



## Rays of Hope for a Brighter Future

[www.Ga-AutismPlan.com](http://www.Ga-AutismPlan.com)

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# Autism Plan for Georgia

## Table of Contents

Vision .....	3
Structure of Autism Plan .....	4
Area 1: Early Identification & Screening .....	5
Area 2: Referral & Diagnosis .....	7
Area 3: Medical, Behavioral Health, & Dental Services.....	9
Area 4: Family Support .....	11
Area 5: Early Intervention & Preschool Services .....	13
Area 6: Elementary & Secondary Education .....	15
Area 7: Community Services & Supports .....	17
Area 8: Transition from Youth to Adult Systems .....	19
Area 9: Adult Services & Support.....	21
Area 10: Emergency Preparedness & First Responders.....	23
Glossary.....	25
References.....	26

# Autism Plan for Georgia

**Autism Planning Grant:** Through the Combating Autism Act, Health Resources and Services Administration's Maternal and Child Health Bureau awarded three-year implementation grants to 18 states to improve access to comprehensive, coordinated health care and related services for children, youth and adults with autism spectrum disorder and related developmental disabilities. Maternal and Child Health Bureau also awarded two-year planning grants to four states – including Georgia – to develop plans to guide the next steps in supporting children with autism and their families.

The Center for Leadership in Disability at Georgia State University received the Georgia Autism Planning Grant in the fall of 2011. We worked with our Advisory Panel to design a structure for the plan, to organize input from varied stakeholders, and to generate preliminary recommendations for next steps that might be included in a future three-year implementation grant.

**Vision:** Our vision for Georgia is that high-quality, family and person-centered, comprehensive, and coordinated systems of services and supports are accessible and available to all children, youth and adults with autism and related disorders. These services and supports are community-based, geographically convenient, culturally and linguistically appropriate, *and* are designed to assist children to reach their full potential and improve their quality of life. These systems require financial support from federal, state, and local governments, as well as the private sector, which are more likely to be provided when the community understands their importance, views them as cost effective, and feels that they are being managed responsibly and transparently.

**Advisory Panel:** The Advisory Panel is comprised of key stakeholders in Georgia representing federal, state, and local governments, children, youth, and adults with autism, parents of individuals with autism, providers, and professional and advocacy organizations. The Advisory Panel includes representatives from:

- Autism Society of America
- Autism Speaks
- Bright From the Start: Georgia Department of Early Care and Learning
- Centers for Disease Control and Prevention
- Private Providers
- Emory Autism Center, Emory University
- Georgia Council on Developmental Disabilities
- Georgia Department of Behavioral Health and Developmental Disabilities
- Georgia Department of Community Health
- Georgia Department of Education, Special Education Services and Supports
- Marcus Autism Center, Children's Healthcare of Atlanta
- Maternal and Child Health Program, Georgia Department of Public Health
- Parent to Parent of Georgia
- Parents
- Self-Advocates
- Spectrum Autism Support Group

**Structure for the Autism Plan for Georgia:** We have organized this plan to address ten areas of activity that emerged from discussions with families, providers, and policy-makers; review of historical documents and related planning efforts in Georgia; the research literature; and examination of autism plans from other states. These ten areas include:

- Area 1: Early Identification & Screening
- Area 2: Referral & Diagnosis
- Area 3: Medical, Behavioral Health, & Dental Services
- Area 4: Family Support
- Area 5: Early Intervention & Preschool Services
- Area 6: Elementary & Secondary Education
- Area 7: Community Services & Supports
- Area 8: Transition from Youth to Adult Systems
- Area 9: Adult Services & Supports
- Area 10: Emergency Preparedness & First Responders

For each of these areas, we developed:

- **Definition** – Specific to the Autism Plan for Georgia
- **Quality Indicators** - Statements describing desired systemic outcomes.
  - **Problem Statements** - Specific issues of concern identified by stakeholders in Georgia. The area includes Parent Focus Group Comments which reflects input from parents, family members, and individuals with autism, and largely expands our understanding of the problems.
  - **Data Drivers** - Documentation of the current status of this area in Georgia (when available) or the United States.
- **Recommendations** - Concrete options to address problems identified by parents, providers, and self-advocates. The recommendations reflect information and suggestions from the Autism Advisory Panel, Families, Self-Advocates, and State Autism Plans throughout the United States.
  - **Objectives**- Specific details, which will eventually include a proposed timeline, of each recommendation. Objectives may include key organizations or activities involved in completing each recommendation.

In addition to the ten areas identified, five areas emerged as the foundational supports of a comprehensive Autism Plan that cut across many of the areas. The foundational areas are **Workforce, Awareness, Informational Resources, Finances, and Policy**. The foundational supports were considered in developing recommendations for each area.

*Note: In the plan we have elected to use the term ‘autism’ to include autism spectrum disorders and related developmental disabilities.*

## Area 1: Early Identification & Screening

### Definition

**Early Identification** refers to a parent, educator, health professional, or other adult's ability to recognize developmental milestones in children and to understand the value of early intervention.

**Screening** refers to the use of standardized developmental or autism specific assessments to identify delays in development that may indicate the need for further evaluation.

### Quality Indicators / Problems / Data Drivers

**QI 1.1: All children receive coordinated broad developmental and autism-specific screening at prescribed intervals, as well as when concerns are raised about a child's development.**

**Problem:** Many primary care practices do not follow the recommended guidelines for screening with standardized developmental or autism-specific assessments. Additionally, many parents feel that their concerns about their child's development are not taken seriously by their primary care providers. Finally, parents across the general population may not be aware of typical development, signs of concern, and need for screening.

