Report to Governor Robert Bentley and the Alabama Legislature

2010 Report

Submitted March 2011

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Submitted by the Alabama Interagency Autism Coordinating Council

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Contents

Topic	Page #
Alabama Interagency Autism Coordinating Council Membership	5
Executive Summary	6
Introduction	7
Background	9
System of Care	10
Values	10
Principles	10
Implementation	11
System of Care Logic Model	12
System of Care Logic Model Visual	13
Long-term Plan	14
Long-term Plan: Step 1 Building the Foundation	14
Strategic Planning Committee	14
Mission Statement	14
Values Statement	15
Definition of Values	15
Priorities and Goals	16
Standards of Practice (SOP) Committee	17
Workgroups	17
Functions	18
Special Projects Committee	19
Autism Awareness Workgroup	19
Community Services Workgroup	19
Developmental Surveillance and Early Screening Workgroup	20
Family Supports Workgroup	20

Long-term Plan: Step 2 Infrastructure	21
Step 2 Proposed Objectives	21
Step 2 Proposed Activities	21
Long-term Plan: Step 3 Functions	24
Policies and Procedures	24
Care Coordination Components	25
Step 3 Proposed Objectives	25
Step 3 Proposed Activities	25
Benefit Design	27
Location Phase Plan	27
Long-term Plan: Step 4 Implementation	28
Step 4 Proposed Objectives	28
Step 4 Proposed Activities	29
Evaluation Plan	30
Process Evaluation	30
Outcome Evaluation	31
Data Management	32
Instruments	33
Data Analysis	33
Reporting and Integration of Data	34
Participant Protection	34
References	35

Alabama Interagency Autism Coordinating Council Membership **Key**: Autism Spectrum Expert Advisor (A.S.E.A.) / Autism Spectrum Family Advisor (A.S.F.A.) Autism Community Advocate (A.C.A.)	
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Terry Graham, Ph.D.	Alabama Institute for the Deaf and Blind
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Executive Summary

This is the Annual Report to Governor Robert Bentley and the Alabama Legislature required by Act#2009-295, the Riley Ward Alabama Autism Support Act of 2009. Act#2009-295 created the Alabama Interagency Autism Coordinating Council (AIACC) and charged the AIACC 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.

The Annual Report begins by providing (a) a brief introduction to ASD, (b) background information on formation of the AIACC, and (c) a general description of a system of care. The remainder of the report is dedicated to a proposed long-term plan toward a comprehensive statewide system of care for individuals with ASD and their families. *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.*

The AIACC is in step one of the proposed long-term plan, building the foundation essential to the SOC through two committee efforts (a) Strategic Planning, and (b) Standards of Practice. In addition, Special Project committee activities, dedicated to meeting currently identified needs in the ASD community, are described. Members of the three committees represent a remarkable collaboration by a diverse group of over 200 stakeholders, all committed to the single goal of improving the lives of Alabamians with ASD and their families.

Step two of the proposed long-term plan address infrastructure necessary for the SOC to be integrated across service sectors, which are collectively responsible for achieving individual, family, and community outcomes. Step three of the proposed long-term plan addresses functions essential to a SOC including policies and procedures, care coordination components, and benefit design. During step four, a Request for Proposals is initiated to inform recommendations for locations and service areas of SOC centers. The Report ends with information addressing other areas important to the system of care success.

Introduction

Autism Spectrum Disorder (ASD) is a group of complex neurological disorders typically present by 3 years of age, characterized by atypical development in socialization and communication, and often accompanied by unusual behavior and interests. The term *spectrum disorder* is used to indicate that ASD characteristics range on a continuum from mild to significantly disabling. Some with ASD also have a range of medical conditions including motor and sensory impairments, seizure disorder, immunological and metabolic abnormalities, sleep problems, and gastrointestinal symptoms, among others. Adequately addressing the extensive challenges requires sophisticated educational and therapeutic interventions.

