

ALABAMA INTERAGENCY AUTISM COORDINATING COUNCIL



2013

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), 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) *2013 Annual Report* provides updates on progress toward achieving goals set out in our State Plan, which is based on recommendations from the Alabama Autism Needs Assessment's 2008 findings. A copy of this report may be accessed at www.autism.alabama.gov.

According to the most recent autism prevalence rate released by the CDC's Autism and Developmental Disabilities Monitoring (ADDM) 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.¹

When applying these statistics to population estimates from the U.S. Census Bureau, there are as many as 54,900 Alabamians affected by ASD.² The number of children under the age of 18 affected by ASD may be as many as 12,800. The number of adults 18 years of age and older may be as many as 42,100.

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.

¹ CDC's Autism and Developmental Disabilities Monitoring (ADDM) Network, http://www.cdc.gov/NCBDDD/autism/states/ADDM_fact_sheet_2012.pdf

² 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.³

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 and May 2008.⁴

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.⁵

³ *Alabama Autism Task Force: Final Report to the Governor and Legislature, January 2009*, http://autism.alabama.gov/Documents/Autism_Task_Force_Final_Report.pdf

⁴ *Statewide Autism Needs Assessment: Final Report, June 2008*, Alabama Autism Collaborative Group, http://autism.alabama.gov/Documents/Autism_Needs_%20Assessment_Full_Report.pdf

⁵ *Alabama Autism Support Act (Act 2009-295)*, 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:⁶

Governor appointed members include:

Karen Amos, A.S.F.A.
Greg Carlson, A.C.A.
Joshua Heard, 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 Health⁷
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

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

⁷ The Alabama Department of Mental Health is the lead agency for the AIACC.

Year in Review

LEGISLATIVE REVIEW

Relevant Legislation

Act 2012-298 required health benefit plans to offer certain coverage for ASD in certain policies and contracts. Under this act, only licensed Board Certified Behavior Analysts (BCBAs) may be reimbursed for providing certain behavioral therapies. However, there is currently not a licensing method in Alabama for BCBAs. In 2013, Senate Bill 305 proposed the creation of the Alabama Behavior Analyst Licensing Board within the Division of Developmental Disabilities of the Alabama Department of Mental Health. This bill was not passed, but it is anticipated that the bill will be reintroduced during the 2014 Legislative session.

Senate Bill 373 proposed that a person with ASD may opt to have the letters “ASD” displayed on his or her driver’s license. This bill was not passed, but is expected to be reintroduced in the 2014 Legislation session.

Budget

Total state dollars allocated to support the mission and recommendations of the AIACC in 2012 amounted to approximately \$91,000. In 2013, the amount of support increased to \$100,468. This came from both the State General Fund (\$36,568) and the Education Trust Fund (\$63,900).

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”.⁸ The Council has had difficulty filling this position. 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 second meeting in November and discussed ways to aid in funding of Autism Regional Networks.

The Alabama Department of Education Special Education Services formed team to focus on new autism initiatives, which include more targeted on-site training, consultation, and a strong focus on evidence based practices of applied behavioral analysis.

The Alabama Department of Mental Health’s Division of Developmental Disabilities is partnering with other agencies and stakeholders to pursue Employment First in Alabama, which will make employment options more available and a higher priority for individuals receiving services.

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 be fully realized when funding is available.

Strategic Planning

⁸ *Alabama Interagency Autism Coordinating Council Bylaws*, <http://autism.alabama.gov/bylaws.html>

The Strategic Planning Committee completed their initial work in May 2011. The Strategic Planning Committee will convene in 2014 to update the Plan, as the timeline and priorities need to be reviewed and updated. The initial work is incorporated into the proposed Long Term Plan (and will be updated pending recommendations made in 2014). To view the 2011 Strategic Plan, visit:

http://autism.alabama.gov/Documents/AIACC_Strategic_Plan.pdf.

Standards of Practice

Recommendations from the Standards of Practice Committee are anticipated to be completed in 2014. All of the recommendations will go through a vetting process. Drafts of these recommendations may be viewed online at www.autism.alabama.gov.