**Data Drivers:** The American Academy of Pediatrics (AAP) has adopted the *Bright Futures* guidelines which recommend that developmental surveillance be incorporated into the 9, 18, and 30-month well-child visits, and autism-specific screening at the 18 and 24-month visits.<sup>1</sup> In addition, parental concerns raised during surveillance should be promptly addressed with standardized developmental screening tests.<sup>1</sup>

**QI 1.2: Developmental concerns of all children are recognized early as part of routine surveillance and screening.**

**Problem:** If developmental concerns are not recognized by parents or providers, children may not be screened or diagnosed, and thus may not receive early intervention services.

**Data Driver:** Children who are screened are more likely to receive early intervention services than their unscreened peers.<sup>2</sup>

**QI 1.3: If developmental concerns are identified, families receive timely referrals for evaluation.**

**Problem:** There are often long delays between screening and referral, as well as between referral and diagnostic appointments. This is especially true for rural families, who experience greater difficulty accessing services.

**Data Drivers:** Most parents identify concerns related to their children's development by 18 to 24 months, 2 to 3 years prior to the average age of diagnosis.<sup>3,4</sup> The delay between an identified parental concern and diagnosis is longer for children from rural areas than those from urban areas; these children are diagnosed at later ages than urban children as well.<sup>5</sup>

## Current Activities in Georgia

Children First (DPH)



Bright from the Start (DECAL)



Easter Seals



GA Chapter of the AAP



Hughes Spaulding



Marcus Autism Center



*Learn the Signs. Act Early.* (CDC)



### Key

In-Person Screening



Telephone Screening



Web-Based Tool



Informational Resources



Awareness



## Recommendations

**Recommendation 1:** Educate primary care physicians and other health professionals on ongoing monitoring and screening guidelines (i.e., screening at 9, 18, 24, and 30 months) and the selection and use of screening tools.

- **Objective 1a:** Outline trainings according to best practices and incorporate resources for healthcare provider education on screening tools.
- **Objective 1b:** Coordinate screening awareness efforts with the Georgia Chapter of the AAP and Georgia Academy of Family Physicians (AFP) to include the importance of early intervention.
- **Objective 1c:** Promote web-based tools and curricula for professional development of practitioners (e.g., Autism Navigator™ and Autism Case Training Curriculum).
- **Objective 1d:** Encourage training of medical residents in early identification and screening.
- **Objective 1e:** Encourage the incorporation of autism-specific content in curricula for future professionals (e.g., therapists, physicians.)

**Recommendation 2:** Develop mechanisms to share screening results across systems of care to facilitate referral and diagnosis, thereby improving timely access to services for families.

- **Objective 2a:** Identify systems of care where screening is routinely being carried out to identify opportunities to streamline information sharing and collaboration.
- **Objective 2b:** Collaborate with Easter Seals to facilitate sharing of results from online administration of the Ages and Stages Questionnaires® with primary care providers in a format consistent with *Bright Futures* guidelines and medical record requirements.

**Recommendation 3:** Increase outreach and awareness efforts on the importance of early screening among families in Georgia, particularly those in historically underserved populations, including culturally and geographically diverse families.

- **Objective 3a:** Collaborate with family-centered community agencies to ensure that outreach and training on the *Learn The Signs. Act Early.* campaign reaches underserved communities.
- **Objective 3b:** Design, implement, and evaluate an outreach program in rural communities to enhance access to screening at recommended time points using mobile electronic devices and web-based tools.
- **Objective 3c:** Encourage the development of culturally and linguistically appropriate trainings and materials to be conducted and disseminated throughout the state of Georgia.

## Area 2: Referral & Diagnosis

### Definitions

**Referral** is a recommendation that a child, who has been screened through a standardized developmental or autism-specific assessment, be further evaluated by a professional qualified to determine a diagnosis and/or eligibility for services.

**Diagnosis** is based on the assessment of an individual using the criteria in the fifth edition of Diagnostic and Statistical Manual of Mental Disorders (DSM-5) developed by the American Psychiatric Association.

### Quality Indicators / Problems / Data Drivers

#### **QI 2.1: Families have a range of referral options so that children with disabilities may receive timely and appropriate evaluations.**

**Problem:** Many Georgia families are unfamiliar with where or from whom to seek services when their child is referred for evaluation. There are relatively few providers who have specific training in autism spectrum disorders and many providers do not accept Medicaid. As a result, this may increase the time between initial referral and the completion of a diagnostic evaluation, thus impacting whether or not a child receives early intervention services and possibly negatively impacting developmental outcomes for children with disabilities. Referral and diagnostic services later in life are difficult to access. Eligibility rules for medical and educational services often prevent children from receiving collaborative and comprehensive interventions in schools and childcare facilities.

**Data Driver:** Early identification of developmental delays, combined with appropriate early intervention supports, improves outcomes for children with disabilities.<sup>5,6</sup> Although people with autism can potentially receive services under Medicaid waivers in some states, many do not because they do not meet eligibility rules or because the states limit enrollment.<sup>23</sup>

#### **QI 2.2: Autism is best evaluated by a team of knowledgeable professionals using validated methods that identify both the needs and strengths of the child, and can differentially diagnose autism from other developmental concerns.**

**Problem:** There are few multidisciplinary teams in Georgia with the expertise to diagnose autism. Additionally, survey results indicate that many parents are unsure which providers are qualified to provide a diagnosis of autism.

**Data Driver:** The assessment and diagnosis of autism requires collaboration between multiple care providers and the use of multiple assessment methods rather than just a single snapshot, which can be confusing for parents.<sup>7</sup>

#### **QI 2.3: Children and families from all racial, ethnic, and cultural backgrounds have access to culturally competent services relating to referral, evaluation, and diagnosis.**

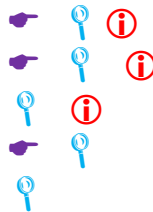
**Problem:** Children and families from diverse backgrounds often face increased difficulty in obtaining timely diagnosis and accessing services. Factors contributing to this disparity have been attributed to combinations of family culture, provider sensitivity, communication styles, and perspectives on child development. Based on our survey, White families (77% of the respondents) generally felt that their services reflected their “family culture, needs, values, and preferences.” The majority of Black families who responded disagreed, however, that services reflected their culture and values.

