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Investigating the Efficacy and Parental Impact of a Novel Community Education Workshop for Caregivers of Individuals with Autism Spectrum Disorder

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INVESTIGATING THE EFFICACY AND PARENTAL IMPACT OF A NOVEL COMMUNITY EDUCATION WORKSHOP FOR CAREGIVERS OF INDIVIDUALS WITH AUTISM SPECTRUM DISORDER

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INVESTIGATING THE EFFICACY AND PARENTAL IMPACT OF A NOVEL COMMUNITY EDUCATION WORKSHOP FOR CAREGIVERS OF INDIVIDUALS WITH AUTISM SPECTRUM DISORDER

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LIFESPAN DEVELOPMENTAL PSYCHOLOGY

ABSTRACT

Autism Spectrum Disorder (ASD) is a neurodevelopmental disability that is characterized by impairments in social communication and repetitive behavior patterns that currently affects one in fifty-four individuals. Individuals with ASD often experience greater health disparities than the general population related to a lack of services that are available and systemic barriers to accessing care. Alabama’s Regional Autism Network is tasked with serving this population to reduce health disparities and increase health equity. One region within the Network created a psychoeducation program for caregivers and providers of individuals with ASD with the goal of providing evidence-based knowledge, teaching ASD intervention skills, and empowering attendees through social support and improved connections to service providers and the ASD system of care. Through a program evaluation and in-depth parent interviews, researchers found the Workshops to be an effective method for increasing knowledge and supporting change in parenting techniques and abilities, as well as improving parents’ self-efficacy, their feelings of social support, and their ability to connect to the ASD system of care. These findings indicate that group-based psychoeducation programs can be an effective and integral part of reducing health disparities for families and individuals within the ASD community and should be considered for large scale replication across settings. In addition, the findings have public health and healthcare policy implications that should encourage the funding and implementation of evidence-based community programming to support the ASD system of care.

Keywords: Autism Spectrum Disorder, psychoeducation, parent training, community-based programming

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INTRODUCTION

Autism Spectrum Disorder (ASD) is a pervasive and lifelong neurodevelopmental disability that affects both the individual with the diagnosis and the members of their family. ASD is characterized by core impairments in social communication and interaction and the presence of restricted and repetitive patterns of behavior, interests, or activities (APA, 2013). The prevalence rate of ASD has been on the rise and currently affects 1 in 54 individuals (Maenner et al., 2020). In addition to the personal effects of ASD, there are also pervasive effects on the family system associated with raising and caring for an individual with ASD (Karst & Van Hecke, 2012). For example, having a child diagnosed with ASD places a strain on family dynamics, restricts parent activity, and alters sibling behavior (Dillenburger, Keenan, Doherty, Byrne, & Gallagher, 2010).

Family stress can have an effect on overall child development and parents of children with ASD are more likely to exhibit family stress compared to families without a child with ASD. Developmental outcomes for children with ASD can be improved by reducing family stress and improving the functional and communicative environment of the family (Hickey, Nix, & Hartley, 2019). Additionally, parents often report feelings of distress in regards to a lack of knowledge related to ASD and its core symptoms, how to best care for their children, and how to access services or navigate systems of care that are often complex. Consequently, this leads to increased parental stress, decreased parental self-efficacy, and feelings of a loss of social support (Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001; Farrugia, 2009; Meadan, Halle, & Ebata, 2010).

Together, these stressors impact the psychological well-being in parents of individuals with ASD and can lead to multiple negative outcomes, including increased social isolation, decreased marital satisfaction, and increased financial strain (Hartley et al., 2010; Horlin, Falkmer, Parsons, Albrecht, Falkmer, 2014; Cidav, Marcus, & Mandell, 2012). However, research has shown that parental resilience and hardiness can counteract the effects of stress, decreased self-efficacy, and decreased social support (Weiss, Robinson, Fung, Tint, Chalmers, & Lunsky, 2013). Parental resilience is defined as “the positive behavioral patterns and functional competence individuals and the family unit demonstrate under stressful or adverse circumstances, which determine the family’s ability to recover.” Additionally, hardiness is a characteristic defined as “a family’s sense of control over life events and stressors, perception of change as beneficial, active orientation to adapting to stressors, and confidence that they can endure challenges;” therefore, hardiness is related to both stressors and positive outcomes (Weiss, Robinson, Fung, Tint, Chalmers, & Lunsky, 2013). These concepts can be taught, promoted, and fostered through education and social support (Black & Therrien, 2018) and that have the potential to reduce the negative outcomes associated with caring for an individual with ASD.

A diagnosis of ASD and the subsequent care and support often has an immense financial impact on families. Research estimates that a diagnosis of ASD and Intellectual Disability has a lifetime cost of $2.4 million. For a child with a diagnosis of ASD, without the presence of an Intellectual Disability, there is a lifetime cost of $1.4 million.

These costs primarily result from medical expenses, therapeutic services (i.e., occupational, physical, speech/language), educational services, and loss of parental productivity in the workforce (i.e., time taken off to attend appointments which results in no pay). Additionally, as the prevalence of ASD has increased, so have the costs associated with adult services for individuals with ASD. These services, including residential living, in-home services, workforce development, and supportive care are often necessary for individuals with ASD to live a meaningful and independent life (Buescher, Cidav, Knapp, & Mandell, 2014). To compound this issue, research posits that the primary therapy source for children with ASD is their school system, and while all school systems are mandated to provide services for the children they serve, financial and geographic constraints limit how effective these services can be (Brookman-Frazee, Taylor, & Garland, 2010).

The increase in prevalence rates of ASD and the rising cost associated with caring for a child with ASD highlight the significant need for the development of efficient and cost-effective intervention and parent education programs. In order for parent education programs to have sustained success, they must be inexpensive, widely accessible, and have strong programmatic fidelity. These factors ensure that programs maximize the time a parent invests in them and allows parents to receive the intended benefits. Moreover, researchers must collaborate with policy makers to create an easier access process to the system of care, streamline services, and increase the number of individuals with ASD that can be served. In turn, this would strengthen families, reduce the use of public funds such as Medicaid, and allow parents and individuals with ASD to return to the workforce

In addition to therapies and interventions designed for individuals and families with ASD, policy initiatives aimed at support programs are necessary for meaningful change to take place. This is especially needed in southern states, and particularly in Alabama. Data from the 2019 Kids Count Data Book, which estimates the state of child health and well-being in Alabama relative to national trends, as well as the changing populations of the nation, region, and state give a bleak outlook of healthcare for children in the state (Annie E. Casey Foundation, 2019). Alarmingly, Alabama ranks 44th nationally in overall Child Well-Being. In addition, data shows that every state has seen an increase in the percentage of children of color. For instance, Alabama has seen the Latino population among children rise from 1% to 8%. However, the country has not been able to eliminate racial and ethnic disparities in healthcare that have existed for decades, such as access to care and insurance coverage. As these minority populations continue to rise in the United States, it is more crucial than ever before for policy makers to address these inequalities (The Annie E Casey Foundation, 2019).

Children with ASD are included in the medical classification of Children with Special Healthcare Needs (CSHCN), which is defined as children "who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health related services of a type or amount beyond that required by children generally" (McPherson et al., 1998). CSHCN often experience health inequalities in a number of ways, including access to healthcare related to financial and geographic limitations, lack of care coordination, and lack of education about specific diagnoses (Toomey, Chien, Elliott, Ratner, & Schuster, 2013). Government organizations, such as the Maternal and Child Health Bureau (MCHB) are tasked with monitoring at-risk populations, including CSHCN, and pursuing actionable change in the community for these populations. CSHCN programs receive funding in their community through MCHB's Title V Block Grant program in order to reduce health disparities among this population and advance overall health (Maternal and Child Health Bureau, 2019).

Parent Training Programs for the Autism Spectrum Disorder Population

In the field of pediatric psychology for typically developing children Parent Training refers to evidence-based programs, such as Parent-Child Interaction Therapy (PCIT), that aim to improve parent and child relationships while reducing disruptive behavior concerns (Lieneman, Brabson, Highlander, Wallace, & McNeil, 2017). PCIT involves the help of a trained therapist to implement effective behavior management techniques to improve parent and child engagement. Sessions are conducted in parent-child dyads and involve changing both the parent's and child's behavior (McNeil et al., 2010). In PCIT, and other specialized parenting programs for the general child population, parents engage directly with their child and with a therapist or instructor who provides feedback and guides further parent-child interactions. Although these types of interventions have become widely utilized for many at-risk families, research is only recently beginning to emerge regarding its application for families of individuals with ASD.

Within the field of ASD therapies and research, there are many different programs that are categorized under the umbrella term "parent training," including programs for care coordination, psychoeducation, interventions for developmental outcomes and disruptive behaviors (Bearss, Burrell, Stewart, & Scahill, 2015). Other terms that are commonly used to describe parent trainings in the ASD literature include: parent education, parent implemented, parent mediated, and caregiver mediated. Without a universal understanding of parent training in regards to ASD, concerns associated with efficacy of programs arise. The use of these varied terms to describe programs intended to accomplish similar goals, and the lack of uniformity when discussing the same program from different stakeholders, has led to confusion among parents, caregivers, providers, policy makers, and funding sources. Researchers posit that consistency and accuracy across agencies when classifying ASD parent training programs will lead to better communication between families and providers, providers and administrators, and providers and funding sources/policy makers (Bearss, Burrell, Stewart, & Scahill, 2015).

The diverse programs that encompass parent training for ASD are intended to serve the broad range of skills and symptoms seen across individuals along the autism spectrum (e.g., language skills, social skills, adaptive skills, age, etc.). However, due to the varied use of terms to describe parent training programs in ASD as noted above, there is often uncertainty as to what actually constitutes parent training. As a result, families' understanding of their child's treatment options and how to assess the benefits of these programs is further complicated. Without a proper understanding of these programs families may miss out on these much needed supports.

To address this confusion Bearss and colleagues proposed a concise taxonomy for classifying parent training programs for ASD (2015). In this classification system, parent training programs are sorted into two categories: Parent Support and Parent Mediated

Intervention (PMI). Parent Support programs are knowledge focused programs in which the parent receives the majority of the information and attention to then use the information with their child in their natural setting. Therefore, the child benefits indirectly from Parent Support programs. Parent Support programming is broken down into two subcategories: Care Coordination and Psychoeducation. Parent Mediated Interventions (PMI) are differentiated from Parent Support programs in that they are technique focused and benefit the child directly. Parent Mediated Interventions (PMI) also have two subcategories: PMI for Core Symptoms and PMI for Maladaptive Behaviors (Bearss et al., 2015) See Appendix A for a visual representation of the Bearss Taxonomy. However, practitioners have noted that while this classification system easily differentiates between programs on paper; real-world programs are often created as a hybrid between Parent Support and Parent Mediated Interventions to allow for the largest parental impact. The term Parent Education and Training can be used to describe the hybrid programs that exist (Dawson-Squibb, Davids, & de Vries, 2019a).

Bearss et al. (2015) further identified five characteristics that can be utilized to classify parent training programs for families of children with ASD more effectively. These characteristics include: format, intensity, location, duration, and target age. Format specifies how the information from the training is presented to the parents and ranges from self-guided (i.e., online material) to therapist guided. Intensity classifies the frequency of the program and can range from low intensity (i.e., a one-time consultation) to high intensity (i.e., more than one session per week). Location of programming can vary and include in home, in school, online, or in a community setting. Duration specifies the time parents spend in the program as a whole and may range from as little as one week to as long as several years (Neftd, Koegel, Singer, & Gerber, 2010; Dawson et al., 2010). Target age classifies the age of the child the programming is designed to serve (i.e., preschool, school-aged, transition aged, etc.) (Bearss, Burrell, Stewart, Scahill, 2015).

In a review of the literature, Suppo and Floyd (2012) detail the vast differences in parent training programs within the ASD field, including setting, frequency, and number of children present. Home-based training is the most translatable, but also the most time intensive and financially straining on families. Facility-based can be a more affordable option, but research shows these therapies do not always translate back to the home environment. In addition, studies have reported training durations to be drastically different from one another, with one intervention requiring only two home visits to teach parents naturalistic strategies for improving augmentative communication strategies in the home (Nunes & Hanline, 2007) and another intervention requiring trainers to meet with parents 1 to 2 times per week for 60 to 90 minutes for 5 to 6 months (e.g., a range of 1,200 to 4,300 minutes of intervention time) to learn teaching strategies to use with their child (Kashinath, Woods, & Goldstein, 2006). While there is great support for the effectiveness of parent training programs, it is evident that programs such as these are not feasible for the majority of families for a variety of reasons (Prata, Lawson, & Coelho, 2018). As such, in order to best serve families with ASD it is imperative to develop concise and effective psychoeducation and parent training programs to supplement the interventions that these children receive.

It is important to note that there is not a large amount of evidence-based research on Parent Support programs for families of children with ASD. However, when considered together, the existing research can provide a clear picture of what has been done, the general benefits of Parent Support programs, and opportunities for future growth and direction within the field. However, the breadth of research on parent training for the ASD population creates a challenge for a concise review of the existing literature. As such, before addressing the specific objectives for this study, literature about parent training programs for the ASD population will be reviewed.

Psychoeducation Programs for Parents of Children with ASD

Psychoeducation refers to any program intended to provide parents with information or teach them skills related to a specific topic (Schultz, Schmidt, & Stichter, 2011). Researchers have noted that psychoeducation aims to increase understanding related to a disorder and develop strategies to use that information in concrete ways with oneself or a family member (Lukens & McFarlane, 2004). Psychoeducation is grounded in several psychological theories; most notably ecological systems theory, which states that children develop in a complex environment consisting of multiple ecosystems (i.e., family, school, community, etc.) and that each ecosystem impacts the child’s development (Bronfenbrenner, 1992). In respect to this approach, psychoeducation seeks to incorporate multiple aspects of an individual’s life into the education process to ensure the best outcomes, including self, family, friends, the community, and the healthcare system (Lukens & McFarlane, 2004).

The variable structure of psychoeducation, which can be held in small- and large-group settings, allows for several secondary benefits beyond an increase in knowledge, including social learning, cooperation, positive reinforcement, creation of a support network, and reduced feelings of isolation. Group problem solving activities allow participants to move beyond didactic lectures to implement materials in diverse cases. Finally, sharing experiences among a supportive group allows parents to recognize strengths and achievements (Lukens & McFarlane, 2004). In this model psychoeducation provides an efficient and cost-effective treatment option for families that are already taxed by the complex care of their child with ASD (Steiner, Koegel, Koegel, & Ence, 2012).

In contrast to parent training and parent mediated interventions, where parents learn intervention programs to use with their children at home, parent education and psychoeducation programs go one step further by educating parents on the components of their child's disability, including general information and evidence-based interventions available (Lukens & McFarlane, 2004). Psychoeducation programs are intended to increase evidence-based knowledge, increase parental confidence and self-efficacy, and promote the generalization and maintenance of skills (McAleese, Lavery, & Dyer, 2014). While there is strong evidence for the effectiveness of psychoeducation in many different medical fields, there is still a lack of robust evidence for its widespread implementation within the ASD field (Lukens & McFarlane, 2004; Schultz, Schmidt, & Stichter, 2011; Dawson-Squibb, Davids, Harrison, Molony, & de Vries, 2019).

In general, autism-specific psychoeducation programs empower parents and allow them to enhance their ability to care for their children with ASD by teaching them knowledge specific to an autism diagnosis, information related to treatment options available, techniques to utilize skills and interventions at home, and methods for decreasing their own stress and anxiety related to caring for their child (Steiner, Koegel, Koegel, & Ence, 2012; Schultz, Schmidt, & Stichter, 2011; & Dawson-Squibb, et al., 2019b). However, as previously mentioned, many different forms of psychoeducation exist that vary greatly in structure, intensity, delivery method, and length (Bearss et al., 2015), and researchers have noted there are relatively few studies assessing group parent education programs within the ASD population (Steiner, Koegel, Koegel, & Ence, 2012).

To counteract the lack of peer-reviewed information on best practices for group-based psychoeducation programs in the ASD community, Steiner and colleagues (2012) attempted to provide a guide for enhancing ASD psychoeducation programs, including a theoretical framework, therapeutic approaches, competencies the instructor should possess, and additional special considerations. To begin, they noted that group psychoeducational programs are cost effective, provide social support, and allow for more formalized didactic lessons to be incorporated into the program. They also noted that psychoeducation programs are most effective when presenters and parents collaborate on treatment goals rather than when presenters instruct parents on goals. This collaboration has been shown to improve parental stress and self-confidence (Brookman-Frazee & Koegel, 2004). Moreover, parents receive the most benefit when goals are approached from a strengths-based system, meaning the presenter and parent work together to identify a child's strengths and then tailor the program and goals around their abilities. Finally, in order for parent education programs to be delivered effectively, presenters must possess the following characteristics: mastery and conceptual understanding of ASD, available interventions, and appropriate procedures; a responsive and collaborative teaching style; expertise in presentation skills; an ability to individualize treatment goals and plans; and be accepting of feedback from parents (Steiner, Koegel, Koegel, & Ence, 2012).

