

# Community Education Workshops Aimed at Reducing Health Disparities and Bridging Gaps in Health Care for the Autism Spectrum Disorder Population in Alabama



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## Population

Autism Spectrum Disorder (ASD) is a neurodevelopmental disability characterized by impairment in social communication and interaction, as well as restricted and repetitive behaviors and interests<sup>[1]</sup>. ASD is prevalent across multiple populations, and symptoms present with wide variation and severity across the lifespan<sup>[2]</sup>. There has been a surge in ASD diagnoses over the last two decades. The CDC Autism and Developmental Disabilities Monitoring Network (ADDM) reported estimates from their active surveillance system tracking prevalence of ASD among 8-year-old children residing in 11 ADDM sites across the United States. Recent estimates from the 2014 surveillance period state 1 in 59 children have been identified with ASD (or 16.8 per 1000 8-year-olds), which is higher than previously reported estimates of 1 in 68 children from the 2012 surveillance period<sup>[3]</sup>. The increase in the number of children diagnosed with ASD has placed additional strain on the system of care in Alabama, which is designated as a Mental Health Professional Shortage state<sup>[4]</sup>. In addition, insurance coverage and policy barriers have further limited access to necessary diagnostic and therapy services for children with ASD in Alabama<sup>[5]</sup>.

## Public Health Significance

Effective, evidence-based treatments for individuals with ASD include intensive interventions

targeting behavior, language and social relatedness. These interventions come at a high cost and require a time commitment that is difficult to sustain for parents and caregivers. Alabama's mental health professional shortage, in addition to high cost of services and exclusionary insurance coverage has led to barriers in accessing care<sup>[4,6]</sup>.

These barriers and inequitable service distribution are of great concern to public health professionals. Children and families of vulnerable populations who are impacted with ASD across Alabama are unable to connect with key interventions that target the core symptoms of ASD. Targeted intervention of the above areas will propel them towards better health outcomes in adulthood by providing skills and supports necessary at a young age that will prove beneficial as they aim for independence and employment within their local communities. Public health practice efforts for the ASD population in Alabama aim to target these issues by developing strategies and implementing programs to bridge gaps in care for families on waitlists for services, supplement the services families are already receiving, and allow caregivers to connect with one another to build a community support network for themselves and their child.

## Intervention

The primary intervention source for children in Alabama is the educational system, which mandates services for

children with special health care needs under the Individuals with Disabilities and Education Act. Due to limited resources as a result of state allocated funding, services for children with ASD across the educational system in Alabama are not equitable, resulting in a public health problem of disparities across demographic groups. A plausible reasoning for these inequities is that families of higher socio-economic status are able to afford housing in the school districts with more resources available to provide intensive services while families of low socio-economic status are faced with resource-poor school systems that are not equipped to serve their children.

In an effort to bridge gaps in services and support the ASD system of care, the Alabama Interagency Autism Coordinating Council, through the state legislature, established a 5-site, university-based Regional Autism Network (RAN) in October 2016. The Network is charged with meeting the growing needs of the ASD community in Alabama through direct interactions with families, offering support to providers, and educating the public on issues that occur across the lifespan of an individual with ASD. The mission of RAN at the University of Alabama at Birmingham (UAB) is aimed at reducing health disparities and improving health equity of all affected by ASD in Alabama by connecting families of low socioeconomic status and diverse ethnic backgrounds to evidence-based intervention strategies. UAB RAN public education aims to fulfill the mission by focusing efforts on connecting the ASD community to evidence-based intervention strategies through free, monthly parent trainings called the Community Education Workshops (CEWs). CEWs have three objectives: to provide ASD specific information to parents and providers, to teach tangible skills for caring for a child with ASD, and to facilitate parent-provider collaborations.

Though workshops are not an effective means of ASD intervention in isolation, they may be able to increase the self-efficacy of parents' ability to manage behaviors in the home and serve as an active team member on their child's treatment team<sup>[7]</sup>. Parent trainings are also useful for caregivers that are unable to connect to services in a timely manner and serve as a bridge to intervention while they wait for services.

### **Implementation**

The UAB RAN hosts free, monthly Community Education Workshops for parents and caregivers of individuals with

ASD. Workshops can be classified according to Bearss et al.'s Parent Training taxonomy as a Psychoeducational Parent Support program that is specialist-led and held in an in-person, group format<sup>[8]</sup>. Through this format, CEWs are interactive and engaging Workshops that allow parents to connect with providers and other parents. CEWs are held local public libraries in the community on the last Monday of every month and are accessible to a multitude of communities due to their central location. The CEWs are designed to be easily reproducible across settings and easy to implement at a low-cost. Once a community-based setting and partnerships with providers are established, material can be obtained from the UAB RAN and implemented by other organizations wishing to provide parent trainings for the ASD community.