**Data Driver:** Children with autism from diverse ethnic and cultural backgrounds are often identified 12 to 18 months later than White children.<sup>8,9</sup>



## Current Activities in Georgia

Babies Can't Wait (DPH)  
Local School Districts  
Marcus Autism Center  
Hughes Spalding Autism Clinic  
Private Providers



<b>Key</b>	
Referral	
Diagnostic Service	
Informational Resources	

## Recommendations

**Recommendation 1:** Expand pool of evaluators competent to diagnose autism and related developmental disabilities.

- **Objective 1a:** Coordinate efforts with the Georgia Chapter of the AAP, Georgia AFP, and Georgia-based colleges, universities, and medical schools, to promote awareness of the shortage of qualified evaluators. This may increase the number of students, residents/fellows, trainees, and early career professionals interested in entering the field.
- **Objective 1b:** Partner with medical residency and other professional programs to encourage training in differential diagnosis.
- **Objective 1c:** Work with the Georgia Departments of Community Health and Public Health to ensure a pool of providers trained in autism who accept Medicaid.

**Recommendation 2:** Create a family-centered information clearinghouse that outlines the components of an effective evaluation and provides information on where to go to obtain one.

- **Objective 2a:** Expand Parent to Parent of Georgia's Concern Guide and begin linking families to this information.

**Recommendation 3:** Increase the cultural competence of providers and organizations so that families from diverse cultural, racial, and ethnic backgrounds have a range of options and feel comfortable in the referral and diagnostic process.

- **Objective 3a:** Through training and awareness campaigns, enhance the communications skills of providers to discuss issues related to autism diagnosis and intervention options in a culturally competent manner.
- **Objective 3b:** Utilize scholarship or grant programs to increase the number of providers from culturally diverse backgrounds.
- **Objective 3c:** Encourage conference planners and organizers to include content on cultural and linguistic competence.

## Area 3: Medical, Behavioral Health, & Dental Services

### Definitions

**Health Services** are the care provided to children, youth, and adults with autism to ensure their physical health and well-being.

**Dental Services** are accessible and comprehensive dental care for patients by dentist and dental hygienists trained in supporting the needs of patients with autism.

**Behavioral Health Services** are comprehensive and coordinated services for children and adults by medical and other health professionals trained in supporting the unique needs of people with autism and other co-occurring behavioral health diagnoses.

In a **Medical Home**, families work closely with primary care providers in ensuring coordinated, comprehensive, and continuous health care. The medical home is a partnership between the physicians and family that addresses both medical and non-medical needs.

### Quality Indicators / Problems / Data Drivers

**QI 3.1: Health care providers, including medical, dental, behavioral health, and other health professionals, are knowledgeable about how to support the routine needs of children with autism and their families.**

**Problem:** Many health care providers are unfamiliar with the resources available to assist families with a child with autism. Georgia has a shortage of practitioners (e.g., physicians, dentists, and optometrists) with the expertise to support children with autism and their families. Those professionals who do have the specific training and knowledge have long waiting lists.

**Data Driver:** Accessing knowledgeable service providers in some areas of Georgia may involve a waiting time of up to 3 years.<sup>10</sup> Waiting time has been identified by parents as the most stressful aspect of obtaining services for their child with autism.<sup>11</sup>

**QI 3.2: Children with autism and their families can access health and dental specialists who are able to support the needs of children with autism.**

**Problem:** Georgia has a shortage of health and dental specialists (e.g., child psychiatrists, developmental pediatricians, pediatric neurologists) to serve children with autism. It is particularly difficult to locate specialist providers for children on Medicaid.

**Data Drivers:** Children with autism have difficulty accessing health care, including medical, behavioral health, and dental care.<sup>12,13</sup> Preventive dental coverage for young adults receiving Medicaid stops at age 21<sup>14</sup> so many young adults do not continue to receive services.

**QI 3.3: Children with autism have access to a medical and dental home that provides comprehensive, coordinated care.**

**Problem:** The medical home model is not in widespread use in pediatric settings.

**Data Driver:** Children with autism receive care in medical homes at lower rates than children with other special healthcare needs or typically developing peers.<sup>15</sup>

**QI 3.4: Children with autism have access to behavioral health professionals who are knowledgeable of and trained in the unique needs of children with autism and their families.**

**Problem:** Georgia has a limited number of behavioral health providers familiar with the unique needs of individuals with autism and the interfering behaviors that are often present. Even fewer behavioral health providers are trained to address the needs of individuals with autism who are experiencing other behavioral health disorders.

**Data Driver:** Children with autism often experience co-occurring behavioral health disorders.<sup>16</sup>

## Current Activities in Georgia

GA AFP  
 GA Chapter of the AAP  
 Emory Autism Center  
 Marcus Autism Center  
 Private Practice Dentistry  
 Private Practice Medical



Key	
Medical Home	
Telemedicine	
Medical	
Dental	
Informational Resources	

## Recommendations

**Recommendation 1:** Increase training for physicians, behavioral health professionals, and dentists on how to best serve children with autism.

- **Objective 1a:** Create, implement and evaluate training with content that improves provider knowledge of autism, as well as strategies to enhance interactions with children, youth and adults with autism and their families.

**Recommendation 2:** Increase number of providers that offer the medical home model of service, which will improve system navigation for families and potentially reduce long periods of time in between appointments.

- **Objective 2a:** Partner with the Georgia AFP to expand current national training offerings to a wider variety of primary care practices in Georgia.
- **Objective 2b:** Partner with medical residency and other health provider training programs to provide education on the medical home model.
- **Objective 2c:** Partner with the Georgia Chapter of the AAP to increase the utilization of the medical home model through conferences and other Continuing Medical Education opportunities. These trainings should be advertised locally and should be made available to private practices, community health centers, and rural providers alike.
- **Objective 2d:** Demonstrate the feasibility and utility of a family navigator working within primary care practices to improve coordinated, comprehensive, and continuous care for children and youth with autism and their families.

