The Alabama Regional Autism Networks:
How can we help you today?

Anne Brisendine, DrPH
University of Alabama  Birmingham Regional  Autism Network

Doris Hill, Ph.D
Auburn University Regional Autism Network

Amy Mitchell, MS CCC SLP
University of South Alabama Regional Autism Network
True or False?

The prevalence of autism in the United States is 1 in 59.
True or False?
The prevalence of autism in the United States is 1 in 59.

True
Estimated Autism Prevalence 2018

CDC increases estimate of autism's prevalence by 15 percent, to 1 in 59 children

Autism Speaks calls on nation's leaders to adequately fund critically needed research and support services.
True or False?

As the diagnosis of autism has increased, the diagnosis of intellectual disability has decreased.
True or False?

As the diagnosis of autism has increased, the diagnosis of intellectual disability has decreased.

True
True or False?

The most accurate way to diagnose autism is through a blood test and a brain scan.
True or False?

The most accurate way to diagnose autism is through a blood test and a brain scan.

False
True or False?

Individuals with autism tend to have larger brains in early childhood than children who do not have autism.
True or False?

Individuals with autism tend to have larger brains in early childhood than children who do not have autism.

True
True or False?

In order to meet criteria for an autism diagnosis, an individual must have deficits in social communication \textit{and} restricted interests/repetitive behaviors.
True or False?

In order to meet criteria for an autism diagnosis, an individual must have deficits in social communication and restricted interests/repetitive behaviors.

• True
True or False?

Vaccines cause autism.
True or False?

Vaccines cause autism.

False
True or False?

The American Academy of Pediatrics recommends autism-specific screening at 18 months and 24 months.
True or False?

The American Academy of Pediatrics recommends autism-specific screening at 18 months and 24 months.

• True
True or False?

• Individuals with autism do not make eye contact.
• Individuals with autism do not have friends.
• Individuals with autism cannot hold down a job.
True or False?

• Individuals with autism do not make eye contact... *sometimes*
• Individuals with autism do not have friends.
• Individuals with autism cannot hold down a job.
True or False?

• Individuals with autism do not make eye contact... **sometimes**

• Individuals with autism do not have friends... **sometimes**

• Individuals with autism cannot hold down a job.
True or False?

• Individuals with autism do not make eye contact... sometimes

• Individuals with autism do not have friends... sometimes

• Individuals with autism cannot hold down a job... sometimes
Did you know…

- Autism affects 1 in 59 children and 1 in 37 boys (4-26-18)
- Autism prevalence figures are growing
- Autism is one of the fastest-growing developmental disorders in the U.S.
- Autism costs a family $60,000 a year on average
- Boys are nearly 5 times more likely than girls to have autism
- There is no medical detection or cure for autism
- Autism does not discriminate against races, ethnic groups, and socioeconomic status

https://www.autismspeaks.org/what-autism/facts-about-autism
## The Numbers

<table>
<thead>
<tr>
<th>Year</th>
<th>Prevalence Rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>1980s</td>
<td>1 in 10,000</td>
</tr>
<tr>
<td>1990s</td>
<td>1 in 2500, 1 in 1000, 1 in 500</td>
</tr>
<tr>
<td>2000</td>
<td>1 in 250</td>
</tr>
<tr>
<td>2002</td>
<td>1 in 150</td>
</tr>
<tr>
<td>2004</td>
<td>1 in 125</td>
</tr>
<tr>
<td>2006</td>
<td>1 in 110</td>
</tr>
<tr>
<td>2008</td>
<td>1 in 88</td>
</tr>
<tr>
<td>2010</td>
<td>1 in 68</td>
</tr>
<tr>
<td>2018</td>
<td>1 in 59</td>
</tr>
</tbody>
</table>
What is Autism Spectrum Disorder (ASD)?

**Diagnostic Criteria** *(DSM 5)*:

- Deficits in social communication and social interaction
  - Reciprocity
  - Nonverbal communicative behaviors
  - Relationships

- Restricted, repetitive behaviors
  - Motor movements
  - Routines
  - Fixated interests
  - Sensory
Considerations for Transition: Areas in Which Individuals May Need Support

- Personal care
- Cleaning and laundry
- Grocery shopping
- Nutrition and cooking skills
- Transportation
- Housing/living arrangements
- Money management / Budgeting
- Medication management
- Socialization
- Relationships / Social cues
- Community Membership
- Hobbies and recreation
- Addressing health needs
- Advocacy
- Oversight/coordination/long term planning
- Guardianship