At present, there is no known biological marker for ASD. Scientists are studying the interaction between a number of genetic, neurological, and environmental factors in the search for causal answers. In the meantime, 1.5 million individuals in the United States are facing a lifetime of challenges associated with their ASD diagnoses. The 2009 report from the Centers for Disease Control (CDC) and Prevention states 1 percent or 1 in every 110 children in the United States has an ASD diagnosis. This national statistic reflects a 57 percent increase in 4 years and underscores the need to regard ASD as an urgent public health concern. Even more alarming is that over the same 4-year period, the ASD rates in Alabama increased by 82 percent.

Although ASD is typically thought of as a childhood disorder, societal and economic costs extend well into adulthood. In fact, lifetime incremental costs for raising a child with ASD are $3-5 million dollars *beyond* those of raising a child with typical development. However, the cost of lifetime ASD care can be reduced by 2/3 with early diagnosis and intervention. Unfortunately, Alabama lags behind the curve in realizing this benefit. According to the 2009 CDC Report, the median age for an ASD diagnosis in Alabama is 51 months of age. This is a reality that must change if Alabama is to realize the benefits associated with early diagnosis and critical early intervention services.

Adding to the long-term concern is that a majority of adults with ASD struggle with ongoing and mostly unmet needs for employment, housing, services, and supports. The 2009 Current State of Services for Adults with Autism reported (a) 74 percent of working-aged adults with

ASD are unemployed, but would like to work; and (b) 84 percent of adults with ASD continue to live with their families.

Compounding these stressors, families of a child with ASD typically lose income, often as a result of one parent leaving the workforce to care for and meet the special healthcare and education needs of the child. The challenge is then to create a comprehensive interagency system of care for individuals with ASD and their families that will improve outcomes, quality of life, and independence of individuals with ASD, while also mitigating the potentially staggering financial and personal costs to families.

Background

The initial work toward addressing the urgent public health concern of ASD in Alabama began with the Alabama Autism Task Force (AATF) created through Alabama House Joint Resolution 23, sponsored by then House Representative and now Senator Cam Ward and Lt. Governor Jim Folsom, Jr., on March 8, 2007. The AATF was comprised of advocates, state officials, educators, physicians, and members of the academic community; and charged with recommending ways to improve treatment for ASD in Alabama.

The AATF Final Report was presented to Governor Bob Riley and the Legislature in January of 2009 with recommendations focused on meeting State needs through a system of care (SOC), namely regional autism centers. The Current State of the State for Systems of Care is reported on in the AATF Final Report Executive Summary and states, "Providers and parents reported that, for all practical purposes, there is no statewide system of care for all individuals with ASD and their families." The Summary continues stating, "Individual providers and specific organizations or groups were frequently cited as being very helpful; however, there appears to be a scarcity of resources and insufficient numbers of diagnosticians and interventionists who can assist those with ASD across the lifespan." In addition, the lack of a centralized service system responsive to all individuals with ASD and their families was reported to create frustration and delay in locating services and resources that do exist.

The AATF recommended (a) an Alabama Interagency Autism Coordinating Council (AIACC) be established and (b) the creation of a State Autism Coordinator position. In April 2009, the Riley Ward Alabama Autism Support Act of 2009, Act#2009-295, created the AIACC and charged the AIACC with developing a long-term plan, to be reviewed annually, for a comprehensive statewide system of care for individuals with ASD and their families. The Department of Mental Health was appointed by Governor Bob Riley to serve as the lead agency for the AIACC. Soon after in May 2009, Act 2009-592 was signed into law providing for the establishment of regional autism centers to meet the identified urgent need for a system of care. The AATF was dissolved upon submission of their Final Report. The AIACC is now working toward a comprehensive statewide system of care for individuals with ASD and their families.

System of Care (SOC)

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

Inputs

Time

Money

Staff

Volunteers

Partners

Facilities

Equipment

Technology

Supplies

Research Base

Outputs

Systems Infrastructure:

State
Region

Pilot Site:

Guide, Family Survey, Provider Survey, Resource Map, Public Forum, Advisory Board, Cost Analysis, Sustainability Plan

Care Coordination:

Guidelines/Training

Individualized Interagency Intervention Plan & Guide

Learn the Signs. Act Early. Campaign

Family Resources:

Resource Directory Navigation Guide Web-site

Outcomes

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

Long-term Plan

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.*

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 Planning Committee

System level change is required to meet the urgent need for a statewide comprehensive SOC for individuals with ASD and their families. The Strategic Plan process has built consensus needed among committee members to guide the system level change. In addition, the process has inspired synergy among stakeholders, for a unified strategy that leverages resources and expertise. The Strategic Plan progress to date effectively communicates the AIACC mission, values, goals, and priorities as outlined below.