As noted above, psychoeducation in the ASD field has taken on many different forms and functions. Some psychoeducation programs incorporate both the child with ASD and the parent into the program (i.e., Connolly et al., 2018; DaWalt, Greenberg, & Mailick, 2018), and others focus on just parents of children with ASD (i.e., Zhou, Yin, Wang, & Wang, 2019; Magana, Lopez, & Machalicek, 2017). Two psychoeducation programs that incorporate both the child with ASD and parents are the Multi-family Psychoeducational Psychotherapy for Children with High Functioning Autism Spectrum Disorder (MF-PEP) and Transitioning Together: A Multi-Family Group Psychoeducation Program for Adolescents with ASD and their Parents (TT) (Connolly et al., 2018; DaWalt, Greenberg, & Mailick, 2018).

The MF-PEP is an 8 session program that also includes social skills training, cognitive-behavioral therapy, and parent training components. Initial qualitative feedback indicated that parents felt an increase in ASD knowledge, social support, and self-efficacy. Program development for the MF-PEP was ongoing and research efforts will seek to refine and generalize the program (Connolly et al., 2018). The TT program consisted of two family sessions to acclimate participating family members to the program and 8 weekly group sessions, for a total of 10 sessions and approximately 14 total hours. In contrast to the MF-PEP program, the parent component of the TT program was purely psychoeducational. The TT program found significant differences in parental well-being from pre- to post-test as well as parental problem solving. Additionally, there was a significant difference in pre- post- measures of parental feelings of happiness or pride for their adolescent with ASD following the program (DaWalt, Greenberg, & Mailick, 2018).

More traditional psychoeducation programs incorporate just the parents into the education process, which often allows for more in-depth discussion and analysis (i.e., Zhou, Yin, Wang, & Wang, 2019; Magana, Lopez, & Machalicek, 2017). One program, the Family-Focused Psychoeducational Therapy (FFPT), incorporated a four-week, group based psychoeducation component into an already existing ASD treatment facility's services in China. Quantitative findings showed improvements in parental self-efficacy and decreases in parental anxiety and depression scores (Zhou, Yin, Wang, & Wang, 2019). One program sought to determine if Latino parents in the ASD community perceived psychoeducation to be beneficial and what those benefits are. This program consisted of two consecutive 8-week modules, with module 1 focusing on general ASD information and module 2 providing information on evidence-based interventions. Qualitative feedback emphasized the importance of an ASD expert that was open and compassionate for the attendees to connect with, the importance of the knowledge parents gained in their ability to care for their child, and the ability to take the evidence-based intervention skills and use them at home (Magana, Lopez, & Machalicek, 2017).

The most comprehensive psychoeducation study to date details the process from developing training materials in conjunction with the parents being served, the time commitment and duration of the program, as well as materials included in the model (Patra, Arun, & Chavan, 2015). This study first conducted interviews with parents of children with ASD interested in completing a psychoeducation program to identify 51 areas of need. They then pared down these needs into general themes and designed a 12 part module to address them. This included providing general information about ASD, interventions for socialization, communication, behavioral problems, and sensory difficulties of the child. Pre-post-design analysis revealed that the psychoeducation program was effective in increasing ASD knowledge and decreasing parental stress, making this method a feasible way to help families of children with ASD (Patra, Arun, & Chavan, 2015).

In addition to psychoeducation serving as the main intervention point, research has shown that psychoeducation can enhance already reliable intervention programs. Black and Therrien (2018) reviewed ASD intervention programs where parent psychoeducation was added as a component of treatment to determine if outcomes were statistically better. Review of the literature showed large discrepancies in the level of psychoeducation required by programs, with some requiring as little as 1 session over the course of treatment and some requiring up to 17 sessions. Also, the description of the psychoeducation programs varied greatly, ranging from descriptions providing no information to those with detailed session-by-session breakdowns of what was covered. While findings are mixed due to low participant numbers, high withdrawal rates, and lack of fidelity reporting, researchers concluded that incorporating psychoeducation into child intervention programs may be more effective than delivering the interventions in isolation (Black and Therrien, 2018).

Parent Perceptions of Parent Support Programs

In addition to the structure of the programs themselves, it is important to understand if parents perceive them as beneficial and worthwhile. A less studied aspect of parent education programs is the parent's perceptions of the programs as beneficial and worth investing in. Preece and colleagues (2016) completed an assessment of parent perspectives regarding the content and delivery method for Parent Support programs in rural locations across Europe where very few ASD service programs existed at the time. This assessment is important in the context of parent training programs in Southern and rural America because the healthcare landscape for the ASD population is similar between the two locations, where many families are underserved, autism services are often clustered in large metropolitan areas that are not easily accessible to rural families, and parents are not generally well-informed regarding an ASD diagnosis and treatment options. Parent-report surveys indicated that 90% of respondents were interested in parent training sessions and workshops. Parents also identified potential barriers to participation, including work requirements and issues securing childcare. Furthermore, findings indicated a desire for local trainings on weekends rather than weekdays to alleviate concerns related to work and transportation. However, parents noted this would increase the need for reliable childcare. When polled on the general themes they wanted to learn more about, parents ranked topics in the following order: general ASD knowledge and information; policy, legislation, and legal rights; community awareness; coping and emotional response to living with ASD; and strategies to raise awareness in family and friends regarding ASD (Preece et al., 2017). When assessing parental interest in specific topics, responses in this study were similar to those from parents in Alabama (Alabama Interagency Autism Coordinating Council, 2018). For example, parents similarly illustrated an interest in including techniques for improving their child's communication, addressing sensory differences, behavior management techniques, and improving their child’s social skills. Of importance to note, parent responses varied statistically by European country, indicating the need for specialized Parent Support programs to be developed that prioritize the needs of local parents over a standardized model to be used across multiple and diverse settings (Preece et al., 2017).

An important secondary benefit of Parent Training within the ASD field is the benefit that parents themselves receive from the training. As a result, parents showed an improved self-efficacy, decreased stress, and improved overall mental health. Researchers have found that participation in ASD-specific Parent Education programs improved parental mental health and well-being. However, this program was very time intensive, requiring a total of 25 hours of parent participation in group and individual family sessions that addressed such topics as ASD education, communication, services available, behavior, etc. (Tonge et al., 2006).

The State of Our State: ASD Care in Alabama

As a state, Alabama has made significant progress in the past decade in caring for individuals with ASD and their families. While progress has been made on the legislative and policy level, there is still room for significant improvement in terms of access to care and systems delivery. The current landscape of the healthcare system in place, as well as significant events and organizations that impact the system of care for individuals with ASD and their families, are discussed in the following section.

Autism-Specific Care System in Alabama

Alabama has several statewide systems in place that serve the ASD population, including Medicaid and the Department of Mental Health (DMH), which also houses the State Autism Coordinator, the Alabama Interagency Autism Coordinating Council (AIACC), and the Regional Autism Network (RAN). Autism-specific Medicaid services are a very recent development for families with ASD in Alabama, with services online November 1, 2019 (Center for Public Representation, 2018). Six Medicaid services are available, including: Intensive Care Coordination, Behavior Supports, Therapeutic Mentoring, In-Home Therapy, Peer Support, and Psychoeducational Services (Alabama Department of Mental Health, 2019). Although these services are now available to families, a delivery system to ensure access is still in the process of being developed. For example, there is a need for including, identifying, and credentialing appropriate providers and educating families on the program's existence. Therefore, this program is not yet developed enough to serve Alabama's growing ASD population adequately.

The Department of Mental Health has been a leading agency for actionable change within the ASD system of care in Alabama. Through state legislation, DMH created the AIACC in accordance with the Alabama Autism Support Act of 2009 (HB 41). The AIACC guides Alabama's government in making decisions regarding ASD care, develops a strategic plan for ASD care in Alabama, and oversees a coordinated system of care for individuals with ASD in the state. DMH and the AIACC also instituted the RAN in 2016 to further meet the growing needs of the ASD community in the state as a result of statewide legislation that was passed. The RAN is discussed in depth in the following section.

The Health Benefit Plan of 2017 (HB 284) was passed through a grassroots organizing campaign within Alabama's ASD community that required "health benefit plans to cover the treatment of Autism Spectrum Disorder under certain health insurance plans and contracts" and "to cover certain treatment for Autism Spectrum Disorder under certain conditions" (Health Benefit Plan of 2017). However, the passing of this bill did not lead to immediate or widespread coverage of ASD therapies across the state as it left the decision up to employers as to whether or not they would pay to cover autism therapies. This ultimately led to confusion and frustration among parents, as they were not often aware this was what the bill mandated.

Healthcare Landscape in Alabama

The current healthcare system in Alabama does not have the adequate professional and education infrastructure to serve all individuals with ASD effectively. Rural areas of the state are disproportionally affected as they are even less equipped to serve children and youth with special healthcare needs. Unfortunately, Alabama ranks close to the bottom when compared to other states in virtually every relevant measure of access to healthcare services for this population. Compounding this issue, 51 of Alabama's 67 counties are considered rural; comprising 41% of the state's population (U.S. Census Bureau, 2018). Almost all counties qualify as medically underserved (Alabama Public Health, 2018a). Furthermore, 61 of the 67 counties also qualify as Mental Health Professional Shortage Areas, with either low income or geographic designations (Alabama Public Health, 2018b). In addition, Alabama ranks last nationally for mental health workforce availability, with one provider for every 1,180 individuals

(Mental Health America, 2019). It is also important to note that rural and low-income areas are disproportionally affected by provider shortages compared to the metropolitan areas of the state.

Several additional factors contribute to the lack of healthcare services in Alabama and to families' difficulty in accessing the available services. Alabama and its citizens have limited economic resources, ranking 46th in the country in per capita personal income at $42,334, which is only 79% of the national average of $53,712 per year (Bureau of Economic Analysis, 2019). Alarmingly, Alabama ranks 44th nationally in Overall Child Well-Being according to the Kids Count Data Book (Annie E. Casey Foundation, 2019). This metric is a combination of state rankings based on four smaller, more specific indicators of well-being, including Economic Well-Being, Education, Health, and Family and Community. Alabama ranks 46th nationally, with 25% of children living in poverty, compared to the national average of 18% (Annie E. Casey Kids Count Data Book, 2019). Fifty-seven percent of Alabama's 3 and 4 year old children are not enrolled in preschool (compared to 52% nationally), which also limits children with ASD's ability to receive services in an already resource poor state. Further compounding access issues, children in Alabama are more likely to live in a single parent household than the average child in America (39% vs 34%) and more likely to live in high poverty areas (15% vs 12%). Positively, only 3% of children in Alabama are uninsured compared to the national average of 5% (Annie E. Casey Foundation, 2019). However, families in Alabama have reported that increases in insurance coverage did not always translate into an increase in services received. This was due to a lack of available providers or the insurance company's unwillingness to reimburse for ASD-related therapies (Alabama Interagency Autism Coordinating Council, 2018).

These socioeconomic and system of care issues place extreme amounts of stress on ASD families in Alabama. In addition to the jarring statistics above, several more indicators must be discussed to highlight the need for improved disability related healthcare policies in Alabama and the nation as a whole. Twenty-two and a half percent of children in Alabama (247,758) qualify as Children with Special Healthcare Needs (CSHCN). Of that number, an estimated 28,645 currently have an autism diagnosis. However, only 26.6% of parents report completing a developmental screener between the ages of 9 and 35 months, which is a crucial time period in recognizing, diagnosing, and treating ASD. Finally, 87.1% of adolescents with special healthcare needs reportedly receive no services necessary to transition to the adult heath care system (Data Resource Center for Child and Adolescent Health, 2018).

The medical home model, founded on "accessible, family centered, continuous, comprehensive, coordinated, compassionate, and culturally effective" care has long been accepted as the gold standard for caring for CSHCN (Homer et al., 2007; Kuhlthau et al., 2011). However, only 40.1% of children in Alabama are served in the medical home model (Data Resource Center for Child and Adolescent Health, 2018). This greatly reduces the health equity of the ASD population in the state.

A final component that contributes to the substantially lacking healthcare system currently in place for children with ASD in Alabama is the number of pediatricians available. The 2010 report by the American Academy of Pediatrics, *Mapping Healthcare Delivery for America's Children*, indicated there are a total of 1,823 pediatricians in the state, which results in a ratio of 1 pediatrician for every 2,229 children, which is significantly worse than the national average of 1 pediatrician per every 1,769 children (American Academy of Pediatrics, 2010). With the increasing number of children identified with a concern, and ultimately a diagnosis, of ASD, a lack of available resources subsequently delays screening, diagnosis, and consequently, initiation of intervention services, which will have significant negative effects on their long-term health outcomes and quality of life.

Alabama Regional Autism Network

In 2016, the AIACC established the Regional Autism Network (RAN) to create a comprehensive care system for individuals with ASD, their families, and providers of individuals with ASD within the state. This 5-site, university-based Network serves four charges for the ASD community including Direct Assistance to families, Technical Assistance and Consultation to providers, Professional Training to providers, and Public Education to individuals, families, and providers.

In order to best serve ASD families in the medically underserved setting of Alabama, the RAN has prioritized the development of Public Education programs. By creating a pyramid-like system of care, with Public Education as the largest component at the base, the RAN is able to decrease the need for their more time- and resource-intensive initiatives, including Direct Assistance and Technical Assistance and Consultation. In this model, a robust Public Education and Professional Training system leads to a decreased need for Technical Assistance and Consultation or Direct Family Assistance requests.

Strong Public Education programs can prepare individuals to seek the appropriate service providers as needs arise.

In addition to addressing the four charges mandated in the legislation, the RAN is responsible for collaborating on ASD policy initiatives in Alabama. Through its direct contact with families, providers, and policy makers the RAN is uniquely positioned to understand the needs of families, the abilities of providers, and the workings of policy makers, which allows the Network to be leaders in change on a state and national level. Through the information gained from needs assessments and research initiatives, the RAN aims to spearhead policy changes to benefit the ASD community.

AIACC Needs Assessment

The AIACC commissioned a Needs Assessment in the fall of 2018 to gauge the system of care in place for individuals with ASD and their families, which resulted in the *State of Alabama's System of Care for Individuals with ASD and their Families: Rapid Environmental Scan and Needs Assessment, 2018*. This Needs Assessment identified several areas of major concern for the autism community in Alabama. Of particular concern was that these parents identified the need for further educational programs to learn how to help their children, what services are available, and considerations for long term care moving forward. The Needs Assessment also revealed that only 50% of parents with school-age children with ASD believe their children always receive the services they need. This number decreases to 33% when considering transition-aged individuals (14 to 20 years old). Parents also indicated that 82% do not have a long-term care plan in place for their child. Furthermore, coding from in-depth interviews revealed five major areas that parents believe they need the most support. These themes include behavior management, parenting support, individual with ASD support, financial and future concerns, and systems navigation. See Appendix B for a list of general themes and specific topics that were identified from the In-Depth Interviews. These findings are being used to target programs and initiatives to better serve families with ASD in Alabama.

Community Education Workshops

The UAB RAN established its Community Education Workshops (CEWs), which are free, monthly, community-based, and open to the general public, to provide an ASD-based psychoeducation program for caregivers and providers in the ASD community. While the UAB RAN hosts the CEWs, they partner with community-based providers and university-based experts to lead and facilitate the workshops. This allows attendees to establish connections to community-based providers that they can connect with for ongoing individual and family support. In essence, CEWs serve as one-dose intervention programs for attendees.

The CEWs are delivered through a three-part model, including a Didactic, Case Study, and Action Plan. The Didactic provides attendees with a base of knowledge and relevant skills, while attendees practice applying this knowledge and skills to a pre-determined situation through the Case Study. Finally, the model culminates with the Action Plan, which allows attendees to tie together the information from the Didactic and their practice from the Case Study in order to complete an Action Plan, specific to their child and situation. Attendees can draw on the information from the Workshop as well as the expertise of the Presenter and Facilitators to complete the Action Plan, which allows them to leave with a concrete plan in place in order to implement skills and strategies in their natural environment for their children. This Workshop model was adapted from Vanderbilt Kennedy Center's Families First Program, which is a parent education program intended for parents of children with ASD from the ages of 2 to 7.

In addition to the information provided and the ability for parents to leave the Workshop with their Action Plan, there are several secondary benefits of the Workshops; mainly the ability of attendees to further connect with the ASD community. Parents are able to make connections with other parents, which in turn, increases social support and provides the opportunity to organize social activities for their children. Parents are also able to connect with community-based providers, which gives them another outlet for resources and information should they need it. Finally, parents are better able to connect to the UAB RAN staff, by meeting face-to-face, discussing needs and programs, and building relationships that increases their confidence in attending future workshops and connecting with the RAN for assistance and information. While the Workshops are not intended to serve as stand-alone intervention services for families of children with ASD, they have the ability to greatly supplement evidence-based interventions and provide an additional support system for the family, as described by several researchers to date (Kataoka, 2012; Black & Therrien 2018). Appendix C lists the community-based providers that facilitated each CEW of 2019.

Public Health Implications

The Community Education Workshops have the ability to improve the public health system for individuals with ASD and their families and caregivers in several ways. The Workshops are intended to reduce health disparities that families of individuals with ASD face by providing them evidence-based knowledge, connecting them to community providers, and introducing peers for social-emotional support. These three components can alleviate financial and time constraints that intensive ASD therapies place on families and counteract the feelings of social isolation that many parents report while raising a child with ASD. In addition, these group-based Workshops help to alleviate the stress of Alabama's mental health professional shortage by allowing one or two expert providers to reach a large group of individuals at once and facilitate a connection for future dialogue. In addition, targeted programs such as this have the ability to intervene early on a large scale, which may promote better health outcomes for children with ASD in adulthood by providing skills and supports necessary at an earlier age than was previously available to them. As noted, public health practice efforts for the ASD population in Alabama must target the above issues by collaboratively implementing programs to bridge gaps in care for families on service waitlists, supplement existing services, and facilitate a community support network for families and their children (Griffith, Clesi, O' Kelley, & Biasini, 2019).

