and common service interests. An Act Early Alabama website is under development (<http://www.uab.edu/civitansparks/act-early-alabama>). In addition, workgroup leader Sarah O’Kelley, Ph.D. and fellow group member Angie Barber, Ph.D. presented during a webinar for the Alabama Public Health Training Network, which reached over 900 people and will continue to be available for 18 months after broadcast. The webinar is available on demand at <http://adph.org/ALPHTN/index.asp?id=5875>. Trainings on early warning signs, appropriate referrals, and treatments continue to be pursued and hosted regionally.

Some of the Special Projects workgroups were restructured to better tailor to the activities that have evolved over time. The **Community Services and Support** workgroup (formerly Family Support and Community Services workgroups) is focusing on a community-based awareness campaign, expansion of *A Child is Missing* to every county in Alabama, continued research into respite opportunities, and the development of a “how-to” portfolio that features contributions from stakeholder on how to navigate the current system of care and how to manage everyday issues specific to ASD. The **Resource Development** workgroup (formerly the Awareness workgroup) continues to collect resources for inclusion into an online and print resource directory. The group is also working to identify an efficient and effective method of online maintenance before the directory can be posted online.

## BARRIERS

The *Diagnostic and Statistical Manual of Mental Disorders (DSM-5)* will be updated to the fifth edition in May of 2013. The projected changes to ASD will update the manual to only have one diagnosis of “Autism Spectrum Disorder” rather than three separate diagnoses of PDD-NOS, Asperger’s Syndrome, and Autistic Disorder. Levels of severity are also said to be part of the proposed changes, allowing diagnosticians to indicate areas of greatest need for support. The upcoming DSM-5 changes will likely result in revision of currently used diagnostic instruments, e.g., the ADOS, ADI, GARS, GADS, etc., which will require the AIACC to update recommendations to prevent them from appearing dated.

The need for funding for Regional Networks for ASD and related disabilities is great. The AIACC is currently searching for grant funding to aid in this process. Regional Networks will provide: staff with expertise in ASD; individual and direct family assistance in the home, community, and school; technical assistance and consultation; professional training programs; and public education programs.<sup>9</sup> Many of these facets are being prepared and developed and collaborations formed; however, funding is the key ingredient for the creation of an Autism Regional Network.

In March of 2012 a new State Autism Coordinator was hired to fill the recently vacant position. Although there was a lapse in the presence of an Autism Coordinator, the committees and workgroups carried on the duties of the Council.

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<sup>9</sup> Act 2009-592, [http://autism.alabama.gov/Documents/Legislation/ACT\\_num\\_09-0592\\_HB0615.pdf](http://autism.alabama.gov/Documents/Legislation/ACT_num_09-0592_HB0615.pdf)



## GENERAL UPDATES

The *AIACC Bylaws* were amended to include “an individual who serves in an executive level capacity from a private health insurance carrier who addresses medical/health policy, appointed by the Governor”.<sup>10</sup> The AIACC also voted on a two term limit (each term is three years) for each appointed member.

The Executive Committee of the AIACC held its first meeting in October. The Committee agreed to more data collection within state agencies and the sharing of this information with the AIACC to provide better collaborations, improved projections of service needs, and a stronger foundation for future grant applications.

# Conclusion

The AIACC has made significant steps toward crafting a system of care that will benefit individuals affected by ASD and their families, as well as those providing services. While there is much left to be done, the cooperation among agencies and individuals has made the process more efficient. Drafts of recommendations that have been made for standards of practice will need to be completed, reviewed, approved, and implemented when the opportunity is available. Cooperation among state agencies is vital in providing a smoother system of care for individuals with ASD. Establishment of a Regional Network hinges on funding availability. However, the AIACC committees are working hard to be prepared for when that funding does become available.

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<sup>10</sup> *Alabama Interagency Autism Coordinating Council Bylaws*, <http://autism.alabama.gov/bylaws.html>

# Alabama Autism Task Force Recommendations

## APPENDIX A

Using the information collected through the Alabama Autism Task Force (AATF), informed by data collected through the *Alabama Autism Needs Assessment* as a guide, the AIACC is making progress toward addressing the identified needs.

### A. DIAGNOSIS AND EARLY SCREENING<sup>11</sup>

#### (1) Diagnostic Services

- A.1.1 The Alabama Autism Task Force recommends establishment of University-Based Regional Interdisciplinary Diagnostic Evaluation Clinics that provide assessments by psychologists, speech/language specialists, education specialists, physicians (e.g., pediatric neurologists, child psychiatrists, developmental-behavioral pediatricians, geneticists), occupational therapists, and other allied healthcare providers. A regional center diagnostic clinic approach would provide greater access to services for families from all areas of the state.
- A.1.2 Regional Autism Centers work collaboratively to develop a protocol of standardized assessments when evaluating children suspected of autism spectrum disorders. At a minimum, these evaluations should include a standardized ASD-specific behavioral observation (e.g., the Autism Diagnostic Observation Schedule), an ASD-specific caregiver interview (e.g., the Autism Diagnostic Interview), a standardized cognitive/intellectual assessment, a standardized language/communication assessment, a medical evaluation and a vision and hearing screen.
- A.1.3 After a child is diagnosed with an ASD at one of the Regional Autism Centers, it is recommended that all agencies that receive state funding (e.g., public schools, mental health facilities, Early Intervention) should accept the diagnosis and provide appropriate services. Thus, the regional centers should work with each state agency to ensure that the necessary assessment information is collected to meet agency requirements.
- A.1.4 Regional Autism Centers should provide student practicum and internship training opportunities to promote the development of well-trained ASD professionals entering the workforce. These training opportunities should, at a minimum, include students in education, communicative disorders, psychology, medicine, nursing, social work, and occupational/physical therapy.
- A.1.5 Regional Autism Centers should collaborate with the State Department of Education to develop guidelines for school personnel to make referrals for school-aged children suspected of autism or Asperger syndrome who have not been identified prior to school entry.
- A.1.6 Third party payors should cover the costs associated with an interdisciplinary diagnostic evaluation.

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<sup>11</sup> See full text of recommendations in the *Alabama Autism Task Force Final Report*, 2009, [http://autism.alabama.gov/Documents/Autism\\_Task\\_Force\\_Final\\_Report.pdf](http://autism.alabama.gov/Documents/Autism_Task_Force_Final_Report.pdf).

PROGRESS TO DATE: *Funding is being pursued to aid in the development of University-based Regional Networks. Recommendations for Standards of Practice regarding a standardized assessment protocol have been developed and is currently being vetted by various stakeholders. Agency collaboration is being reviewed and further developed to move toward a more coordinated SOC for those with ASD. Legislation that provided private insurance coverage for a portion of the policyholders was passed in 2012. This included coverage of screening, diagnosis and treatment of children 9 years of age and younger.*<sup>12</sup>

## (2) Early Screening: Health Care Settings

A.2.1 The Alabama Autism Task Force recommends that all health care practitioners who provide primary care to young children provide universal screening and surveillance for developmental delays/disabilities and for autism spectrum disorders. Health care practitioners are encouraged to conduct ASD-specific screening at the 18 and 24 month well-child visits using instruments with good sensitivity, specificity, and positive predictive value. Currently, two instruments meet these criteria: the Communication and Symbolic Behavior Scales Infant Toddler Checklist and the Modified Checklist for Autism in Toddlers with the associated caregiver interview.

In order to fulfill this recommendation, The Alabama Autism Task Force recommends that the University Based Regional Autism Centers, in collaboration with Alabama Chapter of the American Academy of Pediatrics (AAP), the Medical Association of the State of Alabama (MASA), Alabama Department of Rehabilitation Services, and the Autism Society of Alabama (ASA), promote and conduct the following activities to overcome the barriers to screening:

- A.2.2 Encourage third party payors to reward health care practitioners who routinely provide general developmental and ASD-specific screening (i.e., provide a greater level of reimbursement to providers who administer ASD-specific screening).
- A.2.3 Develop and disseminate educational materials for health care providers in Alabama that both describes the CSBS ITC and the M-CHAT and provide information about the referral process when concerns arise during screening. These “training kit” materials could be presented via a brochure, a training DVD, and online formats.
- A.2.4 Organize and conduct regional and state training for health care professionals on early identification of ASD, administration of the CSBS ITC and the M-CHAT, and referral for follow-up services.
- A.2.5 Provide onsite training and assistance to health care providers to facilitate screening and referral approaches for children who are identified as being at-risk for ASD.