Mission Statement

The Alabama Interagency Autism Coordinating Council guides a collaborative effort to facilitate a lifelong system of care and support for persons and their families living with Autism Spectrum Disorder or associated conditions, so that they enjoy a meaningful and successful life.

Values Statement

We believe that a successful system of care will provide innovative best practices 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.

Definitions of Values

Value	Definition
Person and Family Centered	We respect and value the uniqueness of all individuals. The system of care and support that will serve those with an Autism Spectrum Disorder (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 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 an ASD and their families.
Partnerships in Action	We promote improved public awareness and understanding of those living with an 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 that 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 of 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, Measurable, 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.

Priorities and Goals

Priority	Goal
1	Cultivate an overarching environment of understanding, communication, collaboration, and consensus building among Council membership that extends to the ASD community.
2	Support evidence-based, high quality, cost-effective models and best practices that provide supports to persons with ASD and their families.
3	Raise public awareness of issues/needs affecting persons with ASD and their families across the lifespan.
4	Identify and promote opportunities and create the infrastructure for diversified public

	and private partnerships that expand needed funding.
5	Increase the number of qualified and competent ASD trained professionals /personnel / providers
6	Increase choice among and access to quality services and supports for persons, families, and providers within ASD community-based systems of care.

Standards of Practice (SOP) Committee

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.

SOP Workgroups

1. Diagnostic Clinics
2. Services: Birth-5 Years
3. Services 6-21Years
4. Transition Services
5. Adult Services
6. Professional Preparation & Training

Functions

The SOP will serve three functions related to the System of Care. The SOP will:

1. Advise the AIACC on appropriate standards for programs and services provided or to be provided for individuals with ASD.

2. Provide information to be used in monitoring the implementation of SOP in programs and services.

3. 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:

1. Standards,

2. Accountability measures,

3. Program and provider technical assistance, and

4. Parent/consumer education efforts.

Special Projects Committee

The special projects committee is addressing currently identified needs of the ASD community through four workgroups.

Autism Awareness Workgroup

The Autism Awareness Workgroup is focused on developing resources to help families navigate the current system of services available in Alabama. The first focus has been on developing an Alabama Autism Spectrum Lifespan Resource Tree and Directory with direct links to and contact information for services/providers throughout the State.

- Autism Lifespan Resource Tree: This information graphic is organized by need from birth through adulthood. Under each category, statewide providers/resources are listed with links to the Directory.

- Autism Lifespan Resource Directory: This section provides detailed contact information and direct links (where available) for each of the resources on the Tree.

Community Services Workgroup

The Community Services Workgroup is focused on a Safety Campaign for individuals with ASD. The first AIACC initiative in the Safety Campaign was a *First Responder Training for Autism* provided in collaboration with the Alabama Departments of Public Health and Mental Health, Alabama Council for Developmental Disabilities, and the Autism Society of Alabama. The training was provided by an internationally recognized expert in June 2010 with 118 attendees including police officers, fire department officials, social workers, nurses, counselors, paramedics, rehabilitation counselors, sheriff dispatchers, mental health specialists, behavior analysts, clinical and educational providers, parents, and agency officials.

The second initiative in the Safety Campaign is to register all Alabama law enforcement districts in *A Child is Missing*, a nation-wide program that is provided at no cost to law

enforcement agencies. *A Child is Missing* is one of the fastest and most effective programs law enforcement can activate in the first critical minutes after a child is reported to be missing. When a law enforcement agency calls *A Child is Missing*, 1000 phone calls can be generated in 60 seconds in the calling area where the child was last seen. Adding to its effectiveness, *A Child is Missing* is not restrained by jurisdictional boundaries, which permits alert calls to be made across city, county, and state lines.