Alabama's Title V Maternal and Child Health Bureau report also provides priority needs, objectives, performance measures, and objective measures for improving the public health system for CSHCN in the state. Of importance, they note a "lack of or inadequate access for CSHCN to family-centered, coordinated, ongoing comprehensive care within and medical home” and a “lack of or inadequate access to services necessary for CSHCN to transition to all aspects of adult life” (Maternal and Child Health Bureau, 2019). The identified needs are paired with state and national outcome measures to track change over time for the public health system. The Workshops have the ability to promote these objectives through program building and provider collaboration efforts.

Healthcare Policy Implications

Knowledge translation (KT) and implementation science have become key components of healthcare policy work, with policy makers often referred to as KT users (Boydell et al., 2017). The need for policy makers to understand the research process and to be able to synthesize findings, as well as the need for researchers to comprehend the policy making process, has forced these domains to co-exist with one another. The Canadian Institutes of Health Research defined KT as “a dynamic and iterative process that includes the synthesis, dissemination, exchange, and ethically sound application of knowledge to improve health status, provide more effective health services and products, and strengthen the healthcare system” (2012). In Canada funding sources require a detailed KT plan to ensure that translational and implementation research is being conceived, funded, and conducted appropriately.

Researchers have noted that the need to engage stakeholders in the research process, coupled with the complexity of policy-making, often results in a gap between the two constructs within the healthcare system. (Moat, Lavis, & Abelson, 2013). In order to improve this relationship, researchers have begun to explore the bi-directional interactions between the research process and policy, noting that deliberate dialogues between researchers and policy makers are the most effective way to translate findings to policy. Deliberate dialogues allow research findings to be considered within the perspective, experience, and understanding of those involved in making policy decisions as well as those that will be impacted by the policies. This increases the likelihood that policy decisions will support and fund evidence-based programs. The prevalence of evidence-based policy initiatives is growing and has become the standard for some healthcare disciplines (Boydell et al., 2017).

Reviews of evidence-based policy detail the crucial relationship between policy makers and stakeholders, who can provide insight based on personal experience. They also note continued and long-running relationships between policy makers and stakeholders allow for actionable change to occur over extended periods of time (Oliver, Innvaer, Lorenc, Woodman, & Thomas, 2014; Orton, Lloyd-Williams, Taylor-Robinson, O'Flaherty, & Capewell, 2011). Literature illustrates how crucial these relationships can be for stakeholders living in rural areas, who often deal with a lack of qualified service providers, a lack of centralized funding, and are more likely to experience financial hardships related to diagnosis and treatment. In addition to the challenges faced by individuals in rural areas when accessing services, they are often left out of the policy making process, as these decisions are primarily made in large metropolitan cities, a process referred to as metro-centric. In order to bridge the metro-centric and rural policy gaps and ensure that initiatives promote policies that benefit all consumers, researchers and policy makers must target relationships with rural and underrepresented stakeholders (Boydell et al., 2017).

Dingfelder & Mandell noted a lack of policy change initiatives that result from empirically based research methods and provide guidelines for translating research to policy (2011). These suggestions include targeting research towards issues that are most pertinent to the public, enhancing the generalizability of the study by including diverse samples and delivering in their natural settings, invoking stakeholders in the research process, including formal data collection and comprehensive follow-up, and planning for intervention maintenance and connection of families to service providers (Dingfelder & Mandell, 2011). Based on the domains identified in the Alabama Needs Assessment, this current research program is designed to satisfy Dingfelder and Mandell's criteria for using research to inform policy changes, while simultaneously having positive and meaningful impact on the daily lives of families in the ASD community (AIACC, 2018).

THE CURRENT STUDY

The current study sought to evaluate the Regional Autism Network's Community Education Workshops, which are a psychoeducation and training program for parents of children with ASD. The study included two major phases. The aim of Phase 1 was to complete a programmatic evaluation and assess implementation fidelity of the Community Education Workshops and determine whether they are effective in increasing evidence-based knowledge of ASD symptomology and treatment practices in attendees. The aim of Phase 2 was to determine whether workshop attendance led to an increase in implementation of evidence-based skills in the attendee's natural environment and confidence in doing so. Finally, in Phase 2, researchers assessed parent perceptions of connectedness to the ASD system of care and social support system.

PHASE 1: EVALUATION OF A NOVEL PSYCHOEDUCATION PROGRAM FOR PARENTS AND PROVIDERS OF INDIVIDUALS WITH ASD

Specific Aims and Hypotheses

Aim 1

Determine the demographic profile of parents that utilize the Community Education Workshops and link service receipt to insurance coverage, geographic location, and need for future service connections.

Hypothesis 1A. Parents of children with ASD in urban counties will be more connected to autism-related services than rural families, as measured by their response on the Parent Demographic Form to their child's connection to ASD- related services.

Hypothesis 1B. Families with private insurance coverage for their child with ASD will be more connected to autism-related services than publicly insured families.

Hypothesis 1C. Families with private insurance coverage for their child with ASD will more frequently report being well connected to autism-related services and fewer barriers to connection than families with public insurance.

Aim 2

Determine whether the Regional Autism Network Community Education Workshop model is delivered effectively and if this model increases the evidence-based knowledge of attendees.

Hypothesis 2A. Presenters will deliver material effectively in accordance with the prescribed learning objectives to enhance evidence-based knowledge gain of attendees, as measured by the Attendee Feedback Form.

- Scores on the Attendee Feedback Form ≥ 3.5 on the 4 point Likert-scale were considered Great and indicate that presenters delivered their Workshop topic effectively according to the pre-determined learning objectives. Scores between 2.51 and 3.49 fall in the Fair range. Scores ≤ 2.50 fall in the Poor range and indicate that presenters did not deliver the Workshop material according to the learning objectives, which may have an overall negative effect on attendee's ability to learn and implement the evidence-based knowledge.
- Qualitative responses from the Attendee Feedback Forms were also coded to categorize what attendees enjoyed most about the workshops and what aspects could be improved.

Hypothesis 2B. The delivery of the prescribed Learning Objectives, through the Workshop model, will lead to an increase in evidence-based knowledge of attendees, as measured by the Pre- and Post-Knowledge Questionnaires.

- Pre- and Post-Knowledge Questionnaires are identical measures that each contain 7 multiple choice questions to assess attendee knowledge of evidence based information related to ASD and the topic of the Workshop. Pre- and Post-Knowledge Questionnaires were made specifically for each Workshop to reflect the content delivered by the presenters. Questionnaires were then graded for correctness and given a score out of 7. Scores will indicate an increase in knowledge if the Post-Knowledge scores are higher than the Pre-Knowledge score. Pre- and Post-Knowledge differences were assessed using an independent samples t test.

Hypothesis 2C. The Workshop will have high programmatic fidelity, as measured by independent video ratings of presenter adherence to the prescribed objectives in the Presenter Checklist.

Methods

Participants

This study recruited attendees of the UAB Regional Autism Network Community Education Workshops. These monthly Workshops are free, open to the public, and generally draw between 20 and 50 attendees per event, therefore, researchers estimated 100 to 200 participants would enroll over the course of the study. One Workshop was cancelled due to COVID-19, which resulted in a final total of 170 parents, caregivers, and providers that attended the four Community Education Workshops included in Phase 1.

This included 109 parents and 61 providers. As each Workshop was considered to be an independent event, attendees could participate in the research aspect in multiple Workshops and be counted as more than one participant. For a complete breakdown of attendee and participant characteristics, see the results section and Tables 1 and 2. Participation in this study was not mandatory for attendance at the Community Education Workshops.

Materials

Parent/Caregiver Demographics Questionnaire. General demographics information of the individual with ASD was collected, including age, race, ethnicity, city and county of residence/service. Parent and caregiver specific information was collected, including age of diagnosis, past and current ASD-related services, professionals seen, desire for future connections, medication history, and educational history. In addition, questionnaires asked whether the participant felt that their child with ASD was well connected to the ASD services they need and any barriers they faced to being well connected. See Appendix D for the Parent/Caregiver Demographics Questionnaire.

*Pre- and Post-Knowledge Questionnaires***.** Pre- and Post-Knowledge Questionnaires were used to assess evidence-based knowledge gained from attending the Workshops. Knowledge questionnaires were developed specifically for each Workshop based on the presentation that was given. Pre- and Post-Knowledge Questionnaires were identical in order to measure change in knowledge from Workshop attendance. See Appendix E for a sample Pre- and Post-Knowledge Questionnaires.

Attendee Feedback Measure. Attendee Feedback Measures were used to assess the effectiveness of the model of the Community Education Workshops. Attendee Feedback Measures were developed specifically for each Workshop based on presenter provided learning objectives. Participants rated their ability to complete tasks described in the learning objectives upon the conclusion of the Workshop on a one to four Likert-scale. The Attendee Feedback Measures also included open response questions on what participants liked best about the Workshop and what could be improved. See Appendix F for a sample Attendee Feedback Measure.

Presenter Checklist. The Presenter Checklist was used by RAN staff to educate presenters on the Workshop model and all necessary components of the Workshops. These components were used to assess programmatic fidelity. See Appendix G for the Presenter Checklist.

Procedure

Attendees of the UAB RAN Community Education Workshops were given the option to participate in this study upon checking in at the Workshop. Participation did not affect their ability to attend the Workshop in any way. If attendees wished to participate in this study, they were given Research Information documents and the procedure was explained by the research staff. Before the Workshop began, participants completed the Demographics Form and the Pre-Knowledge Questionnaire. At the conclusion of the Workshop, participants completed the Post-Knowledge Questionnaire and the Attendee Feedback Measure. All measures were returned to research staff upon completion of the individual documents. Participation was estimated to take 15 minutes and participants did not receive any incentive for participating.

Coding Methodology

Qualitative coding was done using the Grounded Theory approach and a Constant Comparative method. In Grounded Theory Approach, researchers generate themes and codes from responses, which they then use to guide further coding and analysis, constantly refining themes and codes as more responses are analyzed (Tolley, Ulin, Mack, Robinson, Succop, 2016; Cresswell, 2014). Responses from the Demographics Forms in relation to the barriers parents face when trying to access the ASD system of care and from the Attendee Feedback Forms, including what attendees liked best about the Workshops and what could be improved, were entered into the coding template. Two research team members completed this portion of the qualitative data analysis. To begin, the two team members coded independently of one another, using predetermined codes from the AIACC Rapid Needs Assessment (2018) and creating new codes where appropriate. After the first round of coding was completed, the team members explained codes for each response, collapsed existing codes, and discussed definitions of newly created codes. After a set list of codes was agreed upon, the two coders recoded the responses independently of one another. A third team member then completed a validity check to determine agreement between the two coders. Agreement from this validity check was 79% (22/28) for access barriers, 87% (72/83) for what attendees liked best about the Workshops, and 84% (31/37) for what could be improved about the Workshops. Finally, the two coding team members met again to discuss the validity check findings and come to consensus regarding coding. Agreement was reached on all codes following the final discussion between coders with the input from the validity check.

Results

Participant Characteristics

In total, 170 parents, caregivers, and providers attended the four Community Education Workshops held in September and November of 2019 and January and February of 2020; including 109 parents and 61 providers. For a complete breakdown of attendance numbers, including number of parents/caregivers and providers registered compared to the number that attended, see Table 1. Of the 109 parents and caregivers, 72 (66.1%) completed the Parent/Caregiver Demographics Questionnaire. Of the 72 attendees who completed the demographics questionnaire, 73.6% were the mother of an individual with ASD, 5.6% were fathers, and 20.8% had some other relationship to an individual with ASD, including grandparents, aunts, and siblings. See Table 2 for the respondent relationship to the individual with ASD for whom they completed the demographic information.

The following statistics describe the individual with ASD for whom the parent or caregiver attended the Workshop. The average age of the individual with ASD was 9.46 years (SD = 5.66 years), with the youngest individual with ASD being 2 years old and the oldest being 26 years old. 76.4% (55) of the individuals were male and 23.6% (17) were female. When broken down by race, 45 (62.5%) were White, 17 (23.6%) were African American, 3 (4.2%) were Multiracial, 1 (1.4%) was Asian, and 6 (8.3%) responded as Other. In addition, 64 (88.9%) individuals were classified as Non-Hispanic while 8 (11.1%) were Hispanic. Within these families, 91.7% (66) speak English in their homes while 8.3% (6) primarily speak Spanish in their home. For the individuals with ASD, 47.2% (34) were privately insured, 39.4% (28) were publicly insured, 8.3% (6) had both private and public insurance, and 5.6% (4) were uninsured. Regarding ASD diagnosis, 95.8% (69) currently had a diagnosis and 4.2% (3) were on a waitlist for an ASD

Table 1

Registration and Attendance Breakdown of the CEWs in Phase 1 Analysis

Date	Topic	Caregivers Registered	Caregivers Attended	Providers Registered	Providers Attended	Total Registered	Total Attended	Show Rate
Sep-19	Sleep Disturbances	41	24	11	10	52	34	65%
Nov-19	Co-Occurring Disorders	42	19	13	9	55	28	51%
Jan-20	Challenging Behaviors	52	36	34	30	86	66	77%
Feb-20	Long Term Planning	58	30	14	12	72	42	58%
Total		193	109	72	61	265	170	64%

Table 2

Respondent Relationships to Individual with ASD

Caregiver Relationship	Completed Demographics	Attended CEW	Registered for CEW
Mother	53 (73.6%)	-	-
Father	4 (5.6%)	-	-
Other	15 (20.8%)	-	-
Total	72	109	193

diagnostic evaluation. Specified by type of diagnosis, 29 (40.3%) had a medical diagnosis alone, 4 (5.6%) had an educational diagnosis alone, and 39 (54.2%) had both a medical and an educational diagnosis. For these individuals, 45 (62.5%) also had a diagnosis of a co-occurring disorder, while 27 (37.5%) did not. See Table 3 for the complete listing of demographic characteristics for the individuals with ASD for whom the parents and caregivers attended the Workshops.

Table 3

Demographic Characteristics of Individuals with ASD for whom Parents Attended CEW

Demographic Characteristic	N	%
Age	M = 9.46	(SD = 5.66)
Sex		
Male	55	76.4
Female	17	23.6
Race		
White	45	62.5
African American	17	23.6
Asian	1	1.4
Multiracial	3	4.2
Other	6	8.3
Ethnicity		
Hispanic	8	11.1
Non-Hispanic	64	88.9
Home Language		
English	66	91.7
Spanish	6	8.3
Insurance Coverage		
Private	34	47.2
Public	28	39.4
Private + Public	6	8.3
Uninsured	4	5.6
ASD Diagnosis		
Yes	69	95.8
No	3	4.2
Type of ASD Diagnosis		
Educational	4	5.6
Medical	29	40.3
Both	39	54.2
Co-Occurring Disorders		
Yes	45	62.5
No	27	37.5
Well Connected to ASD Services		
Yes	39	54.2
No	33	45.8

Aim 1

Hypothesis 1A. The data regarding family's urban versus rural status were not evenly distributed between the rural and urban groups. Of the 72 parents who completed the demographics survey, 62 (86.1%) reported living in an urban county and only 10 (13.9%) reported living in rural counties. While a disproportionate distribution should have been expected given the urban location of the Workshops, this large of a group difference was unforeseen. The original statistical plan was to run an independent samples t test to determine if urban and rural families received autism-related services at a different rate. However, this sample violated the assumption of normality required for an independent samples t test, and therefore, a non-parametric Mann-Whitney U test was used to determine if there was a difference in current ASD service connection between families in urban and rural settings. Distributions of the number of services families were connected to were not similar, as assessed by visual inspection. There was no statistically significant difference in service connections between urban and rural families, $U = 265.5$, $z = -.737$, $p = .461$. The mean number of autism-related services urban families were connected to was 3.31 ($SD = 1.80$), while rural families were connected to an average of 2.90 services ($SD = 1.50$). The number of services that parents reported their children being connected to ranged from 0 to 7, with 19 (26.4%) parents reporting their children were connected to 4 autism-related services. Distinguished by geographic designation, urban families had a broader distribution of service connection, which also ranged from 0 to 7 services, while rural families ranged from 1 to 5 autism-related service connections.

Hypothesis 1B. In terms of insurance coverage, 34 (47.9%) parents reported that their child had private insurance, 28 (39.4%) reported having public insurance, 6 (8.5%) reported having both private and public insurance, and 3 (4.2%) reported being uninsured. For this analysis only privately and publicly insured families were compared. The first comparison was made to determine if these families differed in their number of current service connections (i.e., are they currently connected to a speech/language therapist, occupational therapist, behavioral therapists, etc.). There was a statistically significant difference in mean number of current service connections between privately insured and publicly insured children, t(60) = 3.851, p < .001. Parents reported their privately insured children with ASD were connected to an average of 4.03 (SD = 1.49) services, while parents with publicly insured children reported being connected to 2.61 (SD = 1.40) services. In addition, privately insured children were connected to a wider range of services, from 0 to 7, than their publicly insured peers (0 to 5).

The number of past service connections was not significantly different, t(60) = 0.662, p = .510. Total number of current and past service connections was significantly different between the groups, t(60) = 3.081, p = .003, with the mean number of current and past total services for privately insured children being 5.03 and 3.36 for publicly insured children. In addition, total number of service connections and provider connections was significantly different between the two groups, t(60) = 2.399, p = .020, with the average number of total past and current service and provider connections being 9.12 for privately insured children and 6.93 for publicly insured children.