## Area 4: Family Support

### Definition

**Family Support** refers to the services and supports, both formal and informal that help to enhance a family's ability to thrive while caring for and supporting a child with autism.

### Quality Indicators / Problems / Data Drivers

**QI 4.1: Families have access to comprehensive, flexible, and family-centered supports, such as support groups, parent training and education, respite, and after-school care.**

**Problem:** Parents often do not know where to go for services after their child first receives a diagnosis of autism. The needs assessment survey results suggest families then seek both informal support from networking groups with other families (parent and sibling groups), and formal support from specialized after-school care, respite, and parent training and education opportunities. Additionally, there are a limited number of support groups for siblings of children with autism in Georgia.

**Data Driver:** Families whose children exhibit poor adaptive behaviors or challenging behaviors often experience high stress levels and quality of life restrictions, and require higher levels of support to optimize outcomes for their children.<sup>17</sup>

**QI 4.2: Supports reflect family culture, needs, values, and preferences.**

**Problem:** When available, family supports are not always culturally competent. Supports are often lacking in rural areas. When services do exist, families often can't afford them, even when they have insurance or a Medicaid waiver.


































**Data Driver:** Families with a child with autism have high needs for services and the availability of services, but cannot access them due to long wait lists, distance, or cost.<sup>18</sup>

**QI 4.3: Family supports assist the family in accessing both formal and informal supports in the broader community.**

**Problem:** In Georgia, family supports generally emphasize provider capacity and formal structures, over family-identified concerns and informal supports.

**Data Driver:** Families receiving informal support from their social networks and formal support from agencies and health care providers are more likely to show positive adjustment.<sup>19</sup>

## Current Activities in Georgia

Autism Society of America - GA	 	<p><b>Key</b></p> <p>Training/Workshop </p> <p>Informational Resources </p> <p>Toolkit </p> <p>Dad Support </p> <p>Sibling Support </p> <p>Family Support </p> <p>Grandparent Support </p> <p>Parent Mentoring </p> <p>Camps </p>
Autism Speaks	 	
Emory Autism Center	   	
GA Department of Education (DOE)		
Marcus Autism Center	  	
Parent to Parent of GA	 	
Spectrum Autism Support	    	
Institute for the Study of the Disadvantage and Disability	  	
GA DBHDD funded Provider Agencies		
Families of Children Under Stress (FOCUS)		

## Recommendations

**Recommendation 1:** Establish a statewide Autism Resource Center with telephone and web access that can serve as a first-point of contact and ongoing resource for families and providers.

- **Objective 1a:** Obtain resources to populate a family-centered information clearinghouse that will facilitate families' navigation of systems of care and will allow providers to refer families to more specific resources when needed.

**Recommendation 2:** Collaborate with advocacy and support organizations to establish and deliver training on culturally competent family support throughout the state that may include a focus on parent advocacy, peer support for parents, grandparents, and siblings, and accessing community resources.

- **Objective 2a:** Collaborate with Autism Society of America, Autism Speaks, Department of Behavioral Health and Developmental Disabilities (DBHDD), Parent to Parent of Georgia, and Spectrum Autism Support to expand current trainings and incorporate cultural competence into existing programs.

**Recommendation 3:** Collaborate with state, local, and community agencies, including places of worship and recreation centers, to establish affordable and accessible respite programs with the community.

- **Objective 3a:** Develop, implement, and evaluate a series of trainings for respite providers on supportive and culturally competent methods of serving children with autism and their families. These trainings will be accessible to diverse geographic areas throughout Georgia, as well as within the metro area.

**Recommendation 4:** Establish clear and consistent guidelines across the state on respite.

- **Objective 4a:** Develop statewide policies on respite care, including who can access it, who provides it (with consideration of training requirements), and what it costs, including the availability of a sliding scale.

**Recommendation 5:** Establish a network of regional centers that will assist families and providers in accessing local community resources, coordinating existing supports across agencies, and identifying strategies to address unmet needs.

## Area 5: Early Intervention & Preschool Services

### Definition

**Early Intervention** services provide families of children with developmental disabilities (including autism) between birth and age three with services to enhance development; these are guided by an Individualized Family Service Plan (IFSP) and are coordinated through Babies Can't Wait in Georgia.

**Preschool Services** are the services and supports provided to children with developmental disabilities (including autism) between three and five; these are guided by an Individualized Education Program (IEP) developed to fulfill the mandate for a "free and appropriate public education" and are coordinated through the local school district.

### Quality Indicators / Problems / Data Drivers

**QI 1: Children with autism receive services appropriate for their needs. That is, services are provided by competent providers, with the frequency, duration, and fidelity needed to be effective.**

**Problem:** Many teachers and childcare providers are unfamiliar with autism, which results in repeated complaints to parents about behaviors characteristic of autism. In many areas of Georgia, Babies Can't Wait provides primarily consultative (as opposed to direct) services leaving families largely responsible for providing interventions, thus leaving a question of whether services are being provided in a manner likely to be effective. Babies Can't Wait enrolls the fewest number of children in services relative to the national average; this is due in part to relatively restrictive standards for receiving services.<sup>21</sup> Many families seek services and interventions outside of Babies Can't Wait and preschool special education settings in order to meet the needs of their children – this has a high emotional and financial cost.

**Data Driver:** For some children with autism, early intervention starting between 18 and 30 months (or as early as possible), and provided more than 20 hours per week, is associated with best outcomes.<sup>5, 20</sup>

**QI 2: Professionals and parents work together in planning the transition from an IFSP in Babies Can't Wait to an IEP in preschool.**

**Problem:** The IFSP and IEP are constructed under very different service models and approaches to intervention. Families often report that the transition from Babies Can't Wait to preschool does not go smoothly, and as the emphasis shifts from family to the child as an individual.