The UAB RAN used the fall of 2017 to establish partnerships with presenters and local public libraries and create a 2018 calendar of high-yield topics on issues specific to ASD based on parent feedback from a survey disseminated at the 2017 Alabama Autism Conference. The UAB RAN team began by contacting local public libraries to determine the best location for the workshop while also seeking out community based and UAB affiliated providers to present on topics specific to their area of expertise. Two libraries were chosen for implementation based on their central location and low cost for hosting events, and the team of presenters were half community-based providers and half UAB affiliated providers, chosen to connect caregivers to wide array of evidence-based providers that represent the expertise of individuals in community settings and the academic medical center.

Beginning in January of 2018, seven Workshops were facilitated by 17 presenters from nine university and community-based organizations and three adults on the autism spectrum. During that year the CEWs reached 220 individuals (85% caregivers; 15% providers). The UAB RAN Director and Assistant Director, in addition to one to two other ASD providers, are present at each Workshop to host and help facilitate discussion and answer questions. Additionally, all RAN staff members work collaboratively to schedule Workshops and communicate with providers, collect materials needed for their corresponding Workshop presentation and discuss progress of the evaluation process. Learning objectives are prescribed by the individual presenters and are topic specific for each Workshop.

Thus far in 2019, the UAB RAN has delivered seven Workshops, reaching an audience of 243 individuals (63% caregivers; 37% providers). Monthly topics and

professions of community-based presenters for 2019 are listed in Table 1.

Month*	Topic	Presenter(s)
January	Challenging Behaviors	2 Clinical Psychologists/BCBAs
March	Toilet Training	2 Clinical Psychologists
April	Navigating the School System	1 Clinical Psychologist
May	Into the Community	1 Clinical Psychologist
June	Communication	1 Speech/Language Pathologist, 3 BCBAs
July	Challenging Behaviors	2 Clinical Psychologists/BCBAs
August	Activities of Daily Living	1 Speech Pathologist, 1 Occupational Therapist
September	Sleep	2 Clinical Psychologists
October	Long-Term Planning	1 Special Needs Trust Lawyer
November	ASD & Co-Occurring Disorders	1 Clinical Psychologist, 1 Developmental Behavioral Pediatrician

Small changes were made in 2019 due to the feedback from attendees. The Workshop on Challenging Behaviors was presented twice due to the high level of attendance at the Workshop in 2018. RAN staff chose to start the 2019 series with the Workshop on Challenging Behaviors and repeat the same content in July 2019. Additionally, a new public library location was added in 2019 for the summer Workshops due to the high level of library programs offered at the other locations during the summer months.

Though the CEWs are designed for ease of implementation, there are still critical components of the Workshop that are necessary to uphold the integrity of the model. At its core, the model aims to be interactive, teaching evidence-based strategies and tangible skills that can be implemented by caregivers in the child's home or community-based settings. It's crucial for presenters to maintain the interactive components in their Workshop presentation and include an Action Plan that caregivers fill out based on the needs of their child and family. This approach allows for individualization of skills and strategies and provides caregivers with tangible tools that can be utilized in the home or other settings.

### Evaluation

The evaluation of the CEWs are currently of individual Workshop sessions and not the series in its entirety. Fidelity Measures for individual topics, administered through surveys at the end of each session, are used to determine presenter adherence to learning objectives and assess whether parents believe the CEW attended was effective at teaching evidence-based knowledge and skills that they can be independently implemented. Fidelity Measures include presenter provided learning objectives and assess parents' perception of effective learning through a 4-point Likert-scale, ranging from strongly disagree to strongly agree. In addition, Fidelity Measures include two open-ended response questions allowing participants to provide strengths of the workshop and areas that need improvement.

Participants have rated the workshops to have high fidelity, ranging from 3.69 to 3.86 out of 4, with an average fidelity score of 3.76. Full fidelity data and attendance numbers from the first seven Workshops of 2019 are included in Table 2.