PROGRESS TO DATE: *In addition to the M-CHAT and the CSBS-ITC, the Ages and Stages Questionnaire: Social-Emotional (ASQ-SE) is also being recommended as a screener for developmental disabilities/delays and ASD. The Learn the Signs. Act Early. (L TSAE) project by the CDC provides materials in English and Spanish, which has been adapted to Alabama and is being distributed to parents, early educators, and healthcare professionals across Alabama. Help Me Grow is another partner initiative that aids in training using screeners and appropriate referrals. L TSAE also provides Autism Case Training: A Developmental-Behavioral Pediatrics Curriculum, which trains healthcare professionals in appropriate screening procedures, diagnostic tools, and referrals; planning has begun for strategic dissemination and implementation of this training. In addition, Dr. Sarah O’Kelley and Dr. Angie Barber presented a free Webinar focused on early recognition and referral for ASD that included state-specific information and resources, with over 900 participants watching the live event. This Webinar is archived with CEUs available for several disciplines for 2*

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<sup>12</sup> Riley Ward Act (Act 2012-298)

years at: <http://adph.org/ALPHTN/index.asp?id=5875>. Ongoing efforts include developing a state Act Early website and continuing to conduct regional trainings on the early signs of ASD throughout Alabama.

### (3) Early Screening: At-Risk Early Service Providers

- A.3.1 The Alabama Autism Task Force recommends that all agencies working with at-risk young children (i.e. Early Intervention, Early Head Start) conduct ASD-specific screening among the population of children they serve.
- A.3.2 The Regional Autism Centers should consult and provide instruction on ASD-specific screening instruments to be used in at-risk intervention settings and provide prompt specialized diagnostic evaluations for children who fail these screenings.
- A.3.3 Early Intervention should develop a partnership with referring physicians and provide timely feedback regarding assessments, treatments and progress of the children they serve.
- A.3.4 The Alabama Autism Task Force recommends that early intervention providers administer an evaluation tool that directly measures behaviors that are unique to ASD. This evaluation may be administered in addition to the evaluation measures typically administered to determine eligibility for early intervention services.

In order to fulfill this recommendation, the Alabama Autism Task Force recommends:

- A.3.5 The Regional Autism Centers should provide instruction on tools such as the CSBS, ESCS, and ASQ:SE that may be incorporated into the assessment protocol administered by early interventionists. These assessments are not designed to diagnose ASD, but rather to identify developmental goals related to ASD-specific difficulties in social interaction and nonverbal communication.

*PROGRESS TO DATE: Partnerships with organizations that serve young children have allowed for the continued dissemination of developmental screening materials. Referrals generated because of a failed screener, like the ASQ-SE, are accepted by Early Intervention and evaluated for eligibility for services.*

### (4) Public Awareness

- A.4.1 Future public awareness campaigns should promote the early signs or “Red Flags” of autism spectrum disorders and delineate the actions that parents and health care providers need to follow to ensure that children with ASD are identified early. Such actions include encouraging parents to voice their concerns and to request developmental and ASD-specific screening from their child’s health care provider. The awareness campaign should provide parents and health care providers with the phone number of the Autism Regional Centers and promote referral to service providers through Child Find (1-800-543-3098).
- A.4.2 The Alabama Autism Task Force recommends that the Autism Society of Alabama (or other advocacy agency) receive grant funding to collaborate with a public relations agency to direct an education campaign on ASD screening and referral for diagnostic and intervention services.
- A.4.3 The Alabama Autism Task Force encourages state medical licensing boards to require one hour of Continuing Medical Education on autism spectrum disorders for license renewal. The Center for Disease Control considers ASD to be a public health crisis. Thus, it is important for physicians and other health care providers to be educated about ASD including information on the prevalence of the disorder, identifiable causes, screening, diagnosis, co-morbidities, recurrence risks, medical

treatment, complementary and alternative therapies, educational and behavioral management, and prognosis.

PROGRESS TO DATE: *An awareness campaign has been developed using LTSAE materials and is set to be implemented within the year. This campaign includes various forms of media and is in partnership with the Autism Society of Alabama (through the Developmental Surveillance and Early Screening Workgroup of the AIACC).*

## B. BIRTH TO FIVE SERVICES

### (1) Family Support and Training

**Families have access to the information, support** (empowering families), **training** (specific term used for teaching skills), **and resources they need in their home community.**

- B.1.1 A Parent-to-Parent network will be developed or piggy-backed onto existing systems that will allow veteran parents to be well trained to then provide support to those parents whose child is newly diagnosed.
- B.1.2 Gaps in provision of support and training for caregivers will be identified and local agencies will be recruited to provide these services in these communities.
- B.1.3 Parent training and support will be individualized.
- B.1.4 Web Directory of services in local communities will be enhanced, revised, and updated with additional information from local communities. A statewide calendar of ASD related events will be maintained.
- B.1.5 Existing community supports (ex. Churches and other local supports that people are already comfortable with) will be made aware of the needs of children with ASD and their families in order to better support them.

PROGRESS TO DATE: *The Resource Development Workgroup of the AIACC has been compiling available resources for ASD and is investigating the most efficient and effective online delivery system. A resource list is housed at the Autism Society of Alabama and is available through an information and referral line. The Community Services and Supports Workgroup is developing an awareness campaign for community businesses and services; the campaign will include information on how to better serve people with ASD and their families.*

### (2) Evidence-Based Accessible Services

**Children receive individualized evidence-based and best practice treatments which are readily available in their home communities.**

- B.2.1 There will be a mechanism to review the evidence-base on evaluation, assessment, and diagnostic criteria at regular intervals and update providers and families on best practices.
- B.2.2 Children will be allowed to access services under more flexible eligibility criteria (i.e. those that take into account social-emotional, adaptive, and functional deficits as well as communication, academic, and cognitive) that are consistent across all publicly funded service systems.
- B.2.3 There will be a mechanism to review the evidence-base on treatments at regular intervals and update providers and families on best practices.

- B.2.4 National recommendations and recommendations from updated reviews of the evidence-base will be given to all providers and parents (e.g. given at diagnosis and with the Parent Rights statement at IFSP/IEP) in an easily digestible format.
- B.2.5 Providers in local communities will be trained to provide a variety of specific, targeted, developmentally appropriate, and intensive evidence-based treatments to fidelity using didactic presentations, experiential learning (onsite and hands-on), and ongoing consultation and coaching.
- B.2.6 Provision for ongoing consultation and coaching with treatment experts will be readily available so that providers can easily update their skills.
- B.2.7 Data based decision making (e.g. data on measurable, observable behaviors and skills will be taken at baseline and following brief periods of intervention) about treatment strategies and efficacy for each child will be used. Strategies will be changed if progress is not being observed.

PROGRESS TO DATE: *The Standards of Practice Committee of the AIACC is developing recommendations based on evidence base and best practice resources. It is planned that once completed, these recommendations will go through a full review every five years and otherwise updated as needed. These recommendations will be available in electronic and paper formats when completed.*

### (3) Service Coordination

**Children and families experience a seamless transition between interventions/agencies through service coordination that is maintained from birth to five years of age.**

- B.3.1 Service Coordination (Case Management) will be provided by all agencies providing services to this population to ensure a seamless transition from time of screening to diagnosis to intervention, and across the age range.
- B.3.2 Service Coordinators will be trained to provide support to families and to track children and their services from screening to diagnosis and through the transition to Kindergarten.
- B.3.3 Service Coordination will also ensure that families have knowledge about their rights, the process involved in obtaining services from local agencies, and their choices of service providers.
- B.3.4 Service Coordination will also ensure a seamless transition from AEIS to SDE at three years of age by ensuring that transition meetings are held, a plan is in place, and there is no lapse in services when a child turns three years of age - EI provides services up until the last eligible day and SDE begins services on the first eligible day.
- B.3.5 Alteration to the funding streams will be advocated and considered to ensure seamless services and to allow positive effects of early investments to be experienced by the same funding agency.

PROGRESS TO DATE: *Service/care coordination practice guidelines are being reviewed and will be adapted to better serve ASD-specific needs. This coordination will be provided upon funding and creation of Regional Networks. Advocacy is ongoing.*

### (4) Inclusion in Home Communities

**Children and their families be fully integrated into their home communities**

- B.4.1 Local community organizations (churches, daycare centers, YMCA) will receive awareness information regarding ASD.