Hypothesis 1C. Of the 62 publicly and privately insured families, 34 reported that they believed they were well connected to ASD-related services and 28 reported that they believed they were not well connected to ASD-related services. A chi-square test for association was conducted between type of insurance coverage and perceived connection to ASD-related services. All expected cell frequencies were greater than five. There was a statistically significant association between insurance type and perceived connection to ASD-related services, $X^2(1) = 7.540$, $p = .006$, indicating that parents of children with private insurance were more likely to believe they are well connected to the ASD system of care than the parents of publicly insured children. There was a moderately strong association between type of insurance coverage and perceived connection to ASD-related services, $\varphi = .349$, $p = .006$. Figure 1 displays the chi-square graph for a depiction of the group breakdown of connection to ASD services by insurance coverage.

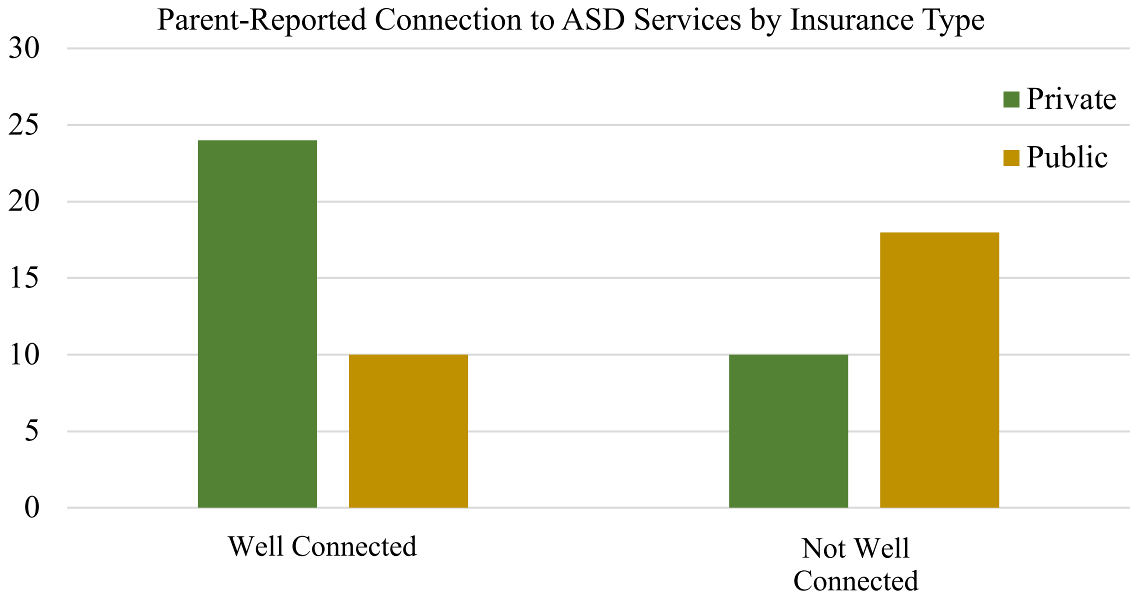

Figure 1. Parent-Reported Perceived Connection to ASD Services by Insurance Type

Parents that reported they did not believe they were well connected to ASD-related services were further asked to explain the barriers to connection they were facing. Of the 62 parents included in this analysis, 28 (45.2%) indicated that they did not believe their child was currently well connected to services, with all 28 parents providing further responses for qualitative analysis. Coding revealed six major themes in terms of barriers to being well connected to ASD services, including Access, Financial Limitations, Provider Awareness and Education, Parent Education, Social Support, and Waitlists. Within these broad codes, Access was further broken down into several areas of need, including Lack of Services, Needing a Specific Service, Transportation, Parent Time Limitations, and Geographic Limitations. From these 28 responses, the researchers assigned 34 total codes. Each Broad and Fine code was assigned the corresponding number of times and examples of each are provided:

- Access (21)
    - Lack of Services (7) - “We need more services for older children. Resources seem to be limited after the age of six or seven”
    - Needing a Specific Service (6) – “He needs a BCBA to address behaviors that have recently come out”
    - Transportation (5) – “transportation to appointments”
    - Parent Time Limitations (2) – “Parents are too busy to follow up with treatments”
    - Geographic Limitations (1) - “We live in a rural area so the only home-based services available are through Medicaid and we were told we do not qualify for Medicaid”

- Financial Limitations (4) – “financial limitation and insurance coverage”
- Provider Awareness and Education (3) – “lack of communication from service systems”
- Parent Education (2) - “Not knowing the options available” and “a lack of information”
- Social Support (2) – “finding social groups for myself”
- Waitlists (2) – “long waitlists”

Most parent reported barriers focused on a lack of services or a lack of access to services for various reasons, including financial and geographic limitations, not knowing how to access a specific service, or encountering long waitlists when they do find the appropriate service. The concept of parent and provider education was also brought up several times, indicating the need for continued psychoeducation programming, such as the Community Education Workshops, to eliminate these gaps.

Aim 2

*Hypothesis 2A***.** Attendees rated the presenters very highly and indicated they believed the presenters delivered their Workshops effectively in accordance with their pre-determined learning objectives through their rating on the Attendee Feedback Measures. Ratings were completed on a 1 to 4 Likert-scale for each learning objective to address the statement “upon completion of today’s Workshop I…,” with the responses of 1 and 4 being anchored by labels of Strongly Disagree and Strongly Agree, respectively.

Overall, 114 attendees completed the Attendee Feedback Form across the four Workshops. The weighted average score on the Form was 3.70, indicating that the presenters consistently delivered their Workshop material according to their pre-determined learning objectives effectively. Analyzed by individual Workshop topic, scores were as follows: Sleep Disturbances and ASD – 3.88, Co-Occurring Disorders – 3.69, Challenging Behaviors and ASD – 3.56, and Long-Term Special Needs Planning – 3.77. Attendee ratings of the presenters' adherence to the individual learning objectives ranged from 3.44 to 3.92. For a complete breakdown of the Attendee Feedback Measures for each Workshop and learning objective, see Table 4.

Table 4

Ratings of Presenter Delivery of Individual Learning Objectives from Attendee Feedback Forms

Topic	Sleep Disturbances	Co-Occurring Disorders	Challenging Behaviors	Long-Term Planning
Learning Objective				
1	3.91	3.92	3.55	3.80
2	3.91	3.67	3.57	3.74
3	3.83	3.67	3.64	3.80
4	-	3.50	3.44	3.74
5	-	3.67	3.59	-
Average	3.88	3.69	3.56	3.77

Additionally, attendees were asked open ended response questions to determine what they liked best about the Workshop and what could be improved. Of the 114 completed Attendee Feedback Forms, 83 (72.8%) included responses to what they liked best and 28 (24.6%) included responses on what could be improved. Qualitative analysis yielded 117 codes from the 83 responses of what the attendees liked best about the Workshops. The resulting broad and fine codes, the number of times they were used, and examples are included below:

- Information Presented (47) – “information is relevant to parents, teachers, therapists and other professionals working with children with autism”
- Format (29) – “I like how the day is organized”
    - Presentation (11) – “the presentation was easy to understand; good explanations”
    - Parent – Presenter Engagement (9) – “question and answer during the Workshop”
    - Table Discussion (4) – “the discussion time”
    - Feedback (2) – “they provided supportive feedback and they offered multiple approaches to challenges”
- Strength of Presenters (18) – “the presenter’s communication” and “presenters were approachable”
- Resources (12) – “lots of useful resources”
    - Handouts (6) – “the handouts and visuals provided”
    - Visuals (3) – “seeing the visuals you can use to help a child sleep at night”
- Examples Provided (7) – “very informative and presented very well; good examples used”
- Everything (4) – “we are new to the ASD world so everything was helpful”

The majority of attendee's responses focused on the relevance of the information that was presented, the format of the Workshops, and the strength of the presenters. Many respondents believed the presenters were approachable and that they presented novel and complex information in a way that was easy to comprehend. Attendees also liked the presentation format, including the use of the Case Studies and Action Plan, as well as the engagement with the presenters throughout the Workshop to answer questions and consult on a case by case basis to help complete their respective Action Plans.

Additionally, qualitative analysis of the 28 responses to what could be improved from the Workshops yielded 30 individual codes. The corresponding codes, the number of times they were used, and examples are included below:

- Longer Sessions (6) – "extend by 30 minutes to account for more questions"
- More Sessions (6) – "make this two parts so more co-occurring disorders can be discussed"
- More Case Studies (6) – "more on intervention strategies – maybe case studies, more examples or brainstorming"
- Offer Advanced Sequel (4) – "I love this basic workshop. I would love to see an advanced course for people who have completed this one"
- Address Distractions (3) – "address side-talking while presentation is in session"
- Improve Accessibility (2) – "translate to Spanish" and "would love audio recording to share with spouse"
- Clarify and Define More (2) – "for those who are new to ASD; need definitions of some of the key terms"
- Shorter Sessions (1) – "shorter program, no lunch"

Most responses for this portion of the Attendee Feedback Form focused on the desire for more, including more sessions, more time during the existing sessions, more examples, and more advanced sequels to be offered as follow-up. An important area for improvement that was brought up was to improve accessibility of the Workshops; notably to improve access for families that primarily speak Spanish by more frequently offering translated materials as well as having live translation services available. These responses will be used to guide future outreach and program improvement initiatives.

Hypothesis 2B. Attendees learned evidence-based knowledge and improved their understanding of ASD and corresponding services and interventions as a result of attending the Community Education Workshops. There was a significant difference in scores on the Pre-Knowledge Questionnaires (M = 3.92 , SD = 0.88) and scores on the Post-Knowledge Questionnaires (M = 6.14 , SD = 0.60), t (3) = 8.89, p = .003. Each Workshop saw an increase from Pre- to Post-Knowledge scores, indicating that evidence-based learning occurred. Pre-Knowledge raw scores ranged from 2.80 to 4.78 out of 7, corresponding to a percentage range of 40.0 to 68.3 percent. Post-Knowledge raw scores ranged from 5.30 to 6.73, corresponding to a percentage range of 75.8 to 96.1 percent. Finally, raw score changes ranged from an average increase of 1.49 points to an increase of 2.58 points, corresponding to a percentage increase of 21.3 to 37.0 percent. For a complete breakdown of the Pre- and Post-Knowledge Questionnaire scores by Workshop, including raw and percentile scores as well as change scores, see Table 5.

Table 5

Scores on Pre- and Post-Knowledge Questionnaire by Workshop

Topic	Pre Raw	Post Raw	Raw Change	Pre Percent	Post Percent	Percent Change
Sleep	4.78	6.27	+1.49	68.3%	89.6%	+21.3%
Co-Occurring Disorders	4.43	6.73	+2.30	63.3%	96.1%	+32.8%
Challenging Behaviors	3.68	6.26	+2.58	52.5%	89.5%	+37.0%
Long Term Planning	2.80	5.30	+2.50	40.0%	75.8%	+35.8%
Average	3.92	6.14	+2.22	56.03%	87.74%	+31.72%

Hypothesis 2C. Members of the research team analyzed video recordings, responses from the Attendee Feedback Forms, interviews with RAN staff, and dialogue from the in-depth parent interviews to rate the fidelity of the Community Education Workshops and the presenters' adherence to Workshop goals and structure. Workshop fidelity was rated in accordance with the Presenter Information and Checklist that the researcher discussed in depth with each of the Workshop presenters. Critical components of the Workshop include materials that are prepared for attendees and interactive components during the Workshop itself. Materials that must be prepared include the didactic presentation, at least one Case Study, and an Action Plan template. Presenters are also encouraged to prepare visuals, informational handouts, and any supplementary materials they discuss during their presentation. Interactive components should include an open format where questions are encouraged throughout the presentation, small group discussions to problem solve the Case Studies and Action Plan, and a willingness for the presenters to be available on a one-on-one basis to help attendees complete their Action Plan during the Workshop. Therefore, each Workshop has six points they were rated on in terms of fidelity to the Workshop model. These terms were classified as: Didactic, Case Study, Action Plan, Interactive, Small Groups, and Personal Assistance.

September's Sleep & ASD and October's Co-Occurring Disorders CEWs were rated using Attendee Feedback forms, RAN staff interviews, and in-depth parent interviews. Both September and October's Workshops were rated to have completed all six components that comprise the Community Education Workshop model. Attendees noted how helpful the visuals and handouts for tracking sleep progress were and how impactful the case studies were to discussing how to recognize and work with co-occurring disorders.

January's Challenging Behaviors and February's Long-Term Planning CEWs were primarily rated using video recordings. Ratings were then checked with the Attendee Feedback forms, RAN staff interviews, and in-depth parent interviews. The Challenging Behaviors Workshop successfully implemented four of the six components of the Workshop model, but did not implement the Action Plan or the Personal Assistance in completing the Action Plan. While the Action Plan was provided in the attendees' folders, the presenters were not able to complete their Workshop by covering the Action Plan and assisting attendees in completing it. It should be noted that the presenters intended to follow the Workshop model, but ran out of time at the end of the day due to the time intensive interactive and open format they promoted throughout. The Challenging Behaviors presenters placed an emphasis on answering questions during their presentation, which limited their ability to complete the Action Plan at the end. The presenters did encourage attendees to reach out to them personally should they need assistance with the Action Plan later. While this is not the preferred method for completing the Action Plan, it did further encourage parent-provider relationships outside of the Workshops. February's Long-Term Planning Workshop completed all six components of the Workshop model.

Three of the four Workshops included in the program evaluation phase of this study adhered to the Workshop model for all six identified components. One Workshop completed four of the six components for the Workshop model. In total, 22 of the 24 (91.6%) model components were delivered across the four Workshops; indicating that the Workshops have been delivered with extremely high fidelity to the model. The presenter's adherence to the Workshop model also validates the previous findings related to knowledge gained as a result of attending the Workshops and attendee's perception that they have learned how to implement evidence-based information in caring for their children with ASD.

PHASE 2: PARENT PERCEPTIONS OF THE BENEFITS OF A PARENT PSYCHOEDUCATION PROGRAM FOR THE ASD POPULATION

Specific Aims and Hypotheses

Aim 3

Determine whether workshop attendance leads to a change in implementation of evidence-based skills in the attendee's natural environment, for their child or children.

Hypothesis 3A. Parents will report that Workshop attendance leads to a change in implementation of evidence-based skills in their natural environments, as measured by parents' responses to implementation questions in the in-depth interviews.

Hypothesis 3B. Parents will report that Workshop attendance leads to a change in their confidence in applying evidence-based skills in their natural environments, as measured by parents' responses to questions related to their confidence applying information at home with their children in the in-depth interviews.

Hypothesis 3C. Parents will be able to detail the barriers they face that are limiting the application of evidence-based skills in their natural environments, as measured by parents' responses to questions regarding the barriers they face when attempting to apply evidence-based skills at home in the in-depth interviews.

Aim 4

Determine whether workshop attendance leads to a change in parents' feelings of connectedness and social support within the ASD community.

Hypothesis 4A. Parents will report that Workshop attendance leads to a change in their feelings of social support among other parents and caregivers and create an informal support network amongst peers, as measured by parents' responses to questions regarding social support in the in-depth interviews.

Hypothesis 4B. Parents will report that Workshop attendance leads to a change in their feelings of connectedness to community-based providers, as measured by parents' responses to questions regarding their connectedness to providers in the in-depth interviews.

Hypothesis 4C. Parents will report that Workshop attendance leads to a change in self-efficacy in their ability to connect to and navigate the system of care for their child with ASD, as measured by parents' responses to questions regarding self-efficacy in the in-depth interviews.

Hypothesis 4D. Parents will be able to describe barriers to accessing the system of care for their child with ASD, as measured by parents' responses to questions regarding the barriers they face when attempting to access the system of care in the in-depth interviews.

Methods

Participants

This study recruited volunteers from the attendees of the Community Education Workshops to complete the in-depth interviews. Researchers estimated completing 10 interviews. Participants comprised all females, but were representative of the diverse races, ethnicities, and socioeconomic classes that attended the Workshops. The researchers used a purposive sampling technique to ensure that a representative sample of attendees completed the in-depth interviews, to gain access to relevant information from a diverse sample, and to ensure researchers have access to the opinions of parents who can address the benefits of the Workshops adequately (Tolley, Ulin, Mack, Robinson, Succop, 2016; Cresswell, 2014). Attendees included parents and caregivers of individuals with ASD. Participation in this study was not mandatory for attendance at the Community Education Workshops.

Materials

Demographics Questionnaire. General demographics information of the individual was collected, including age, race, ethnicity, city and county of residence/service. Information regarding the number of workshops attended was also collected. See Appendix H for the demographics questionnaire for the In-Depth Interviews.

Semi-Structured In-Depth Interview. A 30-45 minute semi-structured interview was administered over the phone to parents who volunteer to share their thoughts on the CEWs. See Appendix I for the complete In-Depth Interview guide.

Procedure

An announcement was made at the end of each CEW asking for parent volunteers to complete the Semi-Structured In-Depth Interview. Interested parents provided their name, email, and phone number to be contacted by study personnel. The researcher then reached out to parents via phone and email to schedule an interview time. Once an interview time was scheduled, the parent was sent an electronic link to the demographics questionnaire in Qualtrics (Qualtrics, Provo, UT). After completing informed consent in the Qualtrics system, participants completed the 16 question demographic survey, which took approximately 10 minutes. Once the demographics questionnaire was completed, a researcher called the participant at the predetermined time to complete the in-depth interview.