**Data Driver:** The Georgia pre-kindergarten program makes inclusion opportunities more widely available for four-year-old children with autism, and facilitates the transition from IFSP to IEP.<sup>22</sup>

**QI 3: The IEP identifies the services and supports that meet the child's specific needs in the least restrictive environment, including the consideration of assistive technology and positive behavior supports.**

**Problem:** Parents report that preschool services provided are based on availability of providers or a class grouping at the local level, rather than the child's specific need. Specialized supports such as augmentative communication devices or positive behavior supports are not routinely available.

**Data Driver:** Inclusive preschool programs for children with autism have been demonstrated to be a highly effective intervention approach.

## Current Activities in Georgia

Bright from the Start (DECAL)	 
GA DOE	 
Local School Districts	
Emory Autism Center/Walden	  
Marcus Autism Center	 
Project SCEIs	 

Key	
Training/Workshop	
Informational Resources	
Preschool Special Ed.	
Inclusive Education	
Pre-K Transition	

## Recommendations

**Recommendation 1:** Increase the availability of effective early intervention and preschool services for children with autism.

- **Objective 1a:** In collaboration with the Georgia Departments of Early Care and Learning, Education, and Public Health, provide ongoing training and technical assistance for childcare and early education providers on effective practices for educating young children with autism.
- **Objective 1b:** Collaborate with advocacy groups, professional organizations, and state agencies on the formulation of policies, standards, and financing of comprehensive and coordinated early intervention and preschool services that meet the medical and educational needs of the child. Policies should be inclusive of children with a diagnosis of autism, as well as and those exhibiting signs of developmental delay, but not otherwise eligible for services.

**Recommendation 2:** Strengthen teacher and parent knowledge of appropriate early interventions at school and home.

- **Objective 2a:** In collaboration with state agencies and professional organizations, disseminate the Autism Navigator™ (now in development at the Marcus Autism Center) that provides training on identifying the signs of autism, appropriate methods of communicating teacher concerns regarding a child's development to parents, and effective intervention strategies.
- **Objective 2b:** Design, implement, and evaluate a series of trainings for childcare and early education providers on best practices for family and teacher partnerships, including Head Start and the Childcare and Parent Services (CAPS) programs that serve historically underserved populations.

**Recommendation 3:** Increase the number of inclusive preschool opportunities for children diagnosed with autism throughout the state of Georgia.

- **Objective 3a:** Design, implement, and evaluate a series of trainings for childcare and early education providers on best practices for inclusion, including Head Start and CAPS programs that serve historically underserved populations.
- **Objective 3b:** In collaboration with the Georgia Department of Early Care and Learning, increase the availability of on-site training and technical assistance on supporting children with autism in generic preschool and childcare settings.
- **Objective 3c:** In collaboration with the Georgia Department of Education, support the dissemination of inclusive preschool classrooms for children with autism through on-site training and technical assistance.

## Area 6: Elementary & Secondary Education

### Definition

**Elementary & Secondary Education** refers to services and supports provided to children, youth, and young adults with autism; these are guided by an Individualized Education Program (IEP) developed to fulfill the mandate for a “free and appropriate public education” and are coordinated through the local school district.

### Quality Indicators / Problems / Data Drivers

#### QI 1: Children with autism receive educational supports that maximize their potential.

**Problem:** Many parents feel that they are not fully informed about educational and intervention options. IEPs are often deficit-driven, highlighting what the child with autism cannot do. Children’s capabilities often go unrecognized; this is a concern as children get older as individual skills and interests become an organizing focus for the education of their peers, but students with autism are often confronted with a restricted range of options.

**Data Driver:** In Georgia as in the rest of the United States, less than half of the students with disabilities graduate with a high school diploma; students with autism receive the high school diploma at even lower rates.<sup>24</sup>

**QI 2: Teaching methods address the unique needs of each student with autism while recognizing the student’s strengths and interests. Methods vary based on age and developmental appropriateness. Instruction may, therefore, be delivered individually or in small groups, as well as be embedded into natural routines and large groups.**

**Problem:** Many teachers report that they are unfamiliar with the evidence-based strategies for children with autism that promote communication, socialization, and self-regulation. The diagnosis of autism may overshadow specific instructional needs related to accessing the general curriculum, so that they are less likely to be exposed to the range of evidence-based educational intervention strategies. Some teachers say they are reluctant to communicate with parents about the need for new or additional services for a child because of cost, service availability, and difficulty in providing accommodation or adaptations.

**Data Driver:** Less than 5% of teachers in Georgia report using best practices for students with autism in their classrooms.<sup>25</sup>

**QI 3: Instruction focuses on improving functional communication, socialization, and self-regulation skills, in addition to learning the general curriculum.**

**Problem:** Social skills programs are often not included in the curriculum for students with autism. Many of the behaviors typical of autism are judged as noncompliant or willful, which results in repeated complaints to parents about their children.

**Data Driver:** Research indicates that teaching social skills to students with autism in inclusive classrooms increases social responsiveness and reduces problem behaviors in students with autism as well as their typical peers.<sup>26, 27</sup>



## Current Activities in Georgia

Emory Autism Center/Walden  
 GA DOE  
 Marcus Autism Center  
 Private and Local School Districts



Key	
Training/Workshop	
Informational Resources	
Special Education	
Inclusive Education	
Research	
Educational Assessment	
Outreach	

## Recommendations

**Recommendation 1:** Increase the availability and delivery of effective and appropriate educational strategies for students with autism.

- **Objective 1a:** In collaboration with the Georgia Department of Education, provide ongoing training and technical assistance for educators on effective practices for educating young children with autism, including strategies for enhancing communication, social skills, self-regulation, and inclusion.
- **Objective 1b:** In collaboration with the Georgia Department of Education, provide ongoing training and technical assistance for educators on collaborating with parents in promoting communication, social skills, self-regulation, and inclusion at home and in the community.