“Accessibility in Alabama” – by Brooke Bowles (Triumph Services) and Joe Carter (Glenwood Autism & Behavioral Health Center)
HB284 – Recently Passed Legislation

- **Applies to:**
  - Fully insured large group plans (beginning Oct 1, 2017)
  - PEEHIP (Public Education Employees Health Insurance Plan; January 1, 2018) and SEHIP (State Employee Health Insurance Plan beginning December 31, 2018)

- **Caps:**
  - Birth – 9 years = $40,000*
  - 10 – 13 years = $30,000*
  - 14 – 18 years = $20,000*  
    *yearly
AU Health Insurance Plan: Premium Changes for 2018

Effective January 1, 2018, Auburn University has elected to offer an autism benefit for eligible children age 18 and under who have a diagnosis of autism and who meet certain clinical criteria. The annual maximum coverage allowed in 2018 for this benefit will vary based on the child’s age:

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Maximum Coverage Amount Allowed for 2018</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ages 0-9</td>
<td>$20,000 per child</td>
</tr>
<tr>
<td>Ages 10-13</td>
<td>$15,000 per child</td>
</tr>
<tr>
<td>Ages 14-18</td>
<td>$10,000 per child</td>
</tr>
</tbody>
</table>
(d) Each center shall provide the following:

1. A staff that has expertise in autism and related disabilities.
2. Individual and direct family assistance in the home, community, and school. A center’s assistance may not supplant other responsibilities of state and local agencies, and each school district shall be responsible for providing an appropriate education program for clients of a center who are school age, inclusive of preschool special education.
3. Technical assistance and consultation services, including specific intervention and assistance for a client of the center, the family of the client, and the school district, and any other services that are appropriate.
4. Professional training programs that include developing, providing, and evaluating preservice and inservice training in state-of-the-art practices for personnel who work with the populations served by the centers and their families.
5. Public education programs to increase awareness of the public about autism and autistic-related disabilities.

(Act 2009-592)
MISSION: To foster strong connections and collaborations between individuals and families directly affected by Autism Spectrum Disorder, professionals and providers, and the community to promote quality of life and enrich the fabric of society for all.

VISION: The Regional Autism Network will nurture a system of care that meets the needs of people with Autism Spectrum Disorder and their families – serving, including, and accepting them as valuable, active, and essential members of our community and state.

VALUES:
- Person and Family Centered
- Sense of Urgency
- Partnerships in Action
- Spirit of Collaboration
- Accountability
- Hope
RAN Activities

- Family Assistance and referral

- Technical Assistance and Consultation
  - Healthcare settings and medical procedures
  - Project ECHO

- Professional Training:
  - DHR, Mental Health, AIDB,
RAN Activities

- Public Education
  - Expansion of Community Education Workshops
    - Families
    - Service providers
    - Educators
  - Project ECHO
    - ECHO for Educators in the future
Gaps in Care and Emerging Services

- Adult services
- Comprehensive care
- Inclusion of medical providers
- Insurance barriers
- Medical providers familiar with ASD that accept Medicaid or Medicare
- Service providers that accept Medicaid and Medicare who are familiar with ASD
- Accessibility
- Health disparities among racial and SES groups
- Waitlists
- Waiver limited with extensive waitlist and IQ requirements (69 or below)
- Earlier transition services (age 14)
- More providers taking on ASD in their practices (state and private)
Partner Activities around the State

- First Responder Trainings
- Annual Camps for families
- Annual Autism Day at baseball field (Barons, Biscuits, Bay Bears)
- Sensory Movies
- Legislative Day
- Library Program
- Conferences
Governor Ivey Announces Funding for New Behavioral Health Services

Press Releases

Posted on April 6, 2018

MONTGOMERY — Governor Kay Ivey announced on Friday that Alabama has set aside $11 million in its recently passed budgets for the Alabama Department of Mental Health to expand behavioral health services for Medicaid-eligible children and youth. When combined with federal matching funds, the money is expected to generate more than $36 million in total spending during the 2019 fiscal year, which begins October 1.

The funding will expand services provided at home or in the community to two groups of young people. One group is children and youth with severe emotional disturbance. The other group is children and youth with autism spectrum disorder.

For both groups, these services will be designed to help recipients manage the behavioral aspects of their condition. For example, for both groups, the state will fund therapy teams to work with an affected young person and his or her family members to develop a behavior plan and provide home-based services that reflect the young person’s unique diagnosis and circumstances.

For this reason, the funding is expected to produce savings in other areas of public spending. In the short term, these services should reduce the number of crises experienced by the affected children and youth, thereby reducing the demands on schools and emergency services. Over the longer term, the services should reduce spending on residential mental health treatment.