- B.4.2 Local community organizations will receive information regarding strategies for effective integration of children with ASD and their families.

PROGRESS TO DATE: *An awareness campaign is being developed with anticipated implementation within the year. This campaign will provide awareness and education opportunities, as well as information regarding effective integration strategies for people with ASD and their families.*

## C. SIX TO TWENTY-ONE SERVICES

### (1) Training and Support of Education Personnel

- C.1.1 Teachers (and all school personnel) should receive pre-service and in-service training regarding ASD and specific intervention techniques. There should be a system to monitor and track this training, and the training should include the rationale for why particular methods are of use to the students.
- C.1.2 Teachers should have ongoing access to model sites and individuals who have worked successfully on the spectrum for technical assistance and training.

PROGRESS TO DATE: *Online options that offer technical assistance and training are being pursued, in hopes that it will be used in collaboration with on-site training and consultation once Regional Networks are created. Expansion of training options and opportunities are being reviewed.*

### (2) Specific Interventions

- C.2.1 We should continually monitor the progress of the national projects that are working on creating a list of evidence based practices for this age group.
- C.2.2 As a listing is available, it should be available to the programs that currently exist in our state to train teachers. This list should also be translated into parent friendly terms and distributed to parents and other interested parties.
- C.2.3 Consideration should be given to training teachers in the strategies identified of best practices.

PROGRESS TO DATE: *Evidence based practices are being reviewed through the Standards of Practice Committee.*

### (3) Regional Center Development

- C.3.1 Determine the scope of Alabama's Regional Autism Centers. Careful consideration should be given to the additional services needed in regard to diagnosis and professional training. Legislation should be introduced that will allow the establishment of these centers.
- C.3.2 Utilize the Regional Centers, and the expertise within the University Systems, to move forward research on the causes of ASD and the treatment practices that can be most effective.

PROGRESS TO DATE: *Act 2009-592 allows for the establishment of regional autism centers (Regional Networks) and describes the various duties and responsibilities of the Network. Their establishment, however, is dependent on "when funds are appropriated by the Legislature through a line item appropriation" (when funding is available).<sup>13</sup>*

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<sup>13</sup> Act 2009-592, [http://autism.alabama.gov/Documents/Legislation/ACT\\_num\\_09-0592\\_HB0615.pdf](http://autism.alabama.gov/Documents/Legislation/ACT_num_09-0592_HB0615.pdf)

## D. ADULT (21+) SERVICES

### (1) Range of Housing and Housing Alternatives

- D.1.1 A continuum of residential options specific to individuals with ASD should be established and accessible in each region of the state. Services should include:
- In-home Services- Assistance and training in the home for adults whose families want to continue to provide care in their home.
  - Respite Care – Respite to families, both in-home and out-of-home, to allow families the time to devote to other family activities and for a break from the responsibilities of 24-hour care.
  - Intermittent Services- As needed, intermittent services for those adults who do not need 24-hour care but who do need assistance in particular areas of their daily living.
  - Out-Of-Home Residential Placements- Small, 3 to 4 bed, group homes or apartments in each region of the State with programming and supports specific to the needs of individuals with autism.
- D.1.2 Existing providers and the housing options available for adults with ASD (in-home, respite, intermittent, out-of-home) across the state should be identified. This can be accomplished by developing a comprehensive listing of providers and the housing options available specific to adults with ASD within each region of the state.

PROGRESS TO DATE: *The AIACC has partnered with the Alabama Respite Resource Network to identify available respite resources.*

### (2) Development of a Statewide System to Identify the Number of Adults with ASD in Alabama

- D.2.1 Identify existing providers, specific to ASD, across the state. A listing of ASD specific services available in each region of the state should be compiled.
- D.2.2 Identify the number of adults being served through existing ASD services and a projection of those waiting for services, by region. This can be accomplished by counting the numbers currently served by region and calculating the numbers that may be in need of services in the future.
- D.2.3 Add an indicator for ASD on the Waiver waiting list for services. The Waiver waiting list will then allow us to know the number of people with ASD who are currently waiting for services.
- D.2.4 Identify those young adults transitioning from school. A listing of the number of young adults transitioning from school who will be in need of services or supports within the next three years should be developed.

PROGRESS TO DATE: *A resource directory is being compiled and various data regarding individuals with ASD will be shared by state agencies, per legislative and Executive Committee directive.*

### (3) Develop Services for Adults with High-Functioning ASD

- D.3.1 Develop sources of funding for services to adults with high-functioning ASD.
- D.3.2 The state should develop a high-functioning ASD pilot project to serve a designated number of individuals who are currently ineligible for existing state Waiver services, as other states have done with legislative support.



PROGRESS TO DATE: *There are few services/organizations/agencies in Alabama that offer program opportunities for adults with ASD, but not all of these programs are specific to ASD.*

#### **(4) Promote Employment Opportunities for Adults with ASD**

- D.4.1 Vocational services must be defined and offered in a manner appropriate to adults with ASD. The eligibility for services and length of time supports are in place should be redefined for people with ASD.
- D.4.2 Identify/develop model programs to support young adults with ASD transitioning from school to work. Effective training and resources for young adults transitioning from school to work should be developed.
- D.4.3 Identify/develop model programs to support adults with ASD to gain and maintain integrated community employment.
- D.4.4 Identify the employment needs of adults with ASD. This can be done by conducting a statewide survey of employment needs of individuals with ASD.

PROGRESS TO DATE: *Model programs are being researched and reviewed. Project SEARCH is one project currently being piloted in Alabama in partnerships with Alabama Department of Rehabilitation Services - Vocational Rehabilitation, the Alabama Department of Education, and the Alabama Department of Mental Health. Project SEARCH is not ASD specific.*

#### **(5) Remove Transportation Barriers**

- D.5.1 Identify the extent of existing transportation barriers to services or community involvement. This can be done by conducting a survey of the transportation barriers encountered by individuals with ASD. We must determine to what extent these have interfered with services, employment and participation in other activities of community living.

PROGRESS TO DATE: *A transportation review is pending.*

#### **(6) Adequate Funding for Services**

- D.6.1 Services to individuals with ASD must be life-long rather than time sensitive. To terminate support to individuals because they have reached 21 years of age is not appropriate. The subcommittee understands the limitation of resources within the state of Alabama. However, the quality and quantity of services for adults with ASD is dependent upon an adequate amount of funding to support programs specific to ASD.
- D.6.2 Funding for adults with ASD should be maintained at current levels or ideally increased.
- D.6.3 Increase incentives for program development specific to adults with ASD within each region of the state.
- D.6.4 Evaluate the difference in reimbursement rates between programs for children with ASD versus the reimbursement for programs specific to adults with ASD. Evaluate the difference in reimbursement rates between programs for adults in the DMH DD/ID system and the reimbursement rates for programs specific to adults with ASD.

PROGRESS TO DATE: *Evaluation of reimbursement rates is pending. Funding is being closely watched during economic difficulties.*

## (7) Community Awareness of Adults' Needs

- D.7.1 An ASD awareness campaign to include the needs of adults with ASD, specifically to assist adults with integration into the community. Coordinate public awareness efforts to bring attention to the needs of individuals with ASD, specifically adults. Identify/develop opportunities to link public awareness activities through DMH, SDE, ASA, ACDD, and providers.

*PROGRESS TO DATE: Awareness campaigns are being developed and implementation is anticipated within the year. These campaigns encompass the lifespan rather than adult-specific.*

## (8) Case Management Services

- D.8.1 The system for access to case management and case coordination should be easy for families and individuals. Develop regional service coordination for ASD.
- D.8.2 Develop a provider directory to identify local services within each region of the state for individuals with ASD. Identify resources available to adults with ASD in each region of the state.
- D.8.3 Develop a system to communicate local services available to adults with ASD within each region of the state. Disseminate the provider directory to each regional community services office, VRS office, and ASA chapters/websites.
- D.8.4 Identify a central contact within each region of the state.