Special Projects

The **Developmental Surveillance and Early Screening Workgroup** has formed the Act Early Alabama state team and partnered with the Autism Coordinator (who is also the CDC's Act Early Ambassador for Alabama for 2013-2014). Products from the CDC State Systems grant continue to be distributed and adapted for healthcare, early education, and parental use. An Act Early Alabama website is under development <http://www.uab.edu/civitanisparks/act-early-alabama>. Trainings on early warning signs, appropriate referrals, and treatments continue to be pursued and hosted regionally.

The **Community Services and Support** workgroup is focusing on a community-based awareness campaign called "Autism Friendly", expansion of safety and first responder initiatives in Alabama, and continued research into respite opportunities. The **Resource Development** workgroup continues to collect resources for inclusion into an online and print resource directory. The resources will be housed and maintained by the Autism Society of Alabama (www.autism-alabama.org).

BARRIERS

The *Diagnostic and Statistical Manual of Mental Disorders (DSM-5)* was updated to the fifth edition in May of 2013. The multiple diagnoses that had once comprised the autism spectrum (PDD-NOS, Asperger's Syndrome, and Autistic Disorder) were consolidated into one single diagnosis of "Autism Spectrum Disorder". The *DSM-5* also includes a new list of levels of severity, allowing diagnosticians to indicate areas of greatest need for support. The *DSM-5* revisions are resulting in revision of commonly used diagnostic instruments, e.g., the ADOS, ADI, GARS, GADS, etc. The AIACC continues to update recommendations to reflect these new diagnostic changes.

The need for funding for Regional Networks for ASD and related disabilities is great. 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.⁹ 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, thereby developing the system of care for individuals with ASD.

In a recent review of Medicaid Home and Community Based Waivers in the United States, 32 states include Autism as a qualifying condition to receive specified waiver services. Thirty-eight states (including Washington, D.C.) include Developmental Disabilities as a qualifying condition to receive specified waiver

⁹ Act 2009-592, http://autism.alabama.gov/Documents/Legislation/ACT_num_09-0592_HB0615.pdf

services. Alabama does not specify Autism or Developmental Disabilities as qualifying conditions in any of the waivers it currently offers.

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. Obtaining funding for Autism Regional Networks, updating the AIACC Strategic Plan, and completing the Standards of Practice recommendations are priority activities for the AIACC.

Proposed Long Term Plan

APPENDIX A

Each step in the proposed long-term plan for building the statewide System of Care (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>.

The Alabama Interagency Autism Coordinating Council developed an initial Strategic Plan in 2011. The timeline and priorities are currently being revisited and updated to reflect progress that has been made and needs that must still be addressed.

Strategic Plan¹⁰

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

¹⁰ Alabama Interagency Autism Coordinating Council Strategic Plan, May 2011, http://autism.alabama.gov/Documents/AIACC_Strategic_Plan.pdf

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.