Governor Ivey thanked lawmakers for including this money in the FY 2019 budgets and for embracing this new approach to services.

“These are needed services that I believe will help many of our children and youth live happier, more productive lives,” Governor Ivey said. “At the same time, these services will help us save money in other areas. This proves that in Alabama, we can be both compassionate and good stewards of taxpayer dollars.”

Vivian Spears of Tuscaloosa, who has an adult son with autism spectrum disorder and intellectual disabilities, also applauded the funding. “It definitely should improve the quality of life for children and youth, and it brings hope to families and caregivers who are affected by autism spectrum disorder,” said Ms. Spears.

Governor Ivey thanked two nonprofit advocacy groups—the Alabama Disabilities Advocacy Program and the Center for Public Representation—for working with her administration with respect to these new services. She also acknowledged the role they will play in implementing the new services going forward.
Alabama EPSDT Settlement

The State of Alabama has signed a Settlement Agreement to provide a range of intensive home-based services to thousands of Medicaid-eligible youth with Autism Spectrum Disorder (ASD) or Serious Emotional Disorder (SED). The Agreement, entered in response to a demand letter and proposed ESDPT class action lawsuit prepared by the Alabama Disabilities Advocacy Program (ADAP) and the Center for Public Representation (CPR), requires the State to provide five home-based services are modeled after those ordered in the landmark EPSDT case, Rosie D. v. Romney. The Agreement also requires the State to make significant improvements to its EPSDT screening and assessment process, to eliminate access and eligibility restrictions on existing mental health services for children and youth with SED, to develop medical necessity and program specifications for each new home-based service, and to seek funding over the next two years to develop these new services. Read the Settlement Agreement.
EPSDT Settlement Agreement

- Intensive Care Coordination
- Therapeutic Mentoring
- In-home Behavioral Services
- In-home Therapy
- Family Support/Psychoeducational Services
- Peer Support
What can you do to help?

- Refer!
  - To RAN, AIACC, and other advocacy and service providers previously discussed

- Remember!
  - OK To Approach a Family Having a Hard Time
  - Safe quiet space in office for Melt Downs
  - Speak in clear unrushed manner
  - Convey that you are available to help families that have challenges
  - Fidget toys are nice if available
Your ASD students/families have a Large Community. They Are Not Alone!

1 in 59 are affected.

There are as many as 45,000 individuals affected by ASD in Alabama.
WHO WE SERVE:

Alabama’s RAN serves those who have questions, concerns, or resource needs regarding themselves, a family member, friend, client, patient, or a student with diagnosed or suspected Autism Spectrum Disorder (ASD).

WHAT WE DO:

- Professional training programs
- Technical assistance and consultation services
- Individual and direct family assistance in the home, community, and school
- Public education programs

WHO WE ARE:

Alabama’s RAN is staffed by experts in the field of Autism Spectrum Disorder. Each RAN strives to connect people with ASD, their families, educators, and service providers to the information and/or services that best meet their needs.

CONTACT US:

Region I—University of Alabama in Huntsville 256-824-5700 uahran@uah.edu
Region II—University of Alabama 205-348-3131 ua-ran@ua.edu
Region III—University of South Alabama 251-410-4533 usaran@health.southalabama.edu
Region IV—Auburn University 334-844-2004 aurran@auburn.edu
Region V—University of Alabama at Birmingham 205-934-1112 uabran@uab.edu
Resources

- https://www.autism-alabama.org
- Autism Society of Alabama
- http://adap.ua.edu
- Alabama Disabilities Advocacy Program
- http://www.nationalautismcenter.org
- National Autism Center
- http://autisminternetmodules.org
- Autism Internet Modules
- https://www.autismspeaks.org
- Autism Speaks
Contact Autism Council

Anna.McConnell@mh.alabama.gov
www.autism.alabama.gov
205-478-3402
auran@auburn.edu
334-844-2004
Alabama ECHO®

Project ECHO®

University of Alabama at Birmingham

Children’s of Alabama®

UAB Medicine PEDIATRICS
Mission of ECHO

- The mission of Project ECHO® is to democratize medical knowledge and get best practice care to underserved people all over the world.
Model of ECHO

- **Use technology** to leverage scarce healthcare resources
- **Sharing “best practices”** to reduce disparities
- **Case based learning** to master complexity
- **HIPAA compliant, centralized, web-based database to monitor outcomes**

Hub and Spoke Model

- Spoke Clinic #1
- Spoke Clinic #2
- Spoke Clinic #3
- Spoke Clinic #4

HUB
ECHO Process

- Bi-monthly teleconferences using the Zoom software
- 12 brief didactics given over a 6-month period
- Ongoing case presentations
- Data collection and feedback
Outcomes

- Data shows that the patients of primary care providers (PCPs) who participated in Project ECHO received treatment that was as good and effective as if they obtained care at the University of New Mexico Medical Center.