Interviews were recorded using a personal recording device and recordings were sent to a transcription service to be transcribed into usable text formats. All transcripts were deidentified to protect respondent anonymity. Transcripts were then uploaded into NVivo for coding (Version 12, QSR International, 2018).

Coding Methodology

Qualitative analysis for the in-depth interviews was completed using NVivo 12. All completed interview transcripts were uploaded to NVivo and labelled with their appropriate naming conventions. All qualitative coding for Phase 2 was completed using the Grounded Theory approach and a Constant Comparative method (Tolley, Ulin, Mack, Robinson, Succop, 2016; Cresswell, 2014). An initial list of broad codes was created based on themes that were expected to emerge from the interviews as well as themes from the qualitative coding process included in the program evaluation from Phase 1 of this study. Three members of the research team collaborated for this phase of qualitative analysis. To ensure consistent coding and summarizing across team members, the team coded the first transcript together and discussed possible codes until consensus was reached.

Team members then coded the remaining transcripts individually. Upon completion of all coding, the lead researcher coded 20% of each transcript to determine if coding agreement was still met. Instances of discrepancy were noted and discussed among the coding team during a follow-up coding meeting. Agreement after the first round of coding from the validity checks was 83%. Finally, the coding team further collapsed codes and removed codes with zero or one reference and came to consensus about instances of discrepant coding.

Results

Participant Characteristics

Nine parents completed the semi-structured in-depth interviews to assess the impact that the Community Education Workshops had on their parenting and ability to access the system of care for their children with ASD. All 9 parents were mothers, with a mean age of 40.0 years (SD = 7.12 years) and ranged from 31 to 52 years old. Four parents (44.4%) were African American, 3 (33.3%) were Caucasian (44.4%), and 2 reported their race as other (22.2%). In addition, one parent (11.1%) reported their ethnicity to be Hispanic. Four parents (44.4%) were from Jefferson County, three (33.3%) from Shelby County, one (11.1%) from Tuscaloosa County, and one (11.1%) from St. Clair county.

Of the nine parents, one (11.1%) reported being single, four (44.4%) were married, one (11.1%) was separated, and three (33.3%) were divorced. One parent (11.1%) reported completing some college, one (11.1%) completed an Associate's Degree, four (44.4%) completed a Bachelor's degree, and three (33.3%) completed a Master's degree. Regarding household income, two parents (22.2%) reported an income between \$10,000 and \$19,999, two parents (22.2%) reported an income between \$20,000 and \$29,999, one parent (11.1%) reported an income between \$40,000 and \$49,999, one parent (11.1%) reported an income between \$70,000 and \$79,999, two parents (22.2%) reported an income between \$90,000 and \$99,999, and one parent (11.1%) reported an income between \$100,000 and \$149,999.

In regards to their children, all nine currently had an ASD diagnosis. The parents reported a mean age of 7.78 years (SD = 3.70), with a range of 4 to 16 years. Six (66.6%) of the children with ASD were male and three (33.3%) were female. Five parents (55.5%) reported their child had private insurance while four (44.4%) reported that their child had public insurance. Parents also reported which Workshops they had attended over the last year. For a complete breakdown of monthly attendance, see Table 6, and for a breakdown of which Workshop each parent from interviews attended, see Table 7.

Table 6

Community Education Workshop Attendance for Parents Who Completed the Semi-Structured, In-Depth Interviews

Month & Year	Topic	Parents Attended
March 2019	Toilet Training & ASD	5
April 2019	Navigating the School System	1
May 2019	Into the Community	2
June 2019	Communication & ASD	1
July 2019	Challenging Behaviors	3
August 2019	Activities of Daily Living	4
September 2019*	Sleep & ASD	4
November 2019*	Co-Occurring Disorders	3
January 2020*	Challenging Behaviors	8
February 2020*	Long Term Planning	5

*Denotes Workshops that were also included in the program evaluation study

Six parents were lost to attrition from the time they signed up to participate in the interviews to the time that interviews were conducted. Parents that were lost to attrition either did not respond to attempts to contact them or responded that they no longer had the time to participate in the interview due to the increase in demands on their daily life of caring for their child during the COVID-19 pandemic.

Table 7

Individual Parent Attendance of the Community Education Workshops for Parents Who Completed the Semi-Structured, In-Depth Interviews

Month & Year	Topic	Parent 1	Parent 2	Parent 3	Parent 4	Parent 5	Parent 6	Parent 7	Parent 8	Parent 9
March 2019	Toilet Training & ASD	X				X		X	X	X
April 2019	Navigating the School System									X
May 2019	Into the Community						X			X
June 2019	Communication & ASD									X
July 2019	Challenging Behaviors			X			X			X
August 2019	Activities of Daily Living			X		X	X			X
Sep. 2019*	Sleep & ASD			X		X			X	X
Nov. 2019*	Co-Occurring Disorders			X		X	X			
Jan. 2020*	Challenging Behaviors	X	X		X	X	X	X	X	X
Feb. 2020*	Long Term Planning		X			X	X		X	X

*Denotes Workshops that were also included in the program evaluation study

Aim 3

Hypothesis 3A. Parents overwhelmingly reported that they learned ASD-specific information and were able to implement the information that they learned at home with their children. First, it was important to assess whether parents believed they were learning information related to ASD generally from the Workshops, including information related to an ASD diagnosis and care. Eight of the nine parents reported they did learn general autism information as a result of attending the Workshops, while the one parent who reported that they did not learn general autism information noted it was due to their son's age and that they had been living with and learning about his diagnosis for a long time. This mother noted, "general autism not so much. Like I said, he's 16, so we've been dealing with this for about 16 years. So you know, general knowledge not so much. We've been around it a long time so you know … we're in a different season right now" (Parent 1). Parents also provided key insight into the information they have learned and how they have applied it to their children.

> "Yes. I do feel like my knowledge has changed because I have been equipped on so many different levels of understanding from the workshops alone that I am able to go out and do research if I need to and have the right terminology and the right capacity to think about the things that I have to think about that pertains to what is relevant that has to do with my child. So that for me, that alone is the most powerful thing." (Parent 1)

> “It prepares me to make a decision when a professional or somebody speaks with me. I'm able to speak with them and understand based off of the information I have already been prepared with. I’m able to understand instead of just starting new and fresh with a cloudy understanding of what is going on. The Workshops prepare me to understand going forward when we have to deal with other professionals.” (Parent 2)

> “As educated as I have been on autism and all the research that I have done, there is still so much that I don’t know. I feel like regardless of what knowledge base you enter with, if you come in with the attitude of wanting to learn something, you're going to learn something new each time.” (Parent 3)

> “Well, I didn’t know much at all and one thing that I really took from one of the presentations was … that it’s a neurological disorder. I never thought about it in that way because I was just learning and I was just researching, but learning that it was a neurological disorder seemed to make a difference for me. So this is not something we’re going to be able to fix. We need to learn how to work with it and work around it. That was really what helped me to get focused.” (Parent 7)

All nine parents also reported learning specific evidence-based intervention information from the Workshops. Topics covered by the parents in their interviews included task analysis, the use of timers and picture symbols, and planning for community based outings. Their experiences are also summarized in the quotes below:

> “Timing. You know, using a timer. My child, she struggles with transitioning. So let's say if she's looking at her tablet, instead of just coming up to her, taking it or saying, hey put that away, anything that she's doing it's almost like, okay you have five more minutes or you have two more minutes.” (Parent 4).

> “Activities of daily living definitely was a help as far as how to put together the schedule where you stop and you think through every step of a particular process like brushing your teeth or washing your face or washing your hands. It’s not like just wash your hands, turn the water on, it’s stopping and thinking those things through and putting them into steps. This really made a big difference.” (Parent 7)

Having established that parents believe they are learning both autism-general and intervention-specific knowledge, they also reported that they increased their ability to implement this information at home with their children in all nine of the interviews. The ability for parents to learn information and apply it with their children at home is the ultimate goal of the Community Education Workshops. Parents reported using skills learned in the Workshops to apply to different scenarios with their children, such as using task analysis throughout their day, as well as implementing information to create a long-term care plan for their child.

> “So then we in turn developed a relationship with [the Presenter] there. And she is now currently our lawyer and helping us with our estate planning. So if we hadn’t

> attended that workshop, none of this would have been in the works and we would not be getting our son prepared for the future." (Parent 1)

> "I would say that at this point it's definitely been more helpful in how my husband and I give instructions to the kids because even if we don't have a visual schedule, we have now started, without thinking about, it doing task analysis and breaking it down to the point that we are acting, giving one set of directions as the whole task analysis visual schedule would look. So if you're out in public, you may not have the opportunity to have a binder with all your visual schedules, or if the routine is something totally different or thrown off and you don't have a visual schedule for that, but if you are verbally giving instructions or telling the child what to expect like a verbal social story, then having that knowledge of task analysis and breaking each task down further has helped make our instruction as a parent more effective for a broad variety of situations." (Parent 3)

Hypothesis 3B. All nine parents discussed the ways in which the Workshops have had an impact on their confidence and competence in caring for and planning for their child with ASD. Parent 1 again discussed that due to her son's age, the Workshops have not had an impact on her parenting style or the way in which she parents her son, but that they have impacted the way she plans for her son's future, particularly in regards to long-term special needs planning. She also noted how the RAN's decision to partner with a community-provider impacts her confidence in their ability to help her son.

> “You know, like I said, he’s 16, older…I feel better knowing that we are progressing and that we do have a relationship with a lawyer now. And she is wonderful and if there is anything that I have questions about, I feel comfortable calling and asking her. Coming into a new environment, you have no idea who is good, who’s not. And so I figured that if RAN felt good enough to have these people speak, then they must be really good in what they do. So I felt comfortable using them and going forth with that. I feel a lot better.” (Parent 1)

The parents of younger children made note of the ways in which the Workshops have reinforced some of their parenting beliefs while also improving their confidence in their ability to care for their children with ASD. The ability to reinforce previously held beliefs was noted several times and is an important aspect of increasing parent confidence because it shows parents that they are already successfully caring for their children. This gives parents the confidence to continue trying intervention strategies at home, because they know they have been successful in the past and can continue to be successful with new techniques.

> “I think that for the things that I was more confident about before attending, I had that confidence reinforced. So if there were things that I was like ‘oh well, I’m feeling okay about this, I know this particular thing,’ once I left, I felt like oh wow, I really was doing what I needed to be doing.” (Parent 3)

The Workshops have been able to show parents they are competent caregivers and provide supportive information and presenters in order to improve their abilities and confidence to care for their children. The concepts of empowerment and small wins were also identified in two interviews, further demonstrating the confidence the Workshop instills in the parents that attend and the ability for the Workshops, through the structure and presenters, to positively impact these family's lives.

> "I think I felt like I was actually doing something. I guess it sounds silly but being empowered. I was going- I was learning. I'm trying to take steps to help the situation." (Parent 5)

> "Every time we are able to make a step in making his quality of life better and life as a family better, that makes me feel a little bit more confident, not quite so inept. Since I'm still trying to figure this out because he's my first and only child. Yeah, so I mean every time we have those small little winning days that makes me happy for us." (Parent 8)

Another concept that arose within the broad theme of increasing confidence was that parents realized they were not in this alone. Talking to other parents gave them the opportunity to hear success stories from others and see that they can also succeed and that they are not the only parents to have gone through the challenges of raising a child with autism.

> "You know sometimes you have questions when you find out that you have this special kid. You have many questions. And you think you are the only one. And to find out there's a lot of parents like me and to find out even though it's something that can happen to anybody, like if you are poor, you are rich, it doesn't matter. It can happen to you. You know when you have the information - and I've been learning a lot - it's more confident for me." (Parent 6)

> "Each time I come and talk with the presenters and talk with other people that are there, it strengthens me. There are times when you do feel alone. But I think that the workshops have given me confidence. Like, hey, you're not the only one out here dealing with this and you're going to be okay, you're going to get through it. It's going to get better. You know, you keep trying, you keep pushing because you don't really have anything else to do. You can't give up." (Parent 4)

Hypothesis 3C. Despite each of the parents previously noting their ability to learn information from the Workshops, apply that information at home with their child, and their increased sense of self-efficacy, seven of the nine parents still identified barriers they have faced when attempting to implement the evidence-based knowledge and skills learned from the Workshops with their children. It is important to note here that these parents did not report systematic barriers that are limiting their ability to apply the things learned, but rather individual and child specific characteristics that have limited implementation ability. Four parents reported that they have faced challenges regarding their child’s interest level, such as their child losing interest after a few minutes or their child not being interested in using different visuals or communication techniques.

> “At first he wasn’t really interested, so I had to make it fun a game and once we did that he started to open up. We both were able to successfully do it, as far as the schedule goes.” (Parent 2)

Two parents reported barriers related to their own ability to implement the information learned from the Workshops. One parent noted they struggled not being able to consult with a professional after leaving the Workshop and another noted they struggled with their own consistently implementing the skills and techniques at home.

> “I think the biggest barrier is just having someone to consult with after the fact and thinking about okay, am I doing this right? Because I feel like it looks good. When you're in the meeting I feel encouraged, but then coming home and trying to implement it, I guess daily life gets in the way, and it gets difficult.” (Parent 5)

> “I would say the consistency of it. Just being consistent with it and figuring it out. Sometimes I would start it and do it maybe, one or two, three minutes and then kind of trail off. But in my mind, I'm like, okay, I know I've got to stay consistent with it. So it's something that I've been working on.” (Parent 9)

While barriers still exist for many families, they reported that the Workshops prepare them to implement the information successfully. The child and parent specific barriers mentioned in these interviews can be addressed through further consultation with professionals and interventions can be utilized at home. These barriers also reinforced the previously mentioned need for a more advanced sequel or more personalized follow-up after completing the Workshops.

Aim 4

Hypothesis 4A. Seven of the nine parents interviewed reported feeling a stronger sense of social support among other parents within the ASD community as a result of attending the Community Education Workshops. Parents consistently reported feeling a sense of community and ease related to the idea that they are not the only one going through this and that they are not alone. Several parents also brought up the idea that they feel a sense of an informal support group developing from the Workshops. One parent reported that she has started a small group of mothers that also attend the Workshops and this support system has been vital for her caring for her son with ASD. She reported this small group would meet in person and socialize while letting their children spend time together. She also reported that these connections have been very helpful during the COVID-19 pandemic, as she already had a well-established support group to talk to and discuss raising her son during this time.

"I think that's part of it too. There's an element of support group that comes from these Workshops. They're very informative but there's also this realization that you are not alone, that other parents are experiencing the same things that you are and that there are professionals out there that understand what you're going through as well." (Parent 3)

"I think that I've learned very quickly that it's all about networking and connection and having resources and whether it be someone who's simply there to be a cheerleader or someone who has a particular area of expertise that shares some knowledge with you. We're very much reliant on everyone in the autism community. You have to be. There's a connectional nature about it that's kind of required for survival." (Parent 3)

"I feel like at the Workshop, especially because we do have those opportunities to workshop the case studies together, we're able to share personal experience. There were resources that I was able to give parents that they had not heard of and that they were able to give me that I had not heard of. So I think it kind of gives us some level of empowerment as parents that we are the expert on our child. And sometimes what we might have learned about autism in dealing with our child has helped other parents in working with theirs." (Parent 3)

"Yes. Definitely, so much so that I've started a small group in January and it's still going on, and it was basically an opportunity for parents of kids on the

> spectrum to get together and to socialize and support. Just kind of talk outside away from the kiddos. Now of course with the pandemic, we’ve had to move to email and text messaging because we can’t see each other in person. But that’s been helpful too because we’re all going through similarities, but differences. With the way the kids are home and I work from home, another mom she’s doing some work from home, and the other is not working at all because her work was outside the home. Being able to connect with them has been really beneficial for me. And not just those, there have been others, we didn’t do a small group together but we just had some great conversations and it helped you to feel like okay I can do this, I’m not alone. Others have done this and they’ve made it through, we can too.” (Parent 7)

> “Yes. Absolutely. It definitely has. I always feel so much better when I leave. I'm like, oh, thank God, I'm not the only one, you know? That's one of the main reasons I come, too. Just that helpful networking and speaking with other peers and knowing – and just getting tips from them. How they handle certain situations and – yeah, I learn from that.” (Parent 9)

Of the two parents that did not report feeling a stronger sense of social support among other parents within the ASD community as a result of attending the Community Education Workshops, one had only attended January’s Challenging Behaviors Workshop and responded “No, not yet. I was hoping to do more – but I think the more I attend I think it will, but not from that one specifically” (Parent 5). The other parent who answered no to this question didn't believe there was enough built in time during the Workshops to establish these connections - "No, other than just talking to them while there, I mean I've not exchanged numbers with any of them or anything like that. But I didn't really, there wasn't a whole lot of time I felt for that. Which is fine" (Parent 1).

Hypothesis 4B. All nine parents reported feeling better connected to ASD service providers in the community as a result of attending the Community Education Workshops. Three different areas of improved connection emerged from the parent interviews. The first, and most directly intended aspect of an improved connection to the community-based providers, was the parents who hired and utilized presenters for work with their children after meeting them at the Workshops. Two parents reported using presenters from the Workshops for assistance afterward, including the lawyers that lead the Long-Term Special Needs Planning and the psychologist that led the Challenging Behaviors Workshops.