Developmental Surveillance & Early Screening Workgroup

The Developmental Surveillance and Early Screening Workgroup is focused on implementing a statewide ASD awareness campaign utilizing the *Learn the Signs. Act Early.* materials available from the Centers for Disease Control and Prevention (CDC). The efforts of this group were initially driven by discussions and goals set by a team of lead agencies, service providers, and other consumers attending a CDC sponsored Act Early Summit in October 2009. The workgroup has developed a long-term plan of disseminating information regarding early identification of developmental delays and appropriate referrals for children with known or suspected delays, with a target audience including parents/caregivers, service providers (e.g., physicians), and early childcare providers (e.g., daycare centers, early education training programs).

The workgroup was awarded a grant in the amount of $15,000 from the Centers for Disease Control and Prevention (CDC) and Association of Maternal and Child Health Programs, one of only ten in the Nation. The grant funds will be used to develop a webinar and network of trainers across the state to disseminate the *Learn the Signs. Act Early*. message. The workgroup will be recruiting professionals, family members, and others interested in becoming part of a network to provide presentations in specific geographical areas. The workgroup's goal is to have at least one trainer in each county.

Family Supports Workgroup

The Family Supports Workgroup is focused on respite care in collaboration with the Alabama Lifespan Respite Resource Network. Respite care is temporary short-term relief for caregivers of individuals with special needs. The primary purpose of respite is to give relief to families and caregivers from the extraordinary and intensive demands of providing ongoing care in the home. The workgroup identified and contacted current respite providers in the state and

is creating a Respite Resource Tree for families to streamline the process in obtaining respite services thorough vouchers.

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.

Step 2 Infrastructure
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.

Step 2 Infrastructure
Proposed Activities

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

1.1. Identify goals and guiding principles.
1.2 Maintain web-site to communicate SOC 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 SOC 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, and - 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 III Plan Draft Guide.

1.14 Develop certification application package for SOC 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, and - Define referral and intake mechanisms.
1.16 Determine plans to be coordinated through the III 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 SOC.
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.

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.

Step 3 Functions
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.*

Step 3 Functions
Proposed Activities

Activities All activities will be informed by youth/family participation and specialist consultants.
2.1. 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.
2.2.Continue identifying and utilizing (a) a pool of cultural brokers and (b) non-English SOC information.

2.3. Detail care coordinator responsibilities and requirements.
2.4 Identify III 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) III Plan and Guide.
2.17 Create crisis plan format and procedures.
2.18 Disseminate draft (a) Care Coordination Guidelines and (b) III Plan and Guide, request feedback, and make needed revisions.
2.19 Detail services to be provided in SOC.

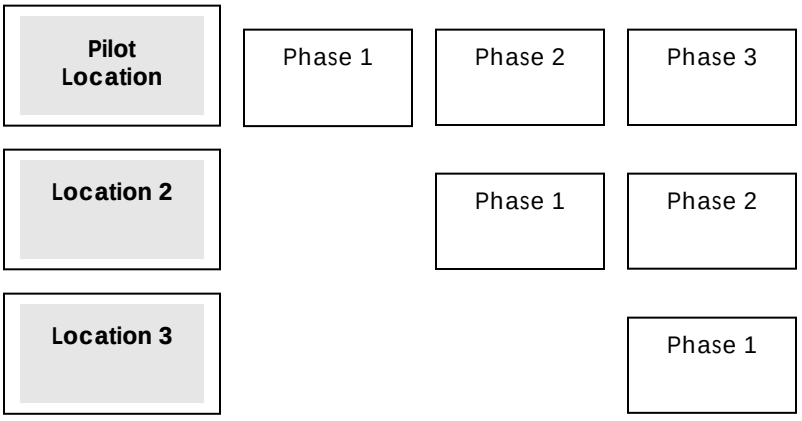
2.20 Secure approvals for III Plan to replace pre-determined existing service plans.
2.21 Develop and implement social marketing plan, regional evaluation plan, and sustainability plan.
2.22 Design Care Coordination training plan and modules.
2.23 Finalize SOC Evaluation Plan.

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



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.

Step 4 Implementation
Proposed Objectives

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

Objective 6. Initiate SOC pilot location.

Step 4 Implementation

Proposed Activities

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 on-going 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.

Data Management

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.

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.

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.

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