**Recommendation 2:** Increase opportunities for students with autism to participate in the general curriculum.

- **Objective 2a:** In collaboration with the Georgia Department of Education, provide ongoing training and technical assistance for educators on instructional strategies, accommodations, and adaptations that promote participation in the general curriculum and progress toward graduation.

**Recommendation 3:** Promote the inclusion of students with autism into the school and community.

- **Objective 3a:** In collaboration with the Georgia Department of Education, develop a training program to increase awareness of autism and effective support practices. Disseminate training program to the broad community of students and school personnel (e.g., teachers, paraprofessionals, administrators, bus drivers, cafeteria staff, and school resource officers).
- **Objective 3b:** Develop and implement strategies for enhancing self-determination of students with autism, through the dissemination of programs such as student-directed IEPs, identification of skills and interests, person-centered planning, and participation in the broad range of school activities (e.g., extra-curricular activities, leadership clubs).

## Area 7: Community Services & Supports

### Definition

*Community Services & Supports promote independence, productivity, and integration and inclusion into the community for children, youth and adults with autism.*

### Quality Indicators / Problems / Data Drivers

**QI 1: Children, youth, and adults with autism and their families have access to services and supports that promote safety, learning, and independence at *home*. Examples include in-home behavior supports, affordable child care, and home instruction in self-help skills.**

**Problem:** In-home services that provide coaching for children and youth to become independent in self-help skills and behavior regulation are not available.

**Data Driver:** Parents of children and youth with ASD often experience difficulty accessing in-home support services.<sup>28</sup>

**QI 2: Children, youth, and adults with autism and their families have access to services and supports that promote safety, learning, and independence in the *community*. Examples include recreational opportunities and camps.**

**Problem:** Children, youth, and adults with autism do not have reliable access to organized community supports and recreational programs with well trained staff. There are few childcare centers, after-school programs, and adult recreation centers with staff trained to work with children with autism.

**Data Driver:** Parents of children with ASD, as well as youth and adults with autism, often experience difficulty accessing community support services.<sup>28</sup>








**QI 3: Professional programs link with community agencies to assist families to access supports and services needed by families of children with autism, including affordable childcare.**

**Problem:** Parents cannot work because they do not have reliable after-school childcare, and when available, care for children with autism often costs more than for their other children.

**Data Driver:** Families with a child with autism are seven times more likely to report that child care problems affected employment than other families.<sup>29</sup>

## Current Activities in Georgia

GA DBHDD funded Provider Agencies  
 Emory Autism Center  
 Parent to Parent of GA  
 Marcus Autism Center  
 Spectrum Autism Support

 B  
  B   
 B   
 B   
 B 

Key	
Training/Workshop	
Informational Resources	
Family Support	
Behavior Support	B
Educational Services	
Inclusion Specialist	

## Recommendations

**Recommendation 1:** Increase families' options for inclusive after-school childcare options.

- **Objective 1a:** Develop and implement an autism awareness training program for childcare and after-school care providers. The program will include the signs of autism, effective interaction and communication strategies, safety procedures, and methods to promote the child's development and participation.
- **Objective 1b:** Encourage collaboration and sharing of techniques and information between parents, and childcare centers to support the needs of children and youth with autism.
- **Objective 1c:** Encourage collaboration between childcare centers and schools to allow sharing of child-specific information with parental permission and participation by childcare personnel in school trainings.

**Recommendation 2:** Educate adults with autism and families of children and youth with autism about strategies and techniques, as well as in-home supports that are available for themselves or their loved ones.

- **Objective 2a:** Develop and implement training programs for families on evidence-based strategies for promoting independence through self-help skills and behavior self-regulation.
- **Objective 2b:** Partner with advocacy and support organizations to advertise current in-home support services.
- **Objective 2c:** Organize classes and training for adults with autism living independently.

**Recommendation 3:** Increase the knowledge of community-based organizations' staff, including recreational leagues and centers, scouts and camps, clubs, and cultural, religious, and/or spiritual groups, on inclusion practices and effective methods for supporting children, youth, and adults with autism.

- **Objective 3a:** Develop and implement an awareness training program for staff members, coaches, and community members to include the signs of autism and effective interaction and methods for supporting and including children, youth, and adults with autism in activities. Training should focus on the strengths of individuals with autism.
- **Objective 3b:** Educate families who receive funding through "Natural Supports Training" that funds may be used to train support personnel.

## Area 8: Transition from Youth to Adult Systems

### Definition

The time of **Transition from Youth to Adult Systems** for individuals with autism is notable for the movement from services and supports that are available as entitlements to those requiring that eligibility be established. This includes the transition from an IEP to employment, post-secondary education, or other supports; the move from pediatric services to adult health providers; and the need for greater independence in utilizing transportation, residential options, and community living. The transition period begins at age 14 and extends to age 22 and older.

### Quality Indicators / Problems / Data Drivers

**QI 1: Professionals, parents, and students work together in planning transitions from one program or service to another with consideration of the individual's gifts, talents, and abilities.**

**Problem:** Transition plans are often based on what was historically available, rather than more contemporary models of support, such as college or employment. Parents are often unprepared to participate in transition IEP meetings when or before their children reach the age of 14 because they are unfamiliar with contemporary and available programs and options.

**Data Driver:** Many parents of secondary school-age students are not well informed about local community adult services. It is not unusual for parents of children with disabilities to be confronted with long waiting lists for those services that do exist.<sup>29</sup>

**QI 2: Youth with autism between the ages of 14 and 22, after career and interest assessments, are provided with a variety of vocational, educational, recreational, and residential opportunities that reflect personal preferences in preparing for the transition to adulthood.**

**Problem:** There are few post-secondary educational opportunities for young adults with autism.






























**Data Driver:** Only 37% of youth and young adults with disabilities enter into some type of post-secondary education; students with autism participate in post-secondary education at even lower rates.<sup>30</sup>

**QI 3: Youth with autism transition to adult medical services provided by primary care providers knowledgeable about autism.**

**Problem:** For those youth and young adults who receive Medicaid, there is inadequate funding available through Medicaid waivers for the number of students transitioning each year out of high school. Many of the families who responded to our survey indicated their children have private insurance coverage, so, like all children who reach adult age, insurance is dropped and these young adults may have difficulty accessing transition services.