> "And so then we in turn developed a relationship with [the Presenter] there. And she is now currently our lawyer and helping us with our estate planning. So if we hadn't attended that workshop, none of this would have been in the works and we would not be getting our son prepared for the future." (Parent 1)

> "I learned a lot of information. In fact, I ended up using the person who did the class... I ended up using her for re-testing my daughter." (Parent 4)

Four parents also reported that they have formed connections with the community-based providers who lead the Workshops and would feel comfortable contacting them to utilize their services in the future, but have not yet had to do so. In this same area, two parents also reported feeling better connected to community-based providers that did not lead the Workshops because they were mentioned as additional resources that may be available to them.

> "Because I have been able to speak with them one on one after the workshop or when we are taking a break, I feel like they generally have our best interest at heart and they are approachable. You can ask them anything. I honestly walk away feeling like I met somebody else that I can put in my arsenal of people that I can refer back to for information." (Parent 2)

> "Well, I feel now that I'm more aware that there are so many of them. I wasn't aware of that. I felt like it was such a small little community. And now it just opened that up and there's many more resources. And so yeah, I think it has changed my feelings that there are opportunities, there are resources. And I can connect with them. So it took a little bit of the stigma that you feel when you feel like you're in a small town or something and you think that's all you know. I feel like this has opened up and I feel more comfortable because if I needed something I can definitely see myself going back a provider who talked about that and

> contacting that person. You know just an email or call can help you get something, so it helps me." (Parent 7)

Finally, two parents reported connecting with community-based providers in different ways, which were not originally thought of as possibilities by the Workshop creators. One parent reported bringing the information related to resources and providers back to their pediatrician, who then shares this information with their other patients. Another parent reported connecting with providers that were also attending the Workshop to learn themselves. The structure of the Workshop allowed her to sit at tables with providers and learn what they do in addition to learning about the Workshop's main topic.

> "So I think it's been very helpful in that sense too. I may not be connecting myself or my child with a particular provider, but if I'm able to take that knowledge to a friend or to the pediatrician, there are networks being made from Birmingham to Tuscaloosa because I'm sharing those resources." (Parent 3)

> "So, just being there. You're sitting at a table and you just never know who's going to sit next to you. And I remember being at one and the lady from [a local developmental center] was in the conference. I think she was the director of the center. And I was able to kind of talk to her and hear her experience. And just get advice from her. I connected with her and, yeah, I feel like other teachers in

> different school systems and just being able to relate to them and find out what they do in their classrooms." (Parent 9)

Parents have connected with their community-based providers in various ways. Importantly, the parents feel comfortable utilizing the connections they have made at the Workshops once they leave, with two parents having already reached out to use the presenter's expertise to benefit their children. The parents that have not yet connected with providers outside of the Workshops all noted they feel more comfortable doing so as a result of attending the Workshops and getting to interact with the providers. The Community Education Workshops have served as a bridge between parents and providers in a way that was previously unseen in the local autism community.

Hypothesis 4C. In conjunction with the parents' responses in Hypothesis 4B, seven of the nine parents said they are now more confident in their ability to connect with ASD service providers and the ASD system of care as a result of attending the Community Education Workshops. Many parents that reported they felt more confident in their ability to access the system of care noted the ability for the Workshops to create an environment where they feel comfortable engaging with presenters and how this enables them to feel more confident engaging with providers outside of the Workshops. In addition, the knowledge related to autism they learned at the Workshops, including general terms and intervention specific information, allows them to feel more confident going into meetings and requesting services from providers and their school systems.

> “I think that it’s given me names to ask for referrals if needed. But there were other connections that we now know of at UAB if we need to access further referrals there. But also just the knowledge that you learn in the workshops helps you with the language or knowing what questions to ask, whether it be in the school environment or with your doctor. So even if I haven't had to implement some of those connections yet, it’s still been helpful in preparing for various appointments and meetings that we’ve had to have.” (Parent 3)

> “I’ve tried to keep everything together and keep a list of all the resources and every time somebody’s suggested anything I’ve written it down, whether I thought it might be good or not. Just to have it, because when all of this started and he was diagnosed I had nothing.” (Parent 8)

Hypothesis 4D. Despite their connection to the Regional Autism Network and the Community Education Workshops, all nine parents still reported some form of access barriers that have limited their ability to connect to the ASD system of care for their children. Their reported barriers coincided with the previously reported access barriers from the Demographics forms included in the program evaluation of Phase 1 of this project and included things such as waitlists, insurance and financial limitations, and geographic limitations.

Two parents reported access barriers related to their geographic location. One parent noted that their family relocated and had a hard time finding comparable services to their old location, while another mother noted their county just did not offer as many services as other local counties and she was not sure how to go about addressing this.

> “The first time that I had difficulty accessing something for him is when we moved from Hoover and he was getting everything at school. Then, we moved to Homewood and I was trying to find him a different school to go to. I was very shocked that still –in 2020, if you find a program, the waiting list is a year or two. (Parent 9)

> “It’s like I think about how come some counties, let me give an example – Hoover has a lot of resources for the people that live there, and my county, St. Clair county, has none. I think it’s nothing to do with you, I think it’s the county but I don’t know how to change that.” (Parent 6)

Four parents noted they have faced barriers when accessing services from their school systems for their child with autism. These barriers ranged from initial access with the school system for transition services to IEP meetings and requesting additional therapies or services to be added to their child’s IEP. The issue of funding for special education within the school system was also brought up by multiple parents as a cause of the barriers they faced when trying to access school-based services.

> “Transitioning into different aspects of the school system, like going from ABA therapy into whatever grade they’re supposed to go, because we face a lot of adversities when we are trying to go from ABA to the school system.” (Parent 2)

> “When you’re dealing with a school system that doesn’t have a budget for special education and a child with needs, you end up leaving that school system, so that school system never... It doesn’t ever get better because no one wants to fight. No one wants to... I mean, it's sad because everybody can't just up and move. But that's what happens. A lot of people move from that school system and go somewhere else where they know they can receive what they need. I think that's why a lot of school systems suffer, who don’t have the budget because, you know... They suffer because they don’t have a budget and nobody's staying there to fight for the budget.” (Parent 4)

Two parents also reported facing long waitlists when attempting to access services. This was a commonly reported access issue in previous portions of this project. Waitlists are often a common issue in Alabama, and similar states, because there is a lack of service providers, especially in the rural parts of the state.

> “I guess the biggest barriers are – well I feel like when I find someone they always either have a waitlist or they don’t have any open appointments or they won’t call you back. Those are my biggest barriers in trying to find providers.” (Parent 5)

> "So, I was trying to find him a different school to go to. And I was very shocked that still –in 2020, if you find a program, the waiting list is, like, a year or two. Getting ABA services was difficult. In fact, we're still down on the waiting list and that was the shortest waiting list." (Parent 9)

One parent noted that their financial limitations do not always make it possible to follow methods that were discussed in the Workshops or in therapy. While only one parent noted this in their interview, this is likely a barrier faced by many parents within the ASD community in Alabama, as the state is largely rural and ranks 46th in the country in per capita personal income at $42,334 (Bureau of Economic Analysis, 2019).

> "I think that the main barriers that we have encountered have either been through lack of a resource that could have helped us in implementing a strategy, because there are some tools that we don't have at our disposal. For instance, we don't have an iPad. We don't have unlimited print capability or laminating capability for all the different resources that most people would love to have on a regular basis. There are also various therapeutic tools that we see in all the therapy catalogs that we follow and they're not always achievable monetarily." (Parent 3)

Finally, seven of the nine parents reported what will hopefully be short-term access barriers related to the current COVID-19 pandemic. Since the pandemic closed schools for the remainder of the school year and largely shuttered outpatient therapeutic services, parents have also taken on some roles of their child's teachers and therapists in addition to their existing duties. Parents also reported they were looking forward to our Community Education Workshop on Navigating the School System, which was cancelled due to the pandemic, in order to help them with their upcoming IEP meetings.

> "The other barrier that I would say that we face right now specific to our son is that we feel like there's some co-occurring diagnoses that have yet to be made. Which we're pursuing calling the doctor's right now, but given the pandemic, that's been put on hold." (Parent 3)

> "And still, of course, with the virus going on, that kind of delayed some things, and that was difficult." (Parent 9).

> "Like I said, I do have a lot of support with the school, with her teachers, her resource teacher, speech teacher. I have a behavior person that I do...that I will return with and connect with every other week, just trying to implement some things here at home. Which is different. You know, the whole school thing is different now." (Parent 4)

> "Well I did want to go to the Workshop the next month. So I'm not exactly sure how in depth that one goes. But I feel like that's one of my big ones coming up is

> Navigating the School System. I don’t know if that one would be available to be rescheduled later.” (Parent 8)

While the Workshops have been able to improve access to information and service providers for families of children with ASD, they cannot remove all access barriers that exist. These findings highlight the need for continued collaboration between statewide systems in order to remove barriers to accessing care. Additionally, these results should be used to plan and implement community-based initiatives moving forward.

DISCUSSION

The current study sought to implement and evaluate the Regional Autism Network's Community Education Workshops, which are a psychoeducation program for parents of children with ASD. The study included two major Phases. Phase 1 aimed to complete a program evaluation and assess implementation fidelity of the Community Education Workshops and determine whether they are effective in increasing evidence-based knowledge of ASD symptomology and treatment practices. Phase 2 sought to determine whether workshop attendance lead to an increase in implementation of evidence-based skills in the attendee's natural environment and their confidence in doing so for their child with ASD. Finally, Phase 2 assessed parent perceptions of connectedness to the ASD system of care and social support system.

Phase one included Specific Aims 1 and 2. Aim 1 intended to determine the demographic profile of the attendees of the Community Education Workshops and link their autism-related service receipt for their children to their demographic characteristics. This study determined that the majority of Workshop attendees were mothers, with a school aged child with ASD. The children with ASD for whom their parents attended the workshops were mostly male and racially and ethnically diverse. These children were also almost equally split between having private insurance and public insurance to cover their healthcare costs.

There was no statistically significant difference between the number of ASD-related services urban and rural families were connected to. However, it is likely that the rural families included in the study comprise a subset of rural families that are most well connected to services, as they are already connected to the Community Education Workshops and have the means and ability to drive into the city to attend the program. However, we saw a greater range in the number of services that urban families were connected to than their rural counterparts. Urban children were sometimes connected to fewer services (i.e., zero or one service connection) and sometimes connected to more services (i.e., six or seven) than the range of services a rural child was connected to, which indicates that there are likely still fewer ASD-related services offered in the rural parts of our state.

There was a statistically significant difference in the number of ASD-related services that privately and publicly insured children were currently connected to. As predicted, privately insured children were connected to more ASD-related services than their publicly insured peers. This construct emerged as a better indicator of a child's ability to connect to ASD services than their rural or urban designation. The differences seen here are likely due to insurance reimbursement, Medicaid approved providers, and the relationship between insurance coverage and socioeconomic status. There was no relationship between a child's insurance coverage and their previous connections to ASD service providers, likely due to the young age of the children included in the sample, which would indicate that they have not had an opportunity to progress out of services yet if they are still new to receiving them. In addition, there was a statistically significant difference between the total number of current and past ASD service connections, although this relationship was likely driven by the significant difference in the number of current services received. The group differences seen between the number of ASD service connections by insurance coverage highlight the inequality in service options for children with public insurance and the challenges their parents face when trying to enroll them in therapies and service options that will have long term positive effects on their developmental outcomes.

Children's insurance coverage was significantly associated with their parent's perception of the quality of their connection to the ASD system of care, where parents of children with private insurance were more likely to report they felt well connected to the ASD system of care. In turn, parents of children with public insurance were more likely to report not being well connected to the system of care and facing barriers when trying to access services. Of the parents that did not believe their child was well connected to the ASD system of care, 85% were able to detail the barriers they faced that limited their ability to connect with services. The main barriers that were discussed included financial limitations, geographic limitations, and their ability to access services, including a general lack of services available, an inability to find or access one specific service, and transportation limitations. Each of these issues are also commonly seen in the wider health disparities discussion, with individuals of lower socioeconomic status often unable to access healthcare for similar reasons. These findings emphasize the need to continue to develop a statewide system of care for the ASD community that fights health inequality and creates an infrastructure that can provide care to all individuals regardless of economic ability and geographic location.

Aim 2 sought to complete a program evaluation of the Community Education Workshops. Attendees rated the Workshop presenters very highly on their respective Attendee Feedback forms, with ratings indicating that presenters consistently delivered each learning objective effectively. Only one rating across the 17 learning objectives was deemed to have been delivered in a less than exceptional manner by the attendees. In addition, each of the four Workshops was rated to have the highest level of adherence to the learning objectives, indicating that the attendees believe the presenters were teaching them what they intended to teach. In addition, attendees were asked what they liked best about the Workshops and what could be improved. The most common themes that emerged in regards to what attendees liked best about the Workshops included the content and relevance of the information that was discussed, the format for the Workshop and its corresponding model, and the strength of the presenters and the comfort level the attendees have with them. The majority of responses in relation to what could be improved about the Workshops detailed the need for more content, including more Workshops, longer sessions during the existing Workshops, more examples during the presentations, and improved access including more frequently offered Spanish translations of the Workshop materials. Ratings and responses from attendees indicate that the Workshops are effectively achieving their programmatic goals by providing attendees with knowledgeable and approachable presenters in a format that supports their learning and engagement.

Additionally, scores were significantly different on the pre- and post-knowledge questionnaires, indicating that the presenters were effective in teaching attendees evidence-based knowledge of ASD, associated symptoms, intervention strategies, and available services. Each Workshop saw an increase of evidence-based knowledge from pre- to post-knowledge scores, with the highest increases occurring from the Challenging Behaviors and Long Term Planning Workshops. The scores from the Long Term Planning Workshop may indicate that this is an area where members of the ASD community currently lack knowledge related to the complexities of the legal system and how to properly prepare for their child's long-term care. Scores from this Workshop saw the second highest percentage increase in pre- to post-knowledge scores, but were still the lowest post-score by over 13%. This Workshop also had the lowest pre-knowledge score by over 12%. These scores support previously reported parent data from the AIACC's Rapid Needs Assessment (2018) that parents feel ill equipped to properly plan for their child's long-term care in relation to their ASD diagnosis. As a whole, the significant increase in scores across all the Workshops indicates that this is an effective, low-cost method for improving the evidence-based knowledge of attendees. Educating parents and providers on the pertinent information related to their diagnosis, the legal system, and how to access the system of care is the first step in reducing health disparities and improving health equity for the ASD population.

Finally within this aim, researchers found that the Workshops were delivered with high programmatic fidelity according to the Workshop model, including the use of the didactic, case studies, and action plan, as well as the presenters' ability to facilitate an open and approachable Workshop for attendees, through the evaluation of recordings, feedback forms, and parent interviews. All but one Workshop adequately delivered the six vital components of the Workshop model, while the one that did not simply ran out of time due to the number of questions they fielded throughout the Workshop. The presenters' ability to deliver the Workshop according to the intended model validates the previous findings that attendees believe the Workshops are effective and that they are learning evidence-based knowledge from the presenters. In addition, these findings allow for the Workshops to be reliably reproduced in other settings with high programmatic fidelity in an effort to serve more families within the ASD community.

Phase two included Specific Aims 3 and 4, which sought to determine the impact the Workshops had on parents and their day-to-day parenting of their children with ASD. Aim 3 assessed whether Workshop attendance led to a perceived change in the parents' ability to implement evidence-based skills in their natural environments. All nine parents that participated in the in-depth interviews reported they learned evidence-based information related to Autism Spectrum Disorder as a result of attending the Workshops and that they were then able to apply the information they learned with their child with ASD. Parents were able to detail how they implemented techniques related to daily living skills and behavior modification as well as how they learned some of the complex legal aspects of long-term special needs planning.

As a result of learning and implementing information, all nine parents also reported that their confidence in their ability to care for their child with ASD increased due to their attendance of the Workshops. A theme that many parents brought up within the realm of increased confidence was the way in which the Workshops reinforced their parenting beliefs and some of the techniques they had already used with their children. Several parents noted how seeing that they were already doing some things right made them more confident in their ability to continue to do the right things with their children with ASD. In turn, parents reported being more likely to try new techniques at home because they had confidence in their ability to be successful. Multiple parents also brought up the concept of “small wins,” noting how seeing their little achievements was empowering to them moving forward. Finally, within the aspect of increased confidence, parents’ ability to talk to other parents at the Workshops and see that they were not going through this process alone empowered several of the mothers. Knowing that others have been successful when faced with the same challenges gave them the confidence to more forward and conquer the task at hand.

Despite the parents’ increased knowledge and confidence, seven still reported facing barriers to accessing the system of care for their children with ASD. Interestingly, these parents reported child and self-specific barriers, such as their child’s attention abilities or their own perseverance with tasks, and not systemic barriers; perhaps indicating that the Workshops have served as a community access system for many families and are a starting point for improving health equity within the ASD population in our community.

Aim 4 assessed the impact Workshop attendance had on parents’ sense of social support within the ASD community and on their ability to connect with and access community-based providers. Seven parents reported feeling a stronger sense of social support from their peers after attending the Workshops and several reported communicating with parents outside of the Workshops through text messaging and newly formed parenting groups. Parents again brought up the sense of not being alone and of going through this together when discussing how the Workshop format encourages them to work in small groups and converse with one another throughout the day.