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

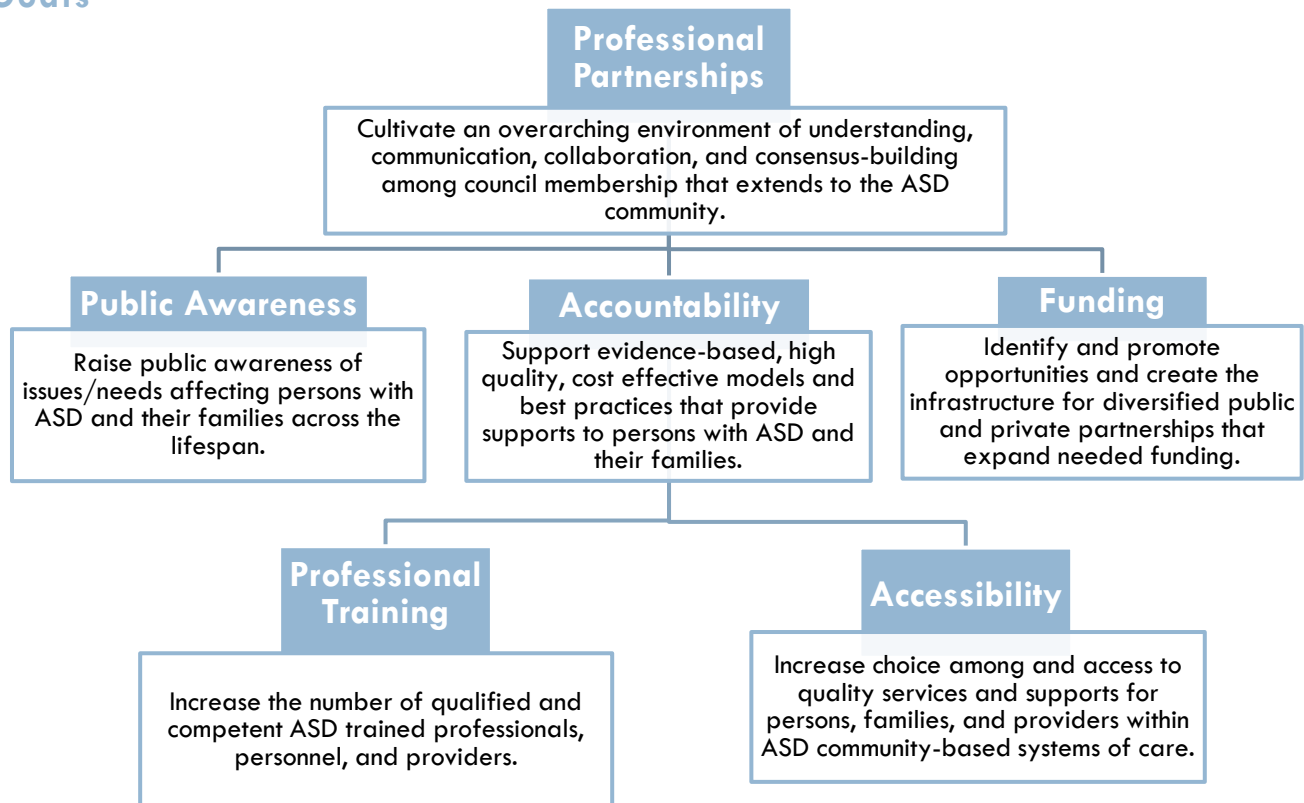
We will pursue innovative best practices to the highest quality for each individual to protect the safety and advance the interests of people affected by an ASD. We will promote a SMART (Specific, Measureable, Achievable, Realistic, and Time-specific) structure for service delivery. This structure will 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.

<u>Key Issues</u>	<u>Impact</u>
Adequate Funding	Level of Services
Competent ASD-Specific Trained Providers	Availability and Accountability for Providing Best Practices Interventions
Access to Care	Comprehensive Community-Based Services
Political Leadership	Advocacy
Public Awareness of ASD	Early Identification and Community Inclusion
True Cooperation within the Autism Community	Comprehensive and Coordinated System of Care

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.

<u>Activities</u>	<u>Measurement</u>	<u>Responsible Persons/Unit</u>	<u>Progress</u>
Identify partnership interests in	Identify agency,	AIACC	Ongoing

addition to those established in goals (i.e., accessibility, professional training, funding, public awareness, and accountability)	organization, or research leaders and interests to approached for collaboration		
Develop partnership talking points (specific to identified interests) for recruitment (e.g., why the partnership is important, benefits to participating agencies or organizations, commitments expected)	Talking points developed	AIACC	Ongoing
Recruit partnership leaders	Partnership leaders recruited	AIACC	Ongoing
Recruit agencies, organizations, stakeholders, and researchers representing a cross-section of each community segment affected by partnership activities	Identify agencies, organizations, stakeholder and researchers to invite to collaborate with AIACC	AIACC	Ongoing
Assist partnerships in consensus on desired priorities, outcomes, and actions toward outcomes	Identify desired outcomes for each collaboration		Ongoing

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.