*PROGRESS TO DATE: Regional Network creation is pending state funding. Care coordination and central point of contact is a part of the duties of the Regional Networks. A Resource Directory is being updated and developed; an efficient and effective online tool to manage this directory is being pursued. A resource directory is available online at the Autism Society of Alabama.*

## (9) Training for Emergency Response Personnel

- D.9.1 Develop a requirement for ongoing training for law enforcement and other emergency responders in Alabama. Training to include: ASD and Law Enforcement training and videos (e.g. by Dennis Debbaudt). Training needs to include emphasis on entire ASD spectrum. Training should assist in:
- Becoming Americans with Disabilities Act (ADA) compliant
  - Increasing responder and citizen safety
  - Enhancing response skills
  - Avoiding litigation
  - Building community partnerships
  - Increasing awareness of ASD
- D.9.2 Identify recommended training for emergency response personnel. Review training and videos by Debbaudt and other sources.
- D.9.3 Recommend/provide information on training to emergency responders within each region of the state. Survey emergency responders for training currently received on autism or developmental disabilities.

*PROGRESS TO DATE: Dennis Debbaudt presented his Autism Risk Management curriculum to first responder and emergency personnel in the First Responders and Autism: Training Symposium in 2010. This training was supported by the Alabama Department of Public Health, Alabama Department of Mental Health, Alabama Council for Developmental Disabilities, and the AIACC. Information regarding tools for First*

Responders, such as A Child is Missing, the Yellow Dot program, and Project Lifesaver, are also being disseminated. Trainings on ASD within the Alabama Fire College are provided within their curriculum as well.

## E. REGIONAL CENTER DEVELOPMENT

### (1) Coordination of Services for ASD throughout the Lifespan

- E.1.1 The proposed regional resource center should be a source for assessment and intervention services information for ASD. Furthermore, the center should serve the entire ASD spectrum, regardless of affected child's or adult's IQ or family resources.
- E.1.2 The regional resource center should be a training site for many professionals – early intervention therapists, physicians, psychologists, speech-language pathologists, teachers, occupational therapists, nurses, therapists, and other providers. In particular, there is a need for pediatrician training and family practice physician training for screening and diagnosis of ASD.
- E.1.3 The regional resource center should identify a **best practices statewide multidisciplinary battery for the assessment of ASD** and an agreed upon **best practices treatment of ASD**. These assessment instruments and treatment recommendations should be research based.
- E.1.4 The regional resource center should **establish a parent to parent support network** to assist families in the transitions from early intervention to preschool to school and to adulthood. In addition, the subcommittee states that the regional resource center for autism should have a **working relationship with the Autism Society of Alabama**. The Autism Society of Alabama is the leading autism advocacy group in the state and can assist with parent networking and family support.
- E.1.5 A **public awareness/education campaign** should be in place in conjunction with the development of the center. This campaign will support families affected by ASD by raising awareness of ASD in the general population and nurturing understanding of those affected.
- E.1.6 The regional resource center should be a **remote consultation site for providers** who are working with ASD clients/patients.
- E.1.7 The regional resource center should assist families with young children in the areas of IEP training, insurance coverage information, respite care services information and crisis management information and referrals.

*PROGRESS TO DATE: Preparations are being made to be ready to perform necessary functions of the Regional Network when it is created (when funding is available). The responsibilities of the Regional Network are outlined in the Alabama Autism Support Act of 2009.<sup>14</sup> Best Practice and Evidence Based recommendations are being prepared for diagnostic assessments, professional preparation and training, and services across the lifespan. The Special Projects Committee of the AIACC is building the awareness/education component, and partner organization Autism Society of Alabama currently provides Information and Referral support and parent networking groups.*

## F. SYSTEMS OF CARE

### (1) Creation of State Autism Coordinator Position

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<sup>14</sup> Alabama Autism Support Act (Act 2009-295)

F.1.1 The State Autism Coordinator should possess the following knowledge, skills, and abilities:

Knowledge:

- ASD through the lifespan
- Best practices in the field of ASD (e.g. instructional strategies)
- Funding avenues
- Home, educational, and community based services
- Child development
- State Government and Non-governmental agencies
- State and Federal rules and regulations regarding ASD and related subject matter

Skills and Abilities:

- Collaboration, negotiation, diplomacy, conflict resolution
- Working with the consumers and families
- Computer/technology
- Grant Writing
- Communication-written and oral
- Financial matters (e.g. budgets, funding sources, grants)
- Communicate effectively and work with primary and secondary groups (e.g. consumers, interest groups both private and public)
- Represent the needs and wants of individuals with ASD and their families
- Professionalism

Duties:

- Bring needs/wants of consumers to the attention of stakeholders
- Represent consumers and/or families
- Bring key agencies together
- Assist in locating and obtaining funding
- Advocate interests of consumers to key agencies, interest groups, and stakeholders
- Travel—may involve extensive travel
- Facilitating key agencies, interest groups, and stakeholders
- Developing Legislative Plan

**PROGRESS TO DATE:** *The Alabama Autism Support Act allows for the hiring of a State Autism Coordinator as a part of the AIACC. The lists above are included in the applicant requirements for the position. A State Autism Coordinator was hired in 2009.*

## (2) Continuity of Ideas

F.2.1 The Interagency Council should develop a set of bylaws that clearly defines goals, responsibilities, representation of council, length of term, how coordinator will report to council, etc.

F.2.2 The subcommittees formed through the AATF should continue to exist. The subcommittees could provide feedback and allow for greater involvement from providers and individuals with ASD and their families.

F.2.3 The chairpersons of each committee should be Council members. This will allow for both the Council and Subcommittees to know what is occurring in each group, provide feedback, and allow for greater knowledge and input from all significant parties.

PROGRESS TO DATE: *The AIACC was created and Bylaws were created in 2009<sup>15</sup>. AATF subcommittees were carried over and are represented in the Standards of Practice Committee, which is chaired by an AIACC member.*

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<sup>15</sup> Alabama Interagency Autism Coordinating Council Bylaws, <http://autism.alabama.gov/bylaws.html>

# System of Care

## APPENDIX B

The AIACC is charged with developing a long-term plan, to be reviewed annually, for a comprehensive statewide SOC for individuals with ASD and their families. The SOC model is an organizational philosophy and framework that involves collaboration across agencies and families for the purpose of improving access and expanding the array of coordinated community-based, culturally and linguistically competent services and supports.

### VALUES

The core values of the SOC philosophy specify that the SOC should be:

1. Individual centered and family focused, with the needs of the individual and family dictating the types and mix of services provided;
2. Community based, with the locus of services as well as management and decision-making responsibility resting at the community level; and
3. Culturally competent, with agencies, programs, and services that are responsive to the cultural, racial, and ethnic differences of the individuals they serve.

### PRINCIPLES

There are ten foundational principles of the SOC philosophy, all addressed in development of the AIACC SOC plan.

1. Individuals should have access to a comprehensive array of services that address their physical, emotional, social, and educational needs.
2. Individuals should receive individualized services in accordance with the unique needs and potential of each Individual and guided by an individualized service plan.
3. Individuals should receive services within the least restrictive, most typical environment that is clinically appropriate.
4. The families should be full participants in all aspects of the planning and delivery of services.
5. Individuals should receive services that are integrated, with linkages between agencies and programs with mechanisms for planning, developing, and coordinating services.
6. Individuals should be provided with care coordination to ensure that multiple services are delivered in a coordinated and therapeutic manner and that they can move through the system of services in accordance with their changing needs.
7. Early identification and intervention for children should be promoted by the SOC in order to enhance the likelihood of positive outcomes.
8. Individuals should be ensured smooth transitions to the adult services system as they reach maturity.
9. The rights of individuals should be protected and effective advocacy efforts should be promoted.
10. Individuals should receive services without regard to race, religion, national origin, sex, physical disability, or other characteristics with services being sensitive and responsive to cultural differences and special needs.

## IMPLEMENTATION

Building a SOC involves processes and structures. Process addresses (a) who is involved in a system-building effort; (b) the roles, rights, and responsibilities each is accorded or assumes; and (c) how the various stakeholders communicate, negotiate, and collaborate with one another. Process also requires strategic planning. Structure refers to those functions that become organized in certain defined arrangements. For example, how individuals enter the system (i.e., Regional Autism System of Care), how care is managed (i.e., Care Coordination), and how services and supports are individualized.