**Table 2.** 2019 Community Education Workshop attendance numbers and average fidelity scores.

Month	Topic	Attendees	Fidelity Score
January	Challenging Behaviors	73	3.72
March	Toilet Training	28	3.81
April	Navigating the School System	29	3.70
May	Into the Community	13	3.86
June	Communication	38	3.75
July	Challenging Behaviors	28	3.82
August	Activities of Daily Living	34	3.69
<b>Total/Average</b>		<b>243</b>	<b>3.76</b>

It is plausible that variable attendance across Workshops correspond with topic areas that are of high importance to the community. It is evident that education on challenging behaviors is needed within the community due to the high rates of attendance in January, which is possibly due to the difficulties from transition that occur as children transition back to school from winter break. Additionally, lower attendance at the May Workshop could be attributed to the end of the school year and the busy season families are in during that time period as they enter the months of summer vacation. Data from the Fidelity Measures reveal that participants acknowledge the value of the Workshop content and gain evidence-based strategies and skills that can be useful to meet the needs of their child. Fidelity data also reveal the strength of the Workshop presenters and their ability to address critical areas of high yield topics that families otherwise have a difficult time accessing.

Additional qualitative data include participants' perception of strengths and needs of the workshop. Participants stated strengths of the Workshop included examples of data tracking sheets, developing a tailored action plan and the ability to interact with presenters and their willingness to answer questions and address areas of concern. Participants also noted areas of need, stating longer Workshop sessions and providing childcare would be beneficial. Qualitative data show participants value the connection with presenters and the ability to engage in conversation and problem solve issues specific to their child. Additionally, participants acknowledge the value of the of model, which includes an Action Plan that allows learned evidence-based strategies and skills to be

individually tailored based on the needs of the family and child. An example of the Fidelity Measure from the 2019 Into the Community Workshop is included in Appendix A.

RAN's continuing research efforts aim to determine Workshop participants' ability to access the system of care for ASD specific services and evaluate if attendance improves parents' ability to apply their Action Plan in the home. Data collected also include demographic information to determine existing disparities based on race, socioeconomic status and insurance coverage.

### Sustainability

Several states, including Alabama, have recently passed legislation requiring improved public and private insurance coverage for the ASD population. Legislation across states most often requires private insurance plans to cover ASD-specific services<sup>[9]</sup>, however this is a new development in Alabama through the passing of House Bill 284 in 2017<sup>[10]</sup>. In addition to passing of legislation in Alabama, ASD intervention services will soon be covered for publicly insured families through Medicaid as a result of a recent settlement agreement signed by the state of Alabama<sup>[11]</sup>. These services will be funded through Medicaid's Early, Periodic, Screening, Diagnosis and Treatment program for children and youth impacted by ASD through the age of 21 provided through the Alabama Department of Mental Health.

Though Alabama has made great strides and policy change in recent years, the surge in ASD diagnoses has

created a public health problem for the ASD population and requires innovative approaches to meet the growing needs of families on a large scale. Parent trainings, or Workshops, serve as reasonable investment due to their sustainability and cost effectiveness. Trainings can be adapted to the specific needs of the ASD population in a given area and implemented in a multitude of settings, including schools or clinics, while placing limited additional burdens on the staff<sup>[12]</sup>. Intervening on this public health issues requires a multitude of approaches working in tandem, including policy and systems level change; however, parent trainings are a useful piece of the puzzle that serve families holistically and provide a community of support to those impacted by ASD.

### Author Contact Information

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Appendix A  
Sample Fidelity Measure from Into the Community Workshop

**UAB Regional Autism Network Community Education Workshop  
May 2019 – Into the Community  
Attendee Feedback Form**

At the end of the session, attendees will:

**Learning Objective 1:** Understand the **Antecedents, Behaviors, and Consequences** (ABCs) of behavior.

**Learning Objective 2:** Learn how to **plan ahead** for including children in different types of settings, activities, and experiences.

**Learning Objective 3:** Develop skills to advocate for **inclusion** of their families or students/clients in the community.

**Learning Objective 4:** Gain awareness of available resources to promote **safety and wellbeing** of individuals with ASD in the community.

**Please complete the following questions by circling the number that best reflects your thoughts.**

Upon completion of today's session, I:	Strongly Disagree	1	2	3	Strongly Agree
1 Understand the <b>Antecedents, Behaviors, and Consequences</b> (ABCs) of behavior.	1		2	3	4
2 Learned how to <b>plan ahead</b> for including children in different types of settings, activities, and experiences.	1		2	3	4
3 Developed skills to advocate for <b>inclusion</b> of families or students/clients in the community.	1		2	3	4
4 Gained awareness of available resources to promote <b>safety and wellbeing</b> of individuals with ASD in the community.	1		2	3	4

What did you like best about this workshop?

What suggestions do you have for improving this workshop?