In addition, all nine parents reported feeling more connected to community-based providers as a result of attending the Workshops. Several parents noted forming working relationships with the presenters after their Workshop, as a result of their knowledge and expertise, but also due to their professional and inviting manner. Parents who had not yet utilized Workshop connections for services noted they would be more comfortable doing so in the future as a result of attending. Two concepts were discussed in the interviews that were unplanned results during Workshop development. Parents noted how they were able to connect with other providers that were also in attendance in meaningful ways for them and their children. One parent reported how she connected with a provider that was seated at the same table as her and then utilized the services that her organization offered for her son. Two parents also noted how they have brought information on providers and services back to other families or their pediatrician to share among their network of patients and professionals; truly expanding the reach of the Workshops to families across the state.

As a result of these increased connections, seven parents reported that their confidence in their ability to navigate the system of care for their child with ASD in order to find and access providers has improved. Parents noted they have learned the "language needed" to access certain services and now know who to ask for services. However, parents still noted facing barriers when trying to access the system of care, including geographic limitations and limitations associated with their school systems. Finally, parents reported facing long waitlists after finding the appropriate services for their children.

An additional unanticipated finding from this research was the challenges that parents have faced as a result of the COVID-19 pandemic when caring for their children with ASD. Several parents noted they were looking forward to learning the information provided from the Navigating the School System Workshop that was cancelled due to the pandemic. Parents were excited about accessing this information and learning from an expert in order to best help their children in the future. In addition, parents noted that the system of care was not set up to handle telemedicine for their children with ASD while they were unable to physically attend appointments. While these restrictions were placed on children all over the world at this time, the limitations of the system of care currently in place in Alabama were highlighted and exacerbated in this time. There is not currently a robust system in place to provide telemedicine services for children with ASD in Alabama. Furthermore, insurance companies were previously reluctant to reimburse appropriately for telemedicine, which severely limited the implementation of these programs. As services begin to return to normal in the coming months, providers should still value and implement telemedicine approaches when appropriate and necessary, such as to provide care for rural families, in order to reduce health disparities related to access and ultimately improve health equity for the ASD community.

Limitations

This study has limitations to implementation that are important to consider when assessing the findings. This study was not conducted in an experimental design with a control and experimental group, but rather it was conducted as a program evaluation.

Therefore, findings cannot be separated from other aspects of ASD treatment in attendees' lives. In addition, there is a possible sampling bias to the in-depth interviews. Since we did not offer an incentive for parents to participate, it is possible that the parents who volunteered represented a sample of the ASD community that is more connected to services than the ASD community in general. In addition, these may have been parents whose views about the Workshops were more positive than the general group of attendees. While the findings from these interviews were impactful, they may be an over-representation of the positive beliefs about the Workshops. Also, there were unequal sample sizes between and within Workshops, as parents are not required to attend multiple Workshop sessions and can choose which of the Workshops may be most beneficial for them. Contributing to the unequal sample sizes, some parents do not complete all of the questionnaires, as they may need to leave early or arrive late. Pre- and post- differences from the Workshops were assessed as group averages rather than matched scores, which did not allow researchers to examine if the Workshops are more effective at teaching a certain demographic of attendee more than others.

Future Directions

In the future researchers should incorporate a true experimental design to assess the impact of the Community Education Workshops and psychoeducation programs in the ASD community. Recruiting attendees to participate as a cohort and requiring attendance in a set number of the Workshops would allow researchers to use control and experimental groups and validated measures to assess parental stress, confidence, and social support. Assessing these constructs with psychometric measures will further allow researchers to generalize the findings from this study as well as make reproduction of the program more likely in various settings. Researchers would also like to assess the effect that education level has on parents' receipt of the Workshops. Parents from the in-depth interviews were well educated, but parent education level was not assessed in Phase 1 and should be collected in future research efforts.

Additionally, future programming and research should include enhanced outreach and support for families who speak Spanish, either as their primary language or as their only language. As noted, some Workshops incorporate translated materials, but additional funds would support the RAN in their ability to offer translated materials at each Workshop as well as in person translation. This would further allow families that primarily speak Spanish at home to benefit from the Workshops and reduce the health disparities they face. Incorporating these families' opinions of the Workshops and their experiences will also be vital to improving the program and serving this population within the ASD community.

Finally, researchers should seek to analyze the impact that technology platforms can have on their ability to provide the Workshop to a wider audience. During the COVID-19 pandemic the Workshops were switched to a virtual format and the general structure and model of the Workshop was kept in place. However, research on the efficacy and impact of the virtual format could allow RAN staff to widen the scope of families that are able to access this service, further expanding health equity within the ASD community and the state as a whole.

Public Health Implications

Findings from this study have shown that group-based psychoeducation programs can help support the public health system of care in the community. The ASD system of care in Alabama is often stressed by a lack of providers and its metropolitan centered service system, which can leave rural families struggling to find available services. Alabama’s Maternal and Child Health Bureau reported a lack of access for CSHCN to family-centered, coordinated, ongoing comprehensive care. This project has shown that the Workshops have the ability to provide family-centered, coordinated care for individuals with ASD, addressing a major need within Alabama’s public health system.

In addition, findings from these studies have shown that parents feel more knowledgeable and empowered as a result of attending the Workshops, with an important component of their empowerment resulting from the connections the Workshops provide to community-based providers. Many parents also reported feeling more confident in their ability to find and access the services they need for their children. These findings indicate the Workshops have the ability to bridge gaps in care and serve as entry points for families to access the system of care for the ASD community.

Healthcare Policy Implications

This study was designed in order to translate the findings to the healthcare policy system to help impact meaningful change for the ASD population within Alabama.

Therefore, the study was designed according to Dingfelder and Mandell's (2011) suggestions for translating research to policy, including targeting research towards issues that are most pertinent to the public, enhancing the generalizability of the study by including diverse samples and delivering in their natural settings, invoking stakeholders in the research process, including formal data collection and comprehensive follow-up, and planning for intervention maintenance and connection of families to service providers. This process was achieved through the study design and the use of the two research phases. The Workshops themselves targeted key issues identified from previous research and was held in a community-based setting. The program evaluation phase comprised the formal data collection and the in-depth interviews entailed the follow-up component.

Following the process for translating research to policy, these findings have the ability to function as a knowledge translation resource for researchers and policy makers. The Regional Autism Network's designation as a state sponsored agency requires quarterly meetings between representatives from the organization, service providers from across the state, legislators, and policy makers. These research findings support a state-funded program in their ability to reduce health disparities and improve health equity for families in the ASD community. By incorporating stakeholder perspectives and qualitative analysis of the in-depth interviews, policy makers will be able to easily assess how their funding decisions have impacted the families they serve. In turn, funders and policy makers must continue to support programs that provide evidence-based information to families of individuals with ASD as a proven method of educating and empowering parents and caregivers.

In closing, the Community Education Workshops were designed to reduce health disparities by increasing evidence-based knowledge of attendees, to increase confidence in applying the knowledge with their children, and to provide parents and providers a platform to engage and collaborate to better serve the ASD community. Results from this study suggest that the Community Education Workshops have created an environment where attendees learn vital information for caring for and serving individuals on the autism spectrum. In addition, the Workshops have created an environment that fosters confidence and support within the ASD community and are a place where parents feel heard and understood, as well as where they feel empowered and supported in many ways. The findings also demonstrate the need for more ASD service providers to offer therapies and intervention services to publicly insured individuals on the spectrum as well as provide care that incorporates technology to improve access to care for all families. Psychoeducation programs like the Community Education Workshops have the ability to bridge the gaps in care for families of children with Autism Spectrum Disorder and by doing so, increase health equity for this vulnerable population.

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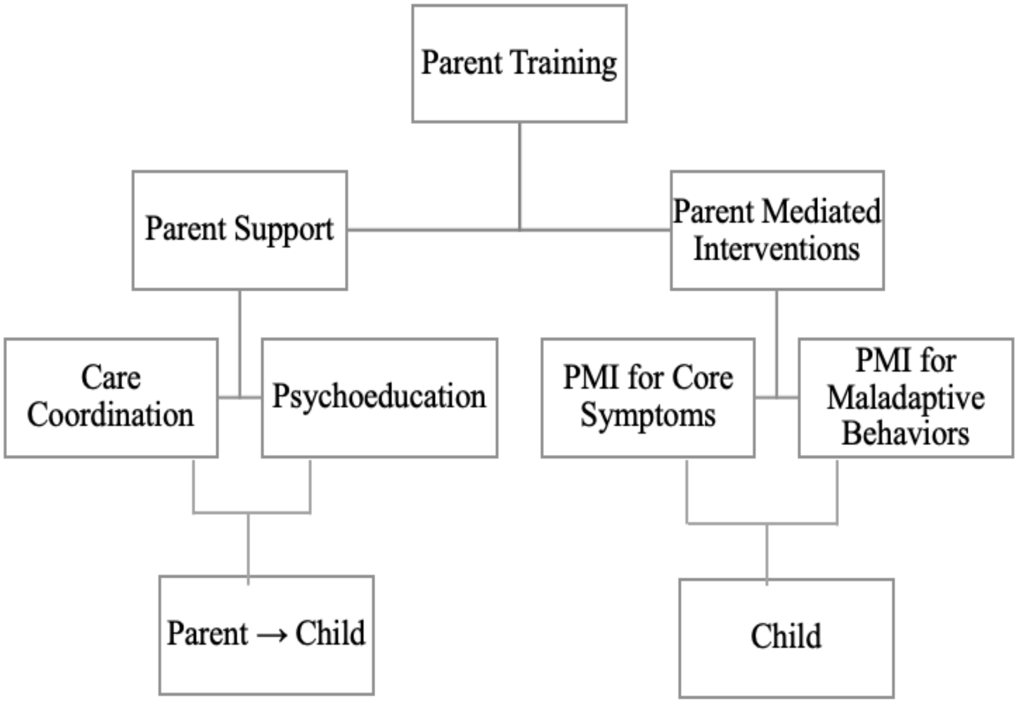
APPENDIX A

BEARSS TAXONOMY FOR PARENT TRAINING PROGRAMS


Parent Training
Parent Support
Parent Mediated Interventions
Care Coordination
Psychoeducation
PMI for Core Symptoms
PMI for Maladaptive Behaviors
Parent → Child
Child

APPENDIX B

AIACC 2018 RAPID NEEDS ASSESSMENT FINDINGS

General Themes	*Specific Topics*
Behavior Management	Applied Behavior Analysis
	Behavior therapy and management
	Coping with tantrums & meltdowns
	"Teen development vs. teen with ASD" behavior
	Transition from early childhood to adolescence
Parenting Support	Parenting skills
	Parenting counseling
	Childcare
	Respite care
Individual with ASD Support	Life Skills
	Socialization
	Transportation
Financial and Future Concerns	Housing
	Financial support for services (i.e., adult activities)
	Future planning
Systems Navigation	“How to get services and support”
	“Just learning how things go”

APPENDIX C

PROVIDER BREAKDOWN OF COMMUNITY EDUCATION WORKSHOPS

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

*No Workshop in February due to overlap with statewide Autism Conference or December due to holiday season

APPENDIX D

PHASE 1 PARENT/CAREGIVER DEMOGRAPHICS FORM

1. What is the age of the individual you are attending the workshop for? _________ years/months (circle one)
2. What is the sex of this individual?
   - ☐ Male
   - ☐ Female
3. What is the race of this individual?
   - ☐ White
   - ☐ African American
   - ☐ Asian
   - ☐ Multiracial
   - ☐ Other, please specify__________________
4. What is the ethnicity of this individual?
   - ☐ Hispanic
   - ☐ Non-Hispanic
5. What is the primary language spoken in the individual's home?

   ____
6. What is your relationship to this individual?
   - ☐ Mother
   - ☐ Father
   - ☐ Guardian
   - ☐ Other, please specify: ________________
7. In what city and county does this individual live?
   - ☐ City: ______________________
   - ☐ County: ___________________
8. Which type of insurance coverage best describes this individual?
   - ☐ Private (Blue Cross/Blue Shield, United, TriCare, etc.)
   - ☐ Public (Medicaid, AllKids)
   - ☐ Uninsured
9. Does this individual currently have a diagnosis of Autism Spectrum Disorder?
   - ☐ Yes
   - ☐ No
10. At what age did this individual receive the diagnosis? _________ years/months (circle one)
    - ☐ If this individual does not have a diagnosis, are they currently on a waitlist for an evaluation?
    - ☐ Yes. How long have they been on the waitlist? _________ years/months (circle one)
    - ☐ No
11. Which type of diagnosis does this individual have? Select all that apply.

- ☐ Educational – completed by the school system
- ☐ Medical/Clinical – completed by a doctor or healthcare provider (psychologist, speech pathologist)
- ☐ Both
- ☐ Neither

12. Does this individual currently have any co-occurring diagnoses other than autism?
    - ☐ Yes, please specify: ____
    - ☐ No

13. Which services is this individual currently receiving or have they received in the past? Check all that apply.

Service	Currently	Previously
Speech/Language therapy		
Occupational therapy		
Physical therapy		
Feeding therapy		
Behavioral Intervention (ABA therapy, Psychologist, etc.)		
Outpatient/Private		
School-Based therapy or Classroom Accommodations		
Home-Based therapy		
Transition services to adulthood (i.e., Vocational Rehabilitation, Supported Employment, etc.)		
Other, please specify:		

14. Which professionals or providers is this individual currently seeing or have they seen in the past?

Professional	Currently	Previously
Medical Doctor/Pediatrician		
Psychologist		
Psychiatrist		
Board Certified Behavioral Analyst		
Therapist (i.e., Speech Pathologist, Occupational Therapist, etc.)		
Other Medical Specialist (i.e., Neurologist, Cardiologist, etc.) Please specify:		

15. Are there any providers you believe this individual still needs to be connected to?
    - ☐ Yes, please specify: ____

☐ No

16. Is this individual currently taking any medication or have they in the past, prescribed or over the counter?
    - ☐ Prescribed: ____
    - ☐ Over the Counter: ____
    - ☐ Past use: ____
    - ☐ Does not take any medication currently.
17. Did this individual receive Early Intervention services (i.e., Speech/Language, Occupational therapy, etc.)
    - ☐ Yes, please specify which services: ____________________________________
    - ☐ No
18. Was this individual ever enrolled in Early Head Start or Head Start?
    - ☐ Yes ☐ No
19. Was this individual ever enrolled in a preschool program not identified as Head Start or Early Head Start?
    - ☐ Yes ☐ No
20. Do you feel that this individual is currently well connected to the services they need?
    - ☐ Yes
    - ☐ No
21. If you answered ‘No’ to Question 20, what barriers do you think are in the way of this individual being well connected (i.e., transportation, etc.)? ______________________
    ____
    ____

APPENDIX E

SAMPLE PRE- AND POST-KNOWLEDGE QUESTIONNAIRES

SLEEP KNOWLEDGE QUIZ (PRE-TRAINING)

1. How many children with Autism Spectrum Disorder (ASD) experience some difficulty with sleep?
    a. One-third
    b. One-half
    c. Two-thirds
    d. All

2. What is the most common sleep disorder in ASD?
    a. Obstructive sleep apnea
    b. Insomnia
    c. Restless leg syndrome
    d. Night terrors

3. Which of the following factors may affect sleep in children with ASD?
    a. Gastrointestinal/stomach issues
    b. Daytime habits
    c. Medications
    d. Difficulty understanding the expectations associated with sleep
    e. All of the above

4. Addressing sleep is so important because it helps with ______________.
    a. Child daytime behaviors
    b. Parent stress
    c. Family well-being
    d. Parent and child sense of competence
    e. All of the above

5. What is the Forbidden Zone?
    a. When all drinks should be avoided to prevent bedwetting
    b. When napping or bedtime should be avoided
    c. McDonald's Drive-Thru
    d. The latest time to allow your child to sleep in the morning

6. Based on what you have learned about challenging behavior, which is most helpful for good sleep habits?
    a. Co-sleeping so you can immediately address when the child wakes up in the middle of the night.
    b. Leaving the television on so the child doesn't get scared of the dark if he wakes up.
    c. Sticking to a routine to help prepare for bedtime.
    d. Make sure s/he gets plenty of exercise and sunshine during the day
    e. Allowing the child to fall asleep on the couch next to you, then carry him to bed once asleep
    f. Both c and d

7. Your child wants a drink of water. S/he usually does this to avoid going to bed. What would be a good strategy to use?
    a. First-Then (First get in bed-Then sip of water)
    b. Use a bedtime pass to get drink of water
    c. Use a timer to limit time out of bed to get water
    d. Use a token board. Child earns a token for every night s/he stays in bed once told good night.
    e. All of the above

SLEEP KNOWLEDGE QUIZ (POST-TRAINING)

1. How many children with Autism Spectrum Disorder (ASD) experience some difficulty with sleep?
   a. One-third
   b. One-half
   c. Two-thirds
   d. All

2. What is the most common sleep disorder in ASD?
   a. Obstructive sleep apnea
   b. Insomnia
   c. Restless leg syndrome
   d. Night terrors

3. Which of the following factors may affect sleep in children with ASD?
   a. Gastrointestinal/stomach issues
   b. Daytime habits
   c. Medications
   d. Difficulty understanding the expectations associated with sleep
   e. All of the above

4. Addressing sleep is so important because it helps with ______________.
   a. Child daytime behaviors
   b. Parent stress
   c. Family well-being
   d. Parent and child sense of competence
   e. All of the above

5. What is the Forbidden Zone?
   a. When all drinks should be avoided to prevent bedwetting
   b. When napping or bedtime should be avoided
   c. McDonald's Drive-Thru
   d. The latest time to allow your child to sleep in the morning

6. Based on what you have learned about challenging behavior, which is most helpful for good sleep habits?
   a. Co-sleeping so you can immediately address when the child wakes up in the middle of the night.
   b. Leaving the television on so the child doesn't get scared of the dark if he wakes up.
   c. Sticking to a routine to help prepare for bedtime.
   d. Make sure s/he gets plenty of exercise and sunshine during the day
   e. Allowing the child to fall asleep on the couch next to you, then carry him to bed once asleep
   f. Both c and d

7. Your child wants a drink of water. S/he usually does this to avoid going to bed. What would be a good strategy to use?
    a. First-Then (First get in bed-Then sip of water)
    b. Use a bedtime pass to get drink of water
    c. Use a timer to limit time out of bed to get water
    d. Use a token board. Child earns a token for every night s/he stays in bed once told good night.
    e. All of the above

APPENDIX F

SAMPLE ATTENDEE FEEDBACK FORM

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**			**Strongly Agree**
1	Understand the **Antecedents, Behaviors, and Consequences** (ABCs) of behavior.	1	2	3	4
2	Learned how to **plan ahead** for including children in different types of settings, activities, and experiences.	1	2	3	4
3	Developed skills to advocate for **inclusion** of families or students/clients in the community.	1	2	3	4
4	Gained awareness of available resources to promote **safety and wellbeing** 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?