**Data Driver:** There are on average 100 Medicaid Waivers granted each year for *all* individuals with developmental disabilities of *all* ages, yet more than 400 students with an autism transition out of Georgia schools each year of whom more than half are estimated to be eligible for Medicaid Waivers.<sup>31</sup>

## Current Activities in Georgia

Emory Autism Center	   	<p><b>Key</b></p> <p>Training/Workshop </p> <p>Informational Resources </p> <p>Employment Services </p> <p>Community Events </p> <p>Medical Services </p> <p>Research </p>
GA Council on Developmental Disabilities	  	
GA Vocational Rehabilitation Services	 	
GA DOE	  	
DBHDD		
GA Advocacy Office	  	
Parent to Parent of GA	 	
The Georgia Learning Resources System	 	
Institute on Human Development & Disability		
Statewide Independent Living Council	 	

## Recommendations

**Recommendation 1:** Provide accurate and up-to-date information on transition and autism for Georgia families through both the Autism Resource Center phone-line and website, and the regional centers recommended under Area 4.

- **Objective 1a:** Work with existing Statewide Transition Steering Committee to develop a resource bank of transition strategies and information to educate students and parents about transition options prior to participating in the middle to high school transition IEP meeting.
- **Objective 1b:** Work with Statewide Transition Steering Committee to develop trainings for families, individuals, and providers on the transition process, community resources, post-secondary opportunities, funding/waivers, assistive technology, transportation, medical homes, housing/residential support, guardianship, in-home and family support, and job support.
- **Objective 1c:** Develop, implement, and evaluate training targeted to school transition departments (including Transition Specialists, Lead Teachers, counselors and Parent Mentors) to familiarize providers with community resources for the students and families they support.

**Recommendation 2:** Support the current efforts in Georgia to provide training for primary care primary practitioners on medical homes, the need for early transition planning, and supporting patients diagnosed with autism and their families through the transition process.

- **Objective 2a:** Develop trainings with the Georgia Chapter of the AAP and Georgia AFP to ensure providers are informed and understand the transition from pediatric to adult medical services.

**Recommendation 3:** Ensure preferences of students, parents, and families are included in transition IEP meetings.

- **Objective 3a:** Provide training in self-determination and self-advocacy curriculum for students in middle school and high school.
- **Objective 3b:** Expand existing efforts, such as ASPIRE (student-led IEP) and Partnerships for Success Leadership classes, to provide students with autism education about their diagnosis, their rights and responsibilities, and options for post-secondary education and employment.

## Area 9: Adult Services & Supports

### Definition

**Adult Services & Supports** promote independence, productivity, citizenship, and inclusion into the community for adults with autism over the age of 21.

### Quality Indicators / Problems / Data Drivers

#### **QI 1: Adults with autism in Georgia are able to support themselves and achieve conventional markers of adulthood.**

**Problem:** Adults with autism face many challenges in achieving the conventional markers of adulthood – becoming employed and self-supporting, living independently, developing a network of friends, and contributing to the community.<sup>32</sup> Adults with autism confront persistent high levels of unemployment or underemployment. While often having well-developed skills for a range of jobs, they may require support in negotiating social and interpersonal skills in maintaining employment.

**Data Driver:** Great advances have been made in customizing employment, that is matching worker skills with workplace demands in a manner that highlights the worker’s strengths and minimizes those aspects of employment that are difficult for the individual to manage.

#### **QI 2: Residential supports and housing are accessible and available to adults with autism.**

**Problem:** Finding and securing housing and residential supports for adults with ASDs can be challenging for adults with autism and their families.

**Data Driver:** While services that support community living have expanded, there are significant gaps in residential supports for housing for people with intellectual and developmental disabilities.<sup>33</sup>

#### **QI 3: Adults with complex needs receive appropriate services, provided by competent providers, with the frequency, duration, and fidelity needed to be effective.**

**Problem:** There are too few providers of specialized in-home or out-of-home residential support, community support, job supports, or day programs. Where services do exist, providers often lack training in addressing the unique challenges often faced by adults with autism

**Data Driver:** Without continued assistance into adulthood, individuals with autism are more likely to regress and lose some of their verbal and social gains.<sup>34</sup>

## Current Activities in Georgia

GA DBHDD funded Provider Agencies  
 Emory Autism Center  
 GA Vocational Rehabilitation Services



Key	
Informational Resources	
Employment Services	
Adaptive Living Services	
Housing Services	
Educational Services	

## Recommendations

**Recommendation 1:** Increase provision of supported and customized employment services for adults with autism.

- **Objective 1a:** In collaboration with Employment First of Georgia, the Georgia Vocational Rehabilitation Services, and Georgia DBHDD, create, implement and evaluate trainings on best practices for individualized employment for adults with autism.
- **Objective 2a:** Develop an awareness campaign to educate adults with autism, their families, and their communities on individualized employment services.

**Recommendation 2:** Expand the number of housing and residential supports available for adults with autism in Georgia.

- **Objective 2a:** In collaboration with the Georgia Department of Community Affairs (DCA), identify resources and options for housing to accommodate individuals with autism.
- **Objective 2b:** Link housing and residential options to education, career development, and other support programs to provide adults with autism the services they need along one continuum.

**Recommendation 3:** Increase the availability of specialized community services, including career & financial supports, for adults with autism who have complex needs.