<u>Activities</u>	<u>Measurement</u>	<u>Responsible Persons/Unit</u>	<u>Status</u>
Identify and communicate <i>values/beliefs leverage points</i> including shared understanding among partnerships	Identify and share with partners an outline of general goals or standard for all partnerships with the AIACC	AIACC	Ongoing
Identify and communicate <i>goal leverage points</i> based on the mission of the AIACC to include adaptation in system structure, information flow, and regulations among partnerships	Goal leverage points are identified as well as system planners and implementations	AIACC	Ongoing
Identify and communicate <i>information leverage points</i> to include structures that provide feedback when and where it is needed among partnerships	Create a model of communication during partnerships	AIACC	Ongoing
Identify and communicate <i>structures leverage points</i> related to specific roles, responsibilities, and authorities that define organizational boundaries and enable the AIACC to	Create a checklist of requirements for partnership with AIACC	AIACC	Ongoing

perform its functions			
Identify opportunities for action across leverage points to support a well-functioning system of care	Progress report of partnership activity		Ongoing

Goal 2

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

<u>Activities</u>	<u>Measurement</u>	<u>Responsible Persons/Unit</u>	<u>Status</u>
Identify the progress on yearly goals of AIACC	Progress report toward goals as identified by the AIACC at beginning of year	Standards of Practice Committee Workgroups Autism Coordinator	Progress updates provided in annual report.
Document year end activities of the AIACC	Yearly report outlining the efforts of the Autism Coordinator and the AIACC	Autism Coordinator	Progress updates provided in annual report.
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 practice provider. Define best practice models by developing criterion to qualify as best practice model. Create competencies for best practice models to analyze quality of model	Treatment centers or individuals that exemplify best practices in diagnosis and treatment in the state are identified and catalogued Best practice models will meet criterion Best practice models will complete competencies	Standards of practice committee workgroups	Best practice criteria identified by Standards of Practice committee. A list of service providers will be available online in partnership with the ASA, but will not include a designation of a best practice provider until an evaluation method is developed.
Review novel therapeutic treatments for those living with an ASD	Report to AIACC at general meeting of therapeutic treatments for those living with an ASD	Best Practices Committee of AIACC Standards of practice committee workgroups	Ongoing
Review novel research in the area of diagnosis and treatment for those	Report to AIACC at general meeting of novel	Best Practices Committee of	Ongoing.

living with an ASD	research in the area of treatment for those living with an ASD.	AIACC Standards of practice committee workgroups	
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Goal 3

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

<u>Activities</u>	<u>Measurement</u>	<u>Responsible Persons/Unit</u>	<u>Status</u>
Develop Alabama Lifespan Resource Tree and Online Directory	Presence of Resource Tree and Online Directory	Special Projects Committee: Public Awareness Workgroup, ASA	In progress. ASA will house resource directory and tree in online format, monitored by a moderator at ASA (in partnership with Vehicle Media). Directory will be updated yearly with print option available.
Develop awareness campaign for resource tree and directory	Calculate hits/month on website & follow-up survey determining usefulness of website		
Develop hard copy of resource tree and directory	Record number of hard copy directories that are distributed		
Implement/Disseminate Learn the signs/Act Early Campaign	Record amount of materials disseminated and to what groups. Record number of public service announcements (radio, TV, billboards, newspaper, support groups)	Special Projects Committee: Public Awareness Workgroup, ASA	2200 materials distributed to advocacy, education, support, and medical groups. PSAs pending.
Develop autism awareness campaign for those not directly affected by autism	Record amount of materials disseminated and to what groups. Record number of public service announcements (radio, TV, billboards, newspaper, support groups)	Special Projects Committee: Public Awareness Workgroup, ASA	Community Services and Supports workgroup is conducting this campaign with a business focus.

Goal 4

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

<u>Activities</u>	<u>Measurement</u>	<u>Responsible</u>	<u>Status</u>
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		Persons/Unit	
Identify funding opportunities for AIACC	Number of options for exploration identified	Funding and Finance Committee AIACC	Ongoing
Establish an avenue of communication amongst the AIACC Executive Committee and the Governor's Office and Legislature	Procedure established for communication with the Governor's Office and with the legislature	AIACC Executive Committee	Relationship with governor's office and legislature developed and ongoing.
Support the Alabama Autism Coordinator in the development of Grant Funding	Timeline for grant development identified	AIACC	Autism Coordinator searches and applies for grant funding, with support and suggestions of AIACC members and partners
Support private business support of AIACC goals	Procedure for inviting private funds for the support of AIACC goals identified	AIACC	To be completed.