## SYSTEM OF CARE LOGIC MODEL

Turning SOC ideas into solid strategies for change requires approaching system development at multiple levels (a) policy and administrative, (b) program implementation, and (c) practice. To accomplish this, stakeholders need to anchor their SOC ideas in clear and specific expectations for the individuals and families they expect to serve, what they hope to accomplish, and how they believe they can effectively achieve their goals. A tool used to describe a theory of change is a logic model. The following logic model outlines activities in the AIACC proposed long-term plan toward a comprehensive SOC with inputs and outputs leading to short-term, intermediate, and long-term outcomes.

# SYSTEM OF CARE LOGIC MODEL

## OUTCOMES

INPUTS	OUTPUTS
Time	<b>Systems Infrastructure:</b> State Region
Money	<b>Pilot Site:</b>
Staff	Guide, Family Survey, Provider Survey, Resource Map, Public Forum, Advisory Board, Cost Analysis, Sustainability Plan
Volunteers	
Partners	
Facilities	<b>Care Coordination:</b> Guidelines/Training
Equipment	Individualized Interagency Intervention Plan & Guide
Technology	Learn the Signs. Act Early. Campaign
Supplies	
Research Base	<b>Family Resources:</b> Resource Directory, Navigation Guide, Web-site

- Short-term**
- Understanding of State and regional systems infrastructure/procedures for system/network
  - Support for system of care values & principles
  - Commitment to care coordination values & principles
  - Awareness of importance of early screening

- Intermediate**
- Infrastructure/procedures/policies implemented for system/network
  - Needs of individual/family dictate services with full family participation
  - Services coordinated with change within system components as needed
  - Services attuned to cultural, racial, and ethnicity of individual/family
  - Agencies/providers collaborate to develop and deliver services/supports
  - Services provided in community, in least restrictive setting

- Long-term**
- Family-centered, community-based and coordinated system of care for individuals with ASD and their families
  - Coordinated system of care meets the multiple and changing needs of individuals and their families
  - Policies and practices reflect system/network of care

## EVALUATION

Measurement of Process Indicators

Measurement of Outcome Indicators



# Proposed Long Term Plan

## APPENDIX C

Each step in the proposed long-term plan for building the statewide SOC involves activities devoted to both process and structure, while adhering to the system of care philosophy (i.e., values and principles). The AIACC is now engaged in activities in step one of a four-step long-term plan toward a comprehensive statewide SOC. The proposed plan is an AIACC work in progress and in no way constitutes policy. In addition, this Annual Report is for information purposes only and is not a request for funds to support AIACC efforts.

### PROPOSED LONG TERM PLAN STEP 1: BUILDING THE FOUNDATION

Step one includes two dedicated committee efforts to support implementation of a comprehensive statewide SOC, (a) Strategic Planning and (b) Standards of Practice. In addition, a Special Projects committee is addressing currently identified needs of the ASD community. Detailed information on committee progress, beyond information presented in this Annual Report, can be accessed at <http://www.autism.alabama.gov>.

#### Strategic Plan<sup>16</sup>

##### **Mission Statement**

The AIACC guides a collaborative effort to facilitate a lifelong system of care and support for persons and their families living with ASD or associated conditions, so that they may enjoy a meaningful and successful life.

##### **Values Statement**

We believe that a successful system of care will provide innovative best practice services for individuals with ASD and their families. These services should be ACCESSIBLE to families across the state of Alabama, provide PERSON AND FAMILY CENTERED services, and promote meaningful PUBLIC AWARENESS and COMMUNITY INTEGRATION AND INCLUSION. We value a system of care that is responsive to the current SENSE of URGENCY, is ACCOUNTABLE for providing best practice services, that includes COLLABORATIVE PARTNERSHIPS, and offers HOPE to families and service providers across the state.

##### PERSON AND FAMILY CENTERED

We respect and value the uniqueness of all individuals. The system of care and support that will serve those with ASD is based upon the individual's distinctive strengths, abilities, interests and choices. We recognize when given the opportunity, each person can make a unique contribution to their family, community and to society. The individual's needs drive their unique program.

##### SENSE OF URGENCY

Due to the overwhelming necessity for quality services and knowledgeable, reputable providers, our focus will be on the steps we can take to respond rapidly, efficiently and effectively to the immediate and life-long needs and challenges of people living with ASD and their families.

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<sup>16</sup> Alabama Interagency Autism Coordinating Council Strategic Plan, May 2011, [http://autism.alabama.gov/Documents/AIACC\\_Strategic\\_Plan.pdf](http://autism.alabama.gov/Documents/AIACC_Strategic_Plan.pdf)

#### PARTNERSHIPS IN ACTION

We promote improved public awareness and understanding of those living with ASD and advocate for public policy and funding that expands medical, therapeutic, educational, vocational, recreational, social and residential options.

#### SPIRIT OF COLLABORATION

Cooperative Partnerships will be created between those living with an ASD and their families and those agencies, organizations, and professionals which serve them. These partnerships will encourage collaboration and lead to an enhanced and more efficient service delivery to their clients. We value partnerships founded on honesty, integrity and mutual respect. We will treat all interested parties with respect, listen to diverse views with open minds, discuss submitted public comments and foster discussions where participants can comfortably offer opposing opinions.

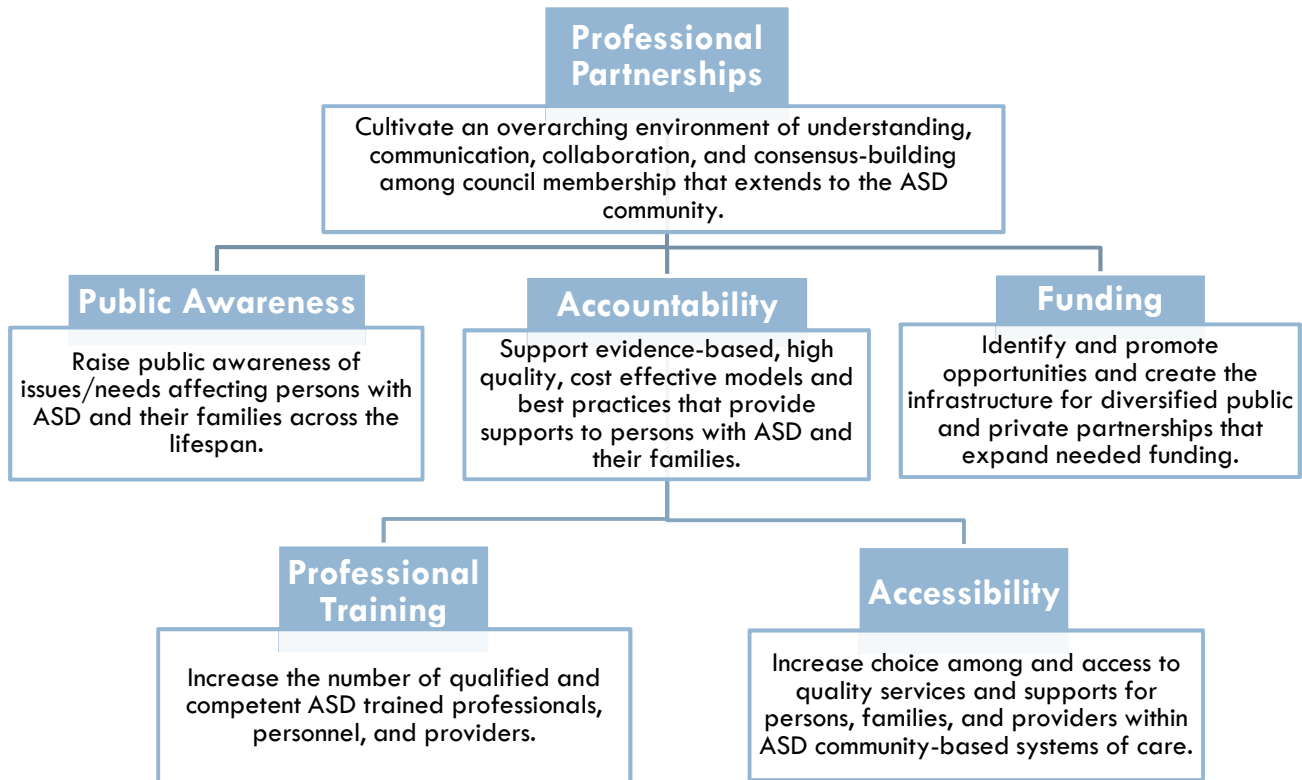
#### ACCOUNTABILITY

We will pursue innovative best practices to the highest quality for each individual to protect the safety and advance the interests of people affected by an ASD. We will promote a SMART (Specific, Measureable, Achievable, Realistic, and Time-specific) structure for service delivery. This structure will be aligned with the needs of each individual with an ASD and their family. Methods will be used to evaluate and determine the success of service delivery. Services will be adjusted as necessary to promote meaningful and successful lives for those living with an ASD.