- **Objective 3a:** In collaboration with DBHDD funded provider agencies, create, implement and evaluate trainings on best practices for support of full community participation for adults with autism.
- **Objective 3b:** Develop marketing and awareness media campaigns to educate adults with autism, their families and their communities on accessing specialized community based services.
- **Objective 3c:** In collaboration with Georgia DBHDD and Georgia DCA, ensure access to needed services and supports using Medicaid and waivers.

## Area 10: Emergency Preparedness & First Responders

### Definitions

**Emergency Preparedness** is the capability of the public health and health care infrastructure, communities, families, and individuals, to prevent, respond to, and recover from emergencies in a coordinated and continuous manner.

**First Responders** are law enforcement, fire, and medical emergency personnel that interact, support, treat, and meet the needs of children, youth and adults with autism.

### Quality Indicators / Problems / Data Drivers

**QI 1: Needs of children, youth, and adults with autism are considered in state and local emergency preparedness plans.**

**Problem:** State disaster response plans that address the needs of children, youth, and adults with disabilities are difficult to locate. In Georgia, local resources exist, but are sparse and incomplete. Additionally, there is no requirement for the coordination of local registries for accommodating the needs of children, youth, and adults with autism in crises.

**Data Drivers:** The 2006 *Nationwide Plan Review Phase 2 Report*, prepared and released following Hurricane Katrina, revealed that few statewide emergency response plans demonstrate the planning required to meet the needs of children, youth, and adults with disabilities before, during, and after emergencies.<sup>35</sup> Furthermore, the state of Georgia lacks a Disability Accommodation Registry, which can assist law enforcement officers in working effectively with children, youth, and adults with disabilities and other health considerations.<sup>36</sup>

**QI 2: Children, youth, and adults with autism are informed and prepared to handle emergencies. For example, families have the knowledge and resources to plan and practice emergency plans.**

**Problem:** Few families have plans for what to do in a disaster or emergency. Vulnerable populations, including children, youth, and adults with disabilities, are even less prepared than the general population.

**Data Drivers:** Behavioral Risk Factor Surveillance Survey data analysis from 2006-2010 of 14 states including Georgia concluded that only one in five families has a written evacuation plan.<sup>37</sup> Additionally, research suggests that for families of children with special healthcare needs, this drops to one eight.<sup>38</sup>

**QI 3: First responders, such as police officers and emergency medical personnel, are equipped to support children, youth, and adults with autism in times of crisis.**

**Problem:** First responders, law enforcement agents, and school safety officers are often unaware of the special considerations needed to protect and serve children, youth, and adults with autism. Additionally, they lack the necessary training for safe and successful interactions with children, youth, and adults with autism, particularly in emergency situations.

**Data Drivers:** An existing body of research suggests that law enforcement officers lack training to effectively protect and serve individuals with autism.<sup>39</sup> Emergency personnel may benefit from this training, as children, youth, and adults with autism are seven times more likely to come in contact with law enforcement than their typical peers.<sup>40, 41</sup>



## Current Activities in Georgia

GA Emergency Preparedness Coalition for  
Individuals with Disabilities and Older Adults  
GA Emergency Management Agency  
GA DPH  
CDC  
Spectrum Autism Support - GA  
All About Developmental Disabilities  
DBHDD  
Red Cross



Key	
Web-Based Tool	
Informational Resources	
Awareness	
Training/Workshop	
Research	
Telephone Support	

## Recommendations

**Recommendation 1:** Collaborate with The Georgia Emergency Preparedness Coalition for Individuals with Disabilities and Older Adults to promote and expand their current train the trainer programs for first responders across the state to support children, youth, and adults with autism and their families.

- **Objective 1a:** Assist the Coalition in making the training available online so that it is accessible to first responders in rural areas.
- **Objective 1b:** Ensure that specific safety concerns, such as wandering, abuse, neglect, and victimization, in children, youth, and adults with autism, are covered in the training.
- **Objective 1c:** Work with members of the Coalition to disseminate current informational resources, such as the First Responders Tip Guide and Functional Need Support Services (FNSS) Resource Guide to more families and providers throughout Georgia.

**Recommendation 2:** Establish an Emergency Preparedness and First Responders Family Partnership with Autism Society – Georgia Chapter, Spectrum Autism Support, and Parent to Parent of Georgia, to offer trainings for children, youth, and adults with autism and their families to prepare for emergencies.

- **Objective 2a:** Collaborate with the Coalition to expand their existing training for individuals with disabilities and older adults to include training relevant to families within the Family Partnership.

**Recommendation 3:** Expand the existing crisis intervention training required for law enforcement personnel into an accredited program including all first responders, law enforcement personal, school resource officers, families and community members.

- **Objective 3a:** Revise, implement, and evaluate classroom and online CIT training.
- **Objective 3b:** Seek approval for accreditation to broaden training recognition and outreach.

**Recommendation 4:** Create a coordinated statewide voluntary disability accommodation registry for people with autism and related developmental disabilities.

- **Objective 4a:** Research best practices across the nation for voluntary Disability Accommodation Registries for people with developmental or physical disabilities, or with mental-health conditions, who may have difficulty communicating their needs to a first responders in an acute crisis

## **Glossary**

Throughout the plan, several abbreviations were used to enhance reading ease and as a space saving measure. These organizations, agencies, and frequently used terms are listed below.

**AAP-** American Academy of Pediatrics

**AFP-** Academy of Family Physicians

**ASPIRE-** Active Student Participation Inspires Real Engagement

**CDC-** Centers for Disease Control and Prevention

**DBHDD-** Department of Behavioral Health and Developmental Disabilities

**DCA-** Department of Community Affairs

**DECAL-** Department of Early Care and Learning

**DOE-** Department of Education

**DPH-** Department of Public Health

**FOCUS-** Families of Children Under Stress

**GA-** Georgia

**IEP-** Individualized Education Program

**IFSP-** Individualized Family Service Plan

**SCEIs-** Skilled Credentialed Early Interventionists

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