APPENDIX G

CEW PRESENTER INFORMATION

CEW Presenter Information

Thank you for agreeing to be a presenter for the UAB Regional Autism Network at one of our monthly Community Education Workshops! These workshops are designed to provide information on evidence-based practices for families and providers of individuals with autism across the lifespan. In order to best serve these families and providers, we have some guidelines and basic information to help you as you prepare your presentation.

General Information:
Location: Community library—(*This location should be updated for each presenter)*
Date: 10:00 am to 1:00 pm, last Monday of every month (subject to change)
Lunch: provided by the UAB RAN for attendees and presenters.
Facilitators: The UAB RAN will arrange for additional professionals within the field to attend the workshop as facilitators. Facilitators will help answer questions during the Case Study and Action Plan portions of the Workshop as well as be available for questions before and after.

Presentation Format:

- Each presentation will follow the predetermined model and include 3 major components:
    - Didactic Information – the didactic information provides general information pertaining to the month's topic and evidence-based information specific to the workshop theme
    - Case Study – the case study should be used to teach parents/providers to identify major components of the topic generally, outside of an example specific to their child.
    - Action Plan – the action plan allows attendees to think through their specific situation and plan ahead/apply the skills discussed to their situations.
- Presenters should incorporate the Case Study and Action Plan into the Didactic session, moving freely from one to the other, rather than completing them sequentially.
- We can provide assistance developing materials for any component of the workshop.

Material Submission and Deadlines:

- All materials should be submitted to the UAB RAN at least **<u>1 month</u>** before your Workshop.
- Materials should be emailed to __________.
- We will print all PowerPoints, case studies, action plans, and additional materials and create folders for attendees.
- Any special instructions about materials should be included at the time of submission.

You will be given access to the UAB RAN CEW Dropbox, which contains materials from past workshops. You can access these materials to help you prepare your presentation. Please do not hesitate to contact us regarding any questions you may have.

Available Tech/AV Supports:

- Laptop
- Projector
- Clicker/Laser pointer
- Access to internet

Below is a list of materials and components that we will require of you as the presenter:

1. **Learning objectives** – Provide 4 – 5 learning objectives for your presentation. These will help you shape your presentation and we will use them to create an Attendee Feedback Form that helps us to evaluate the workshops.
2. **PowerPoint** – Provide a PowerPoint to be used throughout the workshop. This should include your didactic presentation as well as any resources or contact information you would like the attendees to have. You can access past PowerPoints on the UAB RAN CEW Dropbox if you would like.
3. **Case Study** – The case study is a way for attendees to practice applying the information from the didactic to a predetermined situation. The presenter and facilitators can easily answer questions and help attendees work through the case study, which will help them apply the information to the action plan. You can access past Case Studies on the UAB RAN CEW Dropbox if you would like.
4. **Action Plan** – The action plan allows attendees to apply the information from the didactic directly to their situations, at home, in their workplace, or in the community. The action plan should include a thorough step-by-step breakdown for attendees to work through the situation. This will allow them to ask questions to the presenter and facilitators specific to their needs. You can access past Action Plans on the UAB RAN CEW Dropbox if you would like.
5. **Informational Materials** – Any informational materials you reference in your presentation or that you would like families to have should be included. Past presentations have been worksheets to help parents complete the Action Plan or general information about state offered services. Examples of past Informational Materials can also be found on the UAB RAN CEW Dropbox if you would like.
6. **Make and Take Materials** – Make and Take Materials include things such as First/Then Boards, Picture Schedules, etc. If you have anything tangible you would like attendees to leave with, we can prepare them and include them in the folders for attendees. We can also laminate materials if necessary. **All make and take materials must be submitted 1 month prior to the workshop.** Examples of past Make and Take Materials can also be found on the UAB RAN CEW Dropbox if you would like.

APPENDIX H

PHASE 2 DEMOGRAPHICS SURVEY, IN-DEPTH INTERVIEWS

1. Please enter your initials. _______

2. What is your age? _______

3. What is your gender?
    - Male
    - Female
    - Prefer not to say

4. What is your race?
    - White
    - Black or African American
    - American Indian or Alaska Native
    - Asian
    - Native Hawaiian or Pacific Islander
    - Other

5. What is your ethnicity?
    - Hispanic
    - Non-Hispanic

6. In what county do you live? ____________________________

7. What is your marital status?
    - Single
    - Married
    - Separated
    - Divorced
    - Widowed

8. What is the highest level of education you have completed?
    - Less than high school
    - High school or GED
    - Some college
    - 2 year college degree (such as A.A., A.S.)
    - 4 year college degree (such as B.A., B.S.)
    - Master’s degree
    - Doctoral degree
    - Professional degree (such as M.D., J.D.)
9. What is your total household income?
    - Less than $10,000

- $10,000 to $19,999
- $20,000 to $29,999
- $30,000 to $39,999
- $40,000 to $49,999
- $50,000 to $59,999
- $60,000 to $69,999
- $70,000 to $79,999
- $80,000 to $89,999
- $90,000 to $99,999
- $100,000 to $149,999
- Over $150,000

10. Does your child have an Autism diagnosis?
    - Yes
    - No
11. If they do not have a diagnosis, is your child currently on a wait list for a diagnostic evaluation?
    - Yes
    - No

12. What is your relationship to this child?
    - Mother
    - Father
    - Grandparent
    - Other

13. What is the age of your child? _______

14. What is the gender of your child?
    - Male
    - Female

15. Which type of insurance coverage does your child have?
    - Private (Blue Cross/Blue Shield, United, TriCare, etc.)
    - Public (Medicaid, AllKids)
    - Both
    - Uninsured

16. Which of these Workshops have you attended in the last year? Please select all that apply.
    - March - Toilet training
    - April - Navigating the School System
    - May - Into the Community
    - June - Communication
    - July - Challenging Behaviors
    - August - Activities of Daily Living
    - September - Sleep
    - November - ASD & Co-Occurring Disorders
    - January - Challenging Behaviors
    - February - Long Term Planning

APPENDIX I

PHASE 2 IN-DEPTH INTERVIEW GUIDE

1. **Introduction:**

My name is ______ and I am a graduate student working with the UAB Regional Autism Network. I am conducting interviews for a project aimed at determining how UAB RAN's Community Education Workshops has affected your family. We would like to learn about your experiences attending the Workshops and your thoughts regarding their ability to influence your parenting for your child with Autism Spectrum Disorder. We will discuss topics including the workshop structure, the content, what you have learned, how you have applied information and skills to your setting, and various ways applying these things have changed your daily life. Everything you share in this interview will be kept confidential. Responses will be deidentified, and may be presented in various setting without connection to your name. This interview will take approximately 30 - 45 minutes. If you have questions you want to ask about anything we discuss or on other topics, I can assist you after the interview is over.

2. **Interview Topics**:
   - **A. General Info**

     For this first group of questions I want to focus on how you learned about the Workshops and what led you to attend.
     - **i. What led parents to Workshops?**
       1. Please tell me how you first learned of the Workshops.
       2. Please tell me what led you to attend the Workshops.
          - **a. Probe:** Did any aspects of your child's behaviors related to their ASD diagnosis lead you to attend our Workshops?
          - b. **Probe:** Did any aspects of your child's educational experiences lead you to attend the Workshops?
          - c. **Probe:** Did any aspects of your child's therapeutic experiences lead you to attend the Workshops?
   - **B. CEW Quality Improvement**

     For these next few questions I want to focus on your thoughts about the Workshops themselves and how they function as an event.
     - **i. Workshops Structure:** What are your thoughts on the Workshop structure itself, including the PowerPoint/Didactic, the Case Study, and Action Plan?
       1. **Probe**: (If they don't discuss all three components) what about the Case Study/Action Plan?
       2. **Probe**: Do you think these components improve your ability to learn and apply information to your child?
     - **ii. Use of Various Providers as Presenters:** What are your thoughts on using different community-based providers to deliver the Workshops?
       1. **Probe**: Did you feel that having specialist presents for each topic was useful?
       2. **Probe:** Would there have been advantages to have one general presenter instead?
     - **iii. Strengths:** What did you think were the strengths of the Workshops?

    iv. **Weaknesses:** What aspects of the Workshops could be improved?

C. **Knowledge Gain**
    i. **General ASD Knowledge:** Do you think your knowledge of general ASD information has changed as a result of attending the CEWs? If so, how?
        1. **Probe**: Can you give me an example?
        2. **Probe**: Do you feel as if the presenter's expertise in ASD has influenced your ability to learn information?
    ii. **Intervention and Skill Specific Knowledge:** Do you think your knowledge of specific interventions or strategies related to caring for you child with ASD has changed as a result of attending the CEWs? If so, how?
        1. **Probe**: Can you give me an example?
        2. **Probe**: Do you feel as if the presenter's expertise on this specific topic or intervention technique has affected your ability to learn information?

D. **Implementation in Natural Environment/Barriers**
    i. **Implementation:** Have you been able to apply information that you learned at the CEW in your natural environment (at home, in the community, etc.) with your child? If so, how?
        1. **Probe:** What techniques did you learn at the CEWs that you have tried to use with your child?
        2. **Probe:** What was the outcome when you applied this information or these skills with your child?
        3. **Probe:** Did you use the Action Plan you completed during the Workshop to help you implement this at home?
        4. **Probe:** Did you consult with the presenters or RAN staff during the Workshop to help you complete your Action Plan?
        5. **Probe:** Was their helpful to planning and implementation? If so, how?
    ii. **Barriers to Implementation:** Have there been any barriers or challenges you faced when implementing the techniques in your home? If so, what are those barriers?
        1. **Probe:** Have you identified steps you can take to overcome these barriers? If so, what are they?

E. **Parental Gains (does CEW attendance lead to changes in…?)**
    i. **Self-Efficacy:** Have the CEWs changed your confidence in your ability to care for your child with ASD? If so, how?
        1. **Probe:** What about the CEW changed your confidence level?
    ii. **Social Support:** Have the CEWs changed your feelings of social support in regards to caring for your child with ASD? If so, how?
        1. **Probe:** Have you connected with other parents from the Workshop outside of the Workshop itself? If so, how?

        2. **Probe:** Has this affected the way you care for your child? If so, how?
    iii. **Connection to Community-Based Providers:** Have the CEWs changed your feeling of connectedness to community-based providers? If so, How?
        1. **Probe:** Have you utilized these connections to benefit you or your child? If so, how?

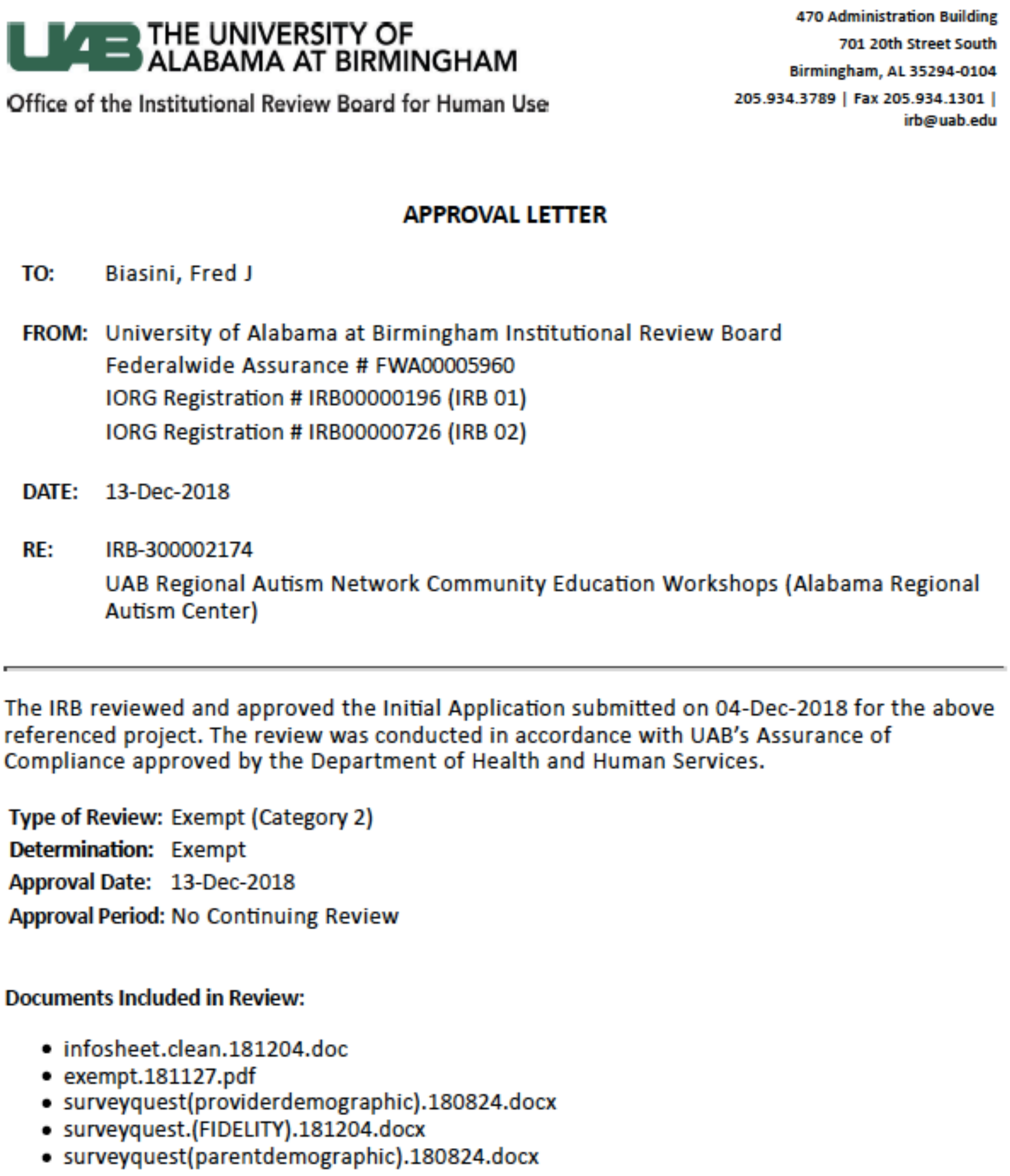
F. **Accessing System of Care (does CEW attendance lead to changes in…?)**
    i. **Confidence Accessing System of Care:** Have the CEWs had an effect on your ability to access the system of care for your child with ASD (e.g., doctors, therapists, school services)? If so, how?
        1. **Probe:** Has having specialized community-based providers as presenters played a role in this change? If so, how?
    ii. **Barriers to Access:** Have you faced any barriers to accessing the system of care? If so, what?
        1. **Probe:** Have you identified steps you can take to overcome these barriers? If so, what are they?

G. **Future Workshop Content:** Are there any topics that you would like future Workshops to cover that have not been covered already? If so, what?
        1. **Probe:** Are there any topics that have been covered that you would like to be repeated or discussed more in depth? If so, what?

H. **Additional Thoughts:** Do you have any additional thoughts relating to the Workshops that you would like to share? If so, what?

APPENDIX J

IRB APPROVAL FORM



THE UNIVERSITY OF
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APPROVAL LETTER

TO: Biasini, Fred J

FROM: University of Alabama at Birmingham Institutional Review Board
Federalwide Assurance # FWA00005960
IORG Registration # IRB00000196 (IRB 01)
IORG Registration # IRB00000726 (IRB 02)

DATE: 13-Dec-2018

RE: IRB-300002174
UAB Regional Autism Network Community Education Workshops (Alabama Regional Autism Center)

The IRB reviewed and approved the Initial Application submitted on 04-Dec-2018 for the above referenced project. The review was conducted in accordance with UAB's Assurance of Compliance approved by the Department of Health and Human Services.

Type of Review: Exempt (Category 2)
Determination: Exempt
Approval Date: 13-Dec-2018
Approval Period: No Continuing Review

Documents Included in Review:

- infosheet.clean.181204.doc
- exempt.181127.pdf
- surveyquest(providerdemographic).180824.docx
- surveyquest.(FIDELITY).181204.docx
- surveyquest(parentdemographic).180824.docx