#### HOPE

Although autism can be an isolating and involved experience, we will encourage hope for the autism community by endorsing our values on each and every service provider, agency, and organization that touches them. We will also promote education for family members and those living with an ASD, so that they will be knowledgeable in what the possibilities are for their lives.

## Goals



### Goal 1

Professional and Research Partnerships – Cultivate an overarching environment of understanding, communication, collaboration, and consensus building among Council membership that extends to the ASD Community.

*Individuals with ASD and their families depend on multiple agencies, providers, community supports, and funders, as well as their own internal resources. Partnerships/collaborations among these entities can increase efficiency, reduce frustration, and ultimately improve outcomes at both the systems and services levels. Likewise, partnerships/collaborations among researchers further applied knowledge in the areas of ASD diagnosis and treatment. Effective partnership/collaboration takes time, energy, attention to relationship building, trust building, capacity building, team building, conflict resolution, and communication.*

INITIATE STATE-WIDE PARTNERSHIPS & COLLABORATIONS: Partnerships on behalf of individuals with ASD and their families can represent an important effort to restructure services to be more responsive to needs and may foster future research.

- 1.1 Identify partnership interests in addition to those established in goals (i.e., accessibility, professional training, funding, public awareness, and accountability).

- 1.2 Develop partnership talking points (specific to identified interests) for recruitment (i.e., why the partnership is important, benefits to participating agencies or organizations, commitments expected).
- 1.3 Recruit partnership leaders.
- 1.4 Recruit agencies, organizations, stakeholders, and researchers representing a cross-section of each community segment affected by partnership activities.
- 1.5 Assist partnerships in consensus on desired priorities, outcomes, and actions toward outcomes.

**IDENTIFY LEVERAGE POINTS IN CONSENSUS BUILDING:** Leverage points are places of influence where system planners and implementers intervene strategically in their existing system context in order to expand capacity to meet needs and maximize available resources.

- 1.6 Identify and communicate values/beliefs leverage points including shared understanding among partnerships.
- 1.7 Identify and communicate goal leverage points based on the mission of the AIACC to include adaptation in system structure, information flow, and regulations among partnerships.
- 1.8 Identify and communicate information leverage points to include structures that provide feedback when and where it is needed among partnerships.
- 1.9 Identify and communicate structures leverage points related to specific roles, responsibilities, and authorities that define organizational boundaries and enable the AIACC to perform its functions.
- 1.10 Identify opportunities for action across leverage points to support a well-functioning system of care.

## **Goal 2**

**Accountability – Support evidence-based, high quality, cost-effective models and best practices that provide supports to persons with ASD and their families.**

- 2.1 Identify the progress on yearly goals of AIACC.
- 2.2 Document year end activities of the AIACC.
- 2.3 Identify diagnostic and treatment programs in the state that are best practices models of diagnoses and treatments. Keep list of provider network meeting criterion as best practices providers.  
  
Define best practice models by developing criterion to qualify as best practice model.  
  
Create competencies for best practice models to analyze quality of model.
- 2.4 Review novel therapeutic treatments for those living with an ASD.
- 2.5 Review novel research in the area of diagnosis and treatment for those living with ASD.

### **Goal 3**

Public Awareness – Raise public awareness of issues/needs affecting persons with ASD and their families across the lifespan.

A.3.1 Develop an Alabama Lifespan Resource Tree and Online Directory.

Develop awareness campaign for resource tree and directory.

Develop hard copy of resource tree and directory.

A.3.2 Implement/disseminate *Learn the Signs. Act Early.* campaign.

A.3.3 Develop autism awareness campaign for those not directly affected by ASD.

### **Goal 4**

Funding – Identify and promote opportunities and create the infrastructure for diversified public and private partnerships that expand needed funding.

A.4.1 Identify funding opportunities for AIACC.

A.4.2 Establish a venue of communication amongst the AIACC Executive Committee and the Governor's Office and Legislature.

A.4.3 Support the Alabama Autism Coordinator in the development of grant funding.

A.4.4 Support private business support of AIACC goals.

### **Goal 5**

Professional Training – Increase the number of qualified and competent ASD trained professionals/personnel/providers.

A.5.1 Determine number of qualified and competent ASD trained providers currently available in the state.

Develop competencies that will be completed by those providers seeking inclusion on AIACC list of best practices providers network.

A.5.2 Establish a database of best practices providers/professionals offering services in the state.

A.5.3 Define best practice quality and competency measures.

A.5.4 Establish and maintain a cooperative relationship between AIACC and Professional and Graduate programs in the state.

A.5.5 Enumerate best practices providers on an annual basis.

### **Goal 6**

Accessibility – Increase choice among and access to quality services and supports for persons, families, and providers within the ASD community-based systems of care.

A.6.1 Determine availability of best practice providers and services throughout the state.

A.6.2 List available providers and services for each region of the state.

- 6.3 Determine availability of best practice providers and services throughout the state.
- 6.4 Support development and increase in choice of approved services.
- A.6.5 Identify possible improvements in accessibility to services in state after the establishment of Autism Regional Network in Alabama.
- A.6.6 After the establishment of and Autism Network for Alabama, establish advocate as the individual is placed into the system to support and direct services.
- A.6.7 Identify the coordination of Medical Community/Professional Community and methods of accessing services at any stage of life (EI, school or adult).

## Standards of Practice

Standards of practice (SOP) are statements that outline what level of service one can expect to be provided and how the service will be provided. The SOP Committee consists of six workgroups addressing SOP from screening and diagnosis through the adult services. The committee’s work has been towards developing SOP based on evidence-based practice, which provides a framework for integrating what is known from research into real-world practice. In effect, evidence-based practice bridges the science-to-practice gap with three core components (a) best research evidence, (b) clinical expertise and judgment, and (c) individual values and preferences.

### Standards of Practice Workgroups

Diagnostic Clinics  
 Services: Birth-5 Years  
 Services: 6-21 Years

Transition Services  
 Adult Services  
 Professional Preparation and Training

### Functions

- Advise the AIACC on appropriate standards for programs and services provided or to be provided for individuals with ASD.
- Provide information to be used in monitoring the implementation of Standards of Practice in programs and services.
- Be used to recognize the achievement of good standards and quality in the provision of programs and services

For the individual with ASD and his or her family, the SOP will (a) tell them what they can expect from a service, (b) give them greater awareness of their rights and responsibilities, (c) give them confidence in the quality of services, and (d) provide them with the opportunity to have a say in the development and review of services.

The SOP will assist the service providers as they work to (a) improve outcomes for individuals and families who use their services, (b) provide opportunities for their staff to improve their skills, (c) improve use of resources, (d) plan and improve their processes and systems, and (e) satisfy accountability requirements.

The resulting SOP will also (a) inform development of a quality rating system (QRS) for programs and providers that participate in the SOC and, and (b) provide parents, policymakers, funders, and the public with information about the level of quality of programs and providers participating in the SOC.

Quality is meeting (and where possible exceeding) the assessed needs and defined expectations of the service user through efficient and effective management and processes. The QRS will be composed of four common elements including:

- Standards
- Accountability measures
- Program and provider technical assistance
- Parent/consumer education efforts

## Special Projects

The Special Projects Committee is addressing currently identified needs of the ASD community through three workgroups.

### Special Projects Workgroups

Developmental Surveillance and Early Screening  
Community Services and Supports  
Resource Development

### Functions

- Develop ways to address currently identified needs through pursuit of grant funding and community support.
- Be used as preparation for Regional Network activities for public education and resource development.

The **Developmental Surveillance and Early Screening workgroup** is tasked with finding ways to increase awareness on red flags of developmental delays and to recommend the appropriate referral stream for identification and treatment. The individuals identified with developmental delays should also be monitored over time to track progress toward goals. The **Community Services and Supports workgroup** will address safety, respite, and community education needs. The **Resource Development workgroup** will identify current service providers and compile a resource directory available in print and electronic formats. This group is also tasked with identifying methods for maintenance of current information and online accessibility.