Goal 5

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

Activities	Measurement	Responsible Persons/Unit	Status
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	Number of available best practices providers identified Competencies developed	Standards of Practice Professional Workgroup	Pending Standards of Practice recommendations regarding best practices. Evaluation method for providers needed.
Establish a database of best practices providers/professionals offering services in the state	Database of best practices providers established and updated yearly	AIACC and Standards of Practice Workgroup	Provided through Standards of Practice recommendations and online directory, but does not evaluate individual provider practices.
Define best practices quality and competency measures	Contacts identified and established	AIACC and Standards of Practice Workgroup	SOP currently completing.
Enumerate best practices providers on an annual basis	Number of available best practices providers identified that meet the	AIACC and Standards of Practice	Pending evaluation method.

	criteria for best practices for subspecialty of therapeutic care for those living with ASD	Workgroup	
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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.

<u>Activities</u>	<u>Measurement</u>	<u>Responsible Persons/Unit</u>	<u>Status</u>
Determine availability of best practice providers and services throughout the state.	Completeness of statewide database information	AIACC	Online provider database in progress.
List available providers and services for each region of the state.	Establish a referral process from providers and professionals across services and systems	AIACC and Autism Coordinator	Will occur through regional autism network once established and through online database.
Support development and increase in choice of approved services.	Certification process, measurement by individual and agency survey	AIACC	To be completed
Identify possible improvements in accessibility to services in state after the establishment of the Autism Regional Network in Alabama	List possible improvements in accessibility after the Regional Network establishment	AIACC	To be completed
After the establishment of an Autism Network for Alabama, establish advocate as the individual is placed into the system to support and direct services	List number of participants; number of advocates; available by region/area	Determine after establishment of ASD Regional Network Center	To be completed
Identify the coordination of Medical Community/Professional Community and methods of accessing services at any stage of life (EI, school or adult).	Establish a referral process from providers and professionals across services and systems	Local Service Coordinator/Advocate identified after Autism Regional Network Center is established	To be completed. Currently developing relationships with providers and professionals.

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.

System Entry/Access
Screening, Assessment, and Evaluation
System Management
Decision-making/Oversight
Outreach and Referral
Crisis Management

Utilization Management
Staffing Structure, Support, and Development
Orientation and Training
External and Internal Communication
Protecting Privacy
Ensuring Rights

*Financing
Purchasing/Contracting
Revenue Generation
Information Management*

*Quality Improvement
Evaluation
System Exit
Technical Assistance*

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.

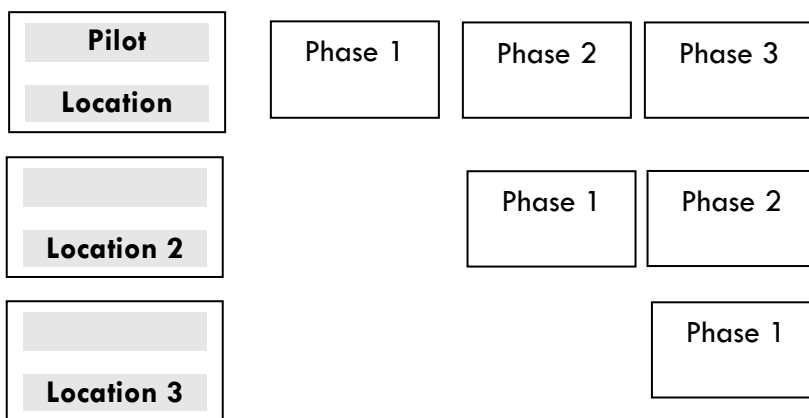
- 2.20 Secure approvals for Ill Plan to replace pre-determined existing service plans.
- 2.21 Develop and implement social marketing plan, regional evaluation plan, and sustainability plan.
- 2.22 Design Care Coordination training plan and modules.
- 2.23 Finalize System of Care Evaluation Plan.

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.

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.

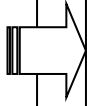
SYSTEM OF CARE LOGIC MODEL

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



- 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