Potential benefits of ECHO model to our health system

- Quality and safety
- Rapid learning and best-practice dissemination
- Reduce variations in care
- Access for rural and underserved patients, reduced disparities
- Democratize knowledge
- Improve professional satisfaction/retention
- Cost effective care - avoid excessive testing and travel
- Prevent cost of untreated disease (e.g.: organ transplant, dialysis)
- Educational advantages for all learners and instructors
TeleECHO Clinics

Adult

- Antimicrobial stewardship
- Bone health
- Cardiology
- Chronic pain and opioid management
- Complex care
- Dementia care
- Endocrinology
- Miners’ wellness
- Tuberculosis
- Palliative Care
- Reproductive Health
- Rheumatology
- Women’s Health

Pediatrics

- Autism
- Child Abuse and Neglect
- Children and Youth with Epilepsy
- Pediatric Growth and Endocrinology
- School Based Mental Health
- Transition into adult care
- Zika Virus
Project ECHO: Autism

• First developed in 2015 at Thompson Center for Autism and Neurodevelopmental Disorders in Columbia, MO

• Goal: Educate and provide support for primary health care providers to care for children with autism in their communities
  • Earlier identification
  • More timely referrals for services
  • Management of common comorbidities
Hub Team

- ECHO Lead: Justin Schwartz, MD, Developmental Behavioral Pediatrician
- Sarah O’Kelley, PhD, Child Psychologist
- Laura Barefield, MD, Child and Adolescent Psychiatrist
- Suzanne Geerts, MS, RD, Dietitian
- Bama Hager, PhD, Parent Expert and Program Manager, Autism Society of Alabama
- Lizzie Griffith, LGSW, Social Worker and Director, UAB - Regional Autism Network
- Tracy Cron, Parent Expert
Topics Covered

• What is Autism?
• “While You Wait”
• Medical Comorbidities
  – Sleep
  – Feeding/Nutrition
  – Constipation
• Psychiatric Comorbidities
  – ADHD
  – Irritability
  – Anxiety
  – Intro to ABA

• Supporting Families
• Special Education Process
• Local Resources
The Many Uses of the ECHO model

• Supporting autism care in medical settings
• Earlier autism diagnosis in primary care
• Supporting educational professionals
• Training allied health providers/therapists
What does this have to do with educators?

• Step 1: Be our ambassadors

• Step 2: ECHO for Educators
ECHO Autism Ambassadors

- Spread the word among your groups

- Talk to your child’s doctor, nurse practitioner, office manager and tell them:
  - THIS IS IMPORTANT TO YOU!
  - 90 minutes every other week (Thursdays 11:45-1:15)
  - CME available
  - EASY to access on phone, computer, tablet
  - WILL PAY OFF IN FEELING BETTER ABLE TO CARE FOR PATIENTS WITH AUTISM
  - They can join an elite group of ECHO Autism Certified Providers
Follow up again, and again

• Give them the ECHO Autism materials
• Ask them to try it for 1-2 sessions
• Offer to join them for a call, show them how to log in, etc.
• Follow up before and after the next scheduled session
ECHO For Educators

• Has been done before
  • Wyoming: Project ECHO WIND (Wyoming Institute for Disabilities)
    • Autism
    • Behavior Supports
    • Assistive Technology
ECHO for Educators

• Didactic Presentation
• Case Presentation
  • Individual and program-wide cases
  • Grade level
  • Primary concern/goal for case
  • Contributing factors, triggers
  • What have you tried?
    • What has worked?
ECHO For Educators

- Examples of sessions for Autism:
  - Teaching Strategies/ Discrete Trial
  - Executive Function/ Self Regulation
  - Bullying
  - Communicating with Parents
  - Visual Supports
  - Deductive Reasoning and Motor Difficulties
  - Increasing Post-High School Employment
  - Summer Ideas
Not just Autism: ECHO at COA/UAB

• Autism: (ongoing)
  • Dr. Justin Schwartz

• Pediatric Growth and Short Stature:
  • Dr. Gail Mick and Dr. Shelly Mercer

• In the works:
  • Neurology/Epilepsy
  • Pediatric Obesity and Diabetes