## PROPOSED LONG TERM PLAN STEP 2: INFRASTRUCTURE

Step two of the proposed long-term plan address infrastructure necessary for the System of Care (SOC) to be integrated across service sectors, which are collectively responsible for achieving individual, family, and community outcomes. The resulting SOC will foster greater efficiency, bolster effectiveness, and alleviate service gaps for individuals with ASD and their families. The SOC is outlined below, although funds to support this initiative have not yet been identified.

### Proposed Objectives

**Objective 1:** Initiate State efforts to improve infrastructure that results in community and State systems that are integrated across service sectors and are collectively responsible for achieving individual, family, and community outcomes.

**Objective 2:** Determine elements for an Individualized Interagency Intervention (III) Plan to facilitate meeting needed services and funding arrangements for the individual and family across a variety of programs, agencies, and services.

## Proposed Activities

*All activities will be informed by youth/family participation and specialist consultants.*

- 1.1 Identify goals and guiding principles.
- 1.2 Maintain website to communication System of Care development.
- 1.3 Develop and follow protocols and mechanisms for ensuring the full participation of families, youth, and advocacy organizations in decision making, governance, and evaluations.
- 1.4 Hire research assistant.
- 1.5 Hire care coordinator.
- 1.6 Hire formal evaluator and draft evaluation plan.
- 1.7 Hire consultants and develop and implement plans for Continuous Quality Improvement, Systems of Care Development, Family Centered Care/Cultural and Linguistic Competence, and Family/Youth Involvement
- 1.8 Identify and organize formal and informal supports to facilitate development of an Individualized Interagency Intervention (III) Plan.
- 1.9 Complete and disseminate Service Provider Standards of Practice.
- 1.10 Review and analyze policies and procedures (legislative, organizational, multi-agency) and identify those that hinder and /or support the System of Care development and implementation.
- 1.11 Generate inventory of: required data elements from statutes, rules, and laws for service plans; common elements among existing service plans; additional required elements for some; additional information required to meet federal and state laws and/or rules.
- 1.12 Review collaborating agency organizational structure to inform building of collaborative governance structure.
- 1.13 Draft principles and values for inclusion in Individualized Interagency Intervention Plan Draft Guide.
- 1.14 Develop certification application package for System of Care service providers (e.g., guide with measurement criteria, process, and application).
- 1.15 Define State Infrastructure for interagency organization: structure of governing body; decision-making process and oversight; identification and roles of participants; define services to be provided; establish formal links between lead agency and other agencies; define referral and intake mechanisms.
- 1.16 Determine plans to be coordinated through the Individualized Interagency Intervention Plan.
- 1.17 Define communications protocol that outlines protocols between participants, state and local governments, the public, elected officials, current and potential funders, families, and other audiences identified by stakeholders.
- 1.18 Identify pilot location for first System of Care.
- 1.19 Generate *Pilot Guide: Steps to a Regional Autism Network of Care*.
- 1.20 Identify and make available documents, materials, and resources other than in English that have been useful in systems of care.
- 1.21 Identify and utilize pool of cultural brokers who will assist families in increasing access and decreasing disparities.



- 1.22 Put into place Memoranda of Understanding to detail roles, responsibilities, and relationships among stakeholders.

## PROPOSED LONG TERM PLAN STEP 3: FUNCTIONS

### Policies and Procedures

Step three of the proposed long-term plan addresses functions essential to a System of Care (SOC) including policies and procedures, care coordination components, and benefit design. An AIACC Policy and Procedures Committee will include a number of workgroups to address areas listed below.

The considerations for policies and procedures listed below are not considered all-encompassing as SOC development is a dynamic process.

<i>System Entry/Access</i>	<i>Protecting Privacy</i>
<i>Screening, Assessment, and Evaluation</i>	<i>Ensuring Rights</i>
<i>System Management</i>	<i>Financing</i>
<i>Decision-making/Oversight</i>	<i>Purchasing/Contracting</i>
<i>Outreach and Referral</i>	<i>Revenue Generation</i>
<i>Crisis Management</i>	<i>Information Management</i>
<i>Utilization Management</i>	<i>Quality Improvement</i>
<i>Staffing Structure, Support, and Development</i>	<i>Evaluation</i>
<i>Orientation and Training</i>	<i>System Exit</i>
<i>External and Internal Communication</i>	<i>Technical Assistance</i>

### Care Coordination Components

Care coordination is a central, ongoing component of an effective SOC. Care coordination engages families in development of a care plan and links them to services that address the full range of their needs and concerns. Principles of care coordination may vary from family to family, but start with identification of individual and family needs, strengths and concerns, and aim simultaneously at meeting family needs, while building family capacity and improving systems of care.

### Proposed Objectives

**Objective 3:** Create foundation for System of Care as informed by the State infrastructure planning.

**Objective 4:** Generate *Care Coordination Guidelines/Training Modules and Individualized Interagency Intervention Plan and Guide*.

### Proposed Activities

All activities will be informed by youth/family participation and specialist consultants.

- 2.1 Provide ongoing consultant training in identified areas including Continuous Quality Improvement, Systems of Care Development, Family-centered Care/Cultural and Linguistic Competence, and Family/Youth Involvement.
- 2.2 Continue identifying and utilizing (a) a pool of cultural brokers and (b) non-English Systems of Care information.
- 2.3 Detail care coordinator responsibilities and requirements.
- 2.4 Identify Ill Plan data tracking system, data elements, and arrangement of data elements.

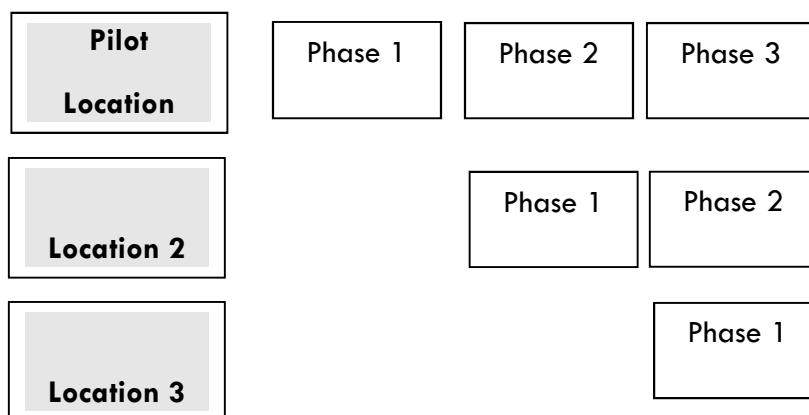
- 2.5 Survey families to assess access to services and supports.
- 2.6 Survey service providers to identify available services.
- 2.7 Analyze SOC environmental strengths, weaknesses, opportunities, and threats.
- 2.8 Map resources, partnerships, and assets.
- 2.9 Schedule and hold public forum to gather information on what different stakeholders want in a SOC.
- 2.10 Create SOC advisory board of stakeholders and agency representatives.
- 2.11 Increase provider and consumer awareness of importance of early screening of children for ASD and related disorders building on a state-wide *Learn the Signs. Act Early.* campaign.
- 2.12 Evaluate current fiscal utilization.
- 2.13 Develop process for case coordination, case review, and continuous quality assurance.
- 2.14 Identify strengths of stakeholders and agencies for collaboration.
- 2.15 Select and complete a cost analysis for the SOC.
- 2.16 Generate Draft (a) Care Coordination Guidelines and (b) Ill Plan and Guide.
- 2.17 Create crisis plan format and procedures.
- 2.18 Disseminate draft (a) Care Coordination Guidelines and (b) Ill Plan and Guide, request feedback, and make needed revisions.
- 2.19 Detail services to be provided in SOC.
- 2.20 Secure approvals for Ill Plan to replace pre-determined existing service plans.
- 2.21 Develop and implement social marketing plan, regional evaluation plan, and sustainability plan.
- 2.22 Design Care Coordination training plan and modules.
- 2.23 Finalize System of Care Evaluation Plan.

## Benefit Design

A key principle of a SOC is that the benefit design incorporates a broad array of services and supports, including both traditional and nontraditional services and supports and both clinical services and natural supports. A second key principle is that benefit structure allow for individualized, flexible service provision with attention to the cultural expectations of each family. An AIACC Benefit Design Committee will determine core system of care services and develop a system for fading in secondary services.

The committee will utilize the Standards of Practice (SOP) and Quality Rating System (QRS) developed in step one of the long-term plan. In order to benefit from lessons learned for the pilot location, new locations will open following a succession as shown below.

### Location Phase Plan



## PROPOSED LONG TERM PLAN STEP 4: IMPLEMENTATION

During step four, a Request for Proposals is initiated to inform recommendations for locations and service areas of System of Care (SOC) centers. Act 2009-592 provides for the establishment of regional autism centers to meet the identified urgent need for a system of care. Act 2009-592 charges the AIACC with recommending the locations and service areas of centers to the Governor, Lieutenant Governor, and the Speaker of the House of Representatives. To ensure fairness and equal opportunity, the AIACC will initiate a Request for Proposals to inform recommendations. The Governor, Lieutenant Governor, and the Speaker of the House of Representatives will then select the locations and service areas of centers.

The first location or pilot location is critical to future success and will undergo evaluation to identify and address the inevitable problems that pilot locations are created to uncover and resolve. The pilot location provides the care coordinators with a tool to evaluate the initial services of the SOC in a manageable environment and, if necessary, make changes before opening subsequent locations.

### Proposed Objectives

**Objective 5.** Initiate a Request for Proposals to inform recommendations of locations and service areas of centers.

**Objective 6.** Initiate Systems of Care pilot location.

### Proposed Activities

All activities will be informed by youth/family participation and specialist consultants.

- 3.1 Complete Request for Proposal process.
- 3.2 Begin pilot location care coordination services.
- 3.3 Provide ongoing training and technical assistance to pilot location
- 3.4 Provide on-going consultant training in identified areas including Continuous Quality Improvement, Systems of Care Development, Family-centered Care/Cultural and Linguistic Competence, and Family/Youth Involvement.
- 3.5 Continue identifying and utilizing (a) pool of cultural brokers and (b) non-English SOC information.
- 3.6 Organize and distribute an updated Alabama ASD Lifespan Resource Tree and Directory.
- 3.7 Create and distribute an *Alabama Family Navigation Guide to ASD services*.
- 3.8 Elicit feedback from all stakeholders to inform revision of process as needed.
- 3.9 Evaluate pilot location effectiveness of services, training, technical assistance, and revise as needed.
- 3.10 Evaluate effectiveness of *Pilot Guide: Steps to a Regional Autism Network of Care*.
- 3.11 Identify pilot replication sites throughout the State.
- 3.12 Disseminate SOC initiatives and results to audiences at events, conferences, state and national events.

## EVALUATION PLAN

Both process and performance assessment activities will be conducted for the System of Care (SOC) utilizing the services of an outside evaluator. Performance assessment activities will be finalized after hiring the evaluator.

## Process Evaluation

Process evaluation will be undertaken to (a) monitor the SOC implementation, (b) document whether or not the SOC is implemented as intended, (c) describe how the implementation is accomplished, and (d) allow for corrective action when objectives are not attained. The process evaluation focuses on factors that succeed or fail in producing the identified results and include but are not limited to factors such as program components, administration, implementation processes, program efficiency, family perceptions, staff perceptions, and the overall effect of the SOC.

Utilizing information gained through process evaluation, efforts will be made to explain how and why desired changes did or did not occur in relation to the SOC implementation protocols. Documentation of the implementation process allows for identification of the factors that contribute to program outcomes, and thereby, support replication of components found to be effective. Questions that will be asked through the SOC process evaluation activities include:

1. How closely did implementation match the SOC Plan?
2. What types of changes were made to the originally proposed Plan?
3. What factors led to the changes in the original Plan?
4. What barriers or opportunities have been encountered relative to implementation of the Plan?
5. What effect did the changes have on the planned intervention and performance assessment?
6. Who provided (program staff, contracted) what services (modality, type, intensity, duration), to whom (individual characteristics), in what context (system, community), and at what cost (facilities, personnel, dollars)?
7. What strategies were used to maintain fidelity to the evidence-based SOC practices or interventions across providers over time?
8. How many individuals were reached through the program?

Answers to these questions and others will be provided through qualitative assessment techniques. Sources of process evaluation will include direct observation of services (e.g., Wraparound Fidelity Assessment System), one-on-one interviews with program participants (e.g., Family-centered Assessment Tool), focus group meetings, stakeholder group meeting minutes, surveys, routine data collected from individuals during the course of service provision, and other methods.

## Outcome Evaluation

Outcome evaluation for the SOC will (a) assess the impact of the SOC and the effectiveness of the SOC in meeting its stated goals, determine what program factors and individual factors were associated with what outcomes, and determine the durability of the effects. The SOC goals and related objectives, thus, serve as the basis of the data collection and analysis process for outcome evaluation, and will answer the following questions.

1. Did the SOC facilitate the development of family-centered, community-based and coordinated SOC for individuals with ASD and their families?
2. Did the SOC provide and promote family-centered, community-based and coordinated care for individuals with ASD and their families?

Outcome evaluation questions will also answer those related to the Healthy People 2010 Objectives and the Maternal and Child Health Bureau Performance Measures.

1. Did partnerships between professionals and families of individuals with ASD improve?

2. Did access to a culturally competent family-centered SOC, which coordinates care with community-based services increase?
3. Did access to adequate health insurance and financing of services improve?
4. Did early and continuous screening for ASD increase?
5. Were community services organized for easy use by families?
6. Did transition services to adults improve?

Answers to outcome evaluation data questions will be provided through analysis of parametric and non-parametric procedures and will include, but not be limited to, individual interviews conducted at intake and follow-up, interviews with staff, record reviews, administration of standardized assessment instruments, and observation of SOC activities.

## Instruments

The following instruments will be considered for use to support evaluation of the SOC goals and objectives:

1. The Wraparound Fidelity Assessment System,
2. Child and Adolescent Needs and Strengths: Autism Spectrum Profile,
3. Supports Intensity Scale,
4. System of Care Practice Review,
5. Family-centered Care Self-Assessment Tool- Family, and
6. Family-centered Care Self-Assessment Tool- Provider.

## Data Analysis

Analysis of data will include the development of descriptive statistics, including tables, which summarize quantitative data (e.g., socioeconomic variables), using Contingency Tables and Chi Square. Analysis will proceed to the calculation of means, ranges, and other descriptive statistics to help describe the target groups and give clues to outcomes, which can be tested with more complex inferential statistical methods and illustrated in figures and tables. Individual outcome data will be analyzed at intake and ongoing follow-up. System and program outcomes will be analyzed on a quarterly basis.

Qualitative data will be analyzed according to procedures established by the evaluator, as appropriate to the variable collected. Quantitative data analysis results will be summarized in tables as well as be presented in narrative form.

Quality of data collection and data processing procedures is essential to the success of the SOC. Principles upon which quality control are based relative to evaluation activities of the SOC include:

1. Use of clearly defined and specific protocols for all SOC evaluation activities, including training for data collection, management, and processing.
2. Ongoing training and re-training of program staff participating in any data collection activities.
3. Administration of evaluation tools and evaluation data collection instruments consistently across all program participants.
4. Validation and verification of all data collection and management procedures through data editing, including use of software capable of checking for out-of range values and other outliers.
5. Consistent meetings and progress reports to provide specific, well documented feedback on SOC staff concerning potential difficulties as well as sufficient follow-up to assure that problem resolution occurs in a timely manner.

The State Autism Coordinator will manage all data collection, entry, editing, generation of reports, and data analysis as informed by the contracted formal evaluator.

### **Reporting and Integration of Data**

Written updates will be provided quarterly to the AIACC and SOC staff regarding evaluation findings. A full report of findings will be disseminated twice a year. Each report will invite feedback relative to suggested improvements. Particular attention will be paid to evidence of disparate outcomes for different racial and ethnic populations, to provide for timely program adjustments as needed.

Information obtained from system, program, and individual evaluation of the SOC will guide development of programming by eliminating what is not working and enhancing what is working. Working in conjunction with the evaluator, the AIACC will establish formal policies and procedures to guide the incorporation of evaluation data and findings into program management and continuous quality improvement processes on an ongoing basis.

### **Participant Protection**

The AIACC will develop and implement appropriate procedures to address confidentiality and other ethical concerns pertinent to the protection of clients. Data management procedures will include stringent security procedures relative to transportation and storing of data. Training in regards to confidentiality and ethics will be provided for all SOC staff participating in the evaluation process.