

# SPECTRUM

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#### Mission Statement

The Autism Society of North Carolina improves the lives of individuals with autism, supports their families, and educates communities.

#### The Spectrum

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#### Work with Us

The Autism Society of North Carolina is always looking for qualified candidates who are passionate about helping individuals on the autism spectrum and their families. ASNC has offices in Asheville, Charlotte, Fayetteville, Greensboro, Greenville, Raleigh, Newport, and Wilmington.

A variety of part- and full-time positions are available. Please visit <a href="https://www.autismsociety-nc.org/careers">www.autismsociety-nc.org/careers</a> to learn more about current ASNC career opportunities. We appreciate referrals; please help us recruit the best talent by sharing the above link.

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# A message from the CEO

It has already been a busy year for the Autism Society of North Carolina. In March, we hosted our first in-person conference since 2019, welcoming individuals and families to

Charlotte for a weekend of learning and connection. We opened a new day program for adults, Ascend, in Asheville (learn more about this program on 14). We enjoyed the Spring Run/Walks in Beaufort, Greenville, and Wilmington, which help people build community while raising funds for local programs. As I write this, summer camps are in full swing at Camp Royall and our Social Recreation Programs in Eastern NC, as are programs for children and adults across the state. This year, the Centers for Disease Control and Prevention (CDC) announced that the prevalence rate for autism is now estimated to be 1 in 36 children, and we are continuing to welcome new people to our community and identify the best ways to serve and support them.

This year will also mark an important change for our organization, as we unveil a new logo featuring the state of North Carolina. As an organization, our commitment is to our entire state; we serve all 100 counties of North Carolina, and using the state's outline reflects that work. We have also heard the feedback from the autistic community that a puzzle piece is not welcoming or inclusive. Our organization is for everyone, so it is important to us to honor that feedback and use a more appropriate logo. You can read more about this change on page 4.

While the logo may change, our mission, vision, and values remain the same. Our vision is to be a trusted, lifelong partner for all people with autism as they build fulfilling lives and for their families as they support their loved one. We know that everyone's journey is unique, but the Autism Society of North Carolina has information and programs available for every stage of that journey. We have created a new online resource, The Autism Journey, which gathers all relevant links for each stage of life, from the early years to adulthood. You can find this new page at *autismsociety-nc.org/journey*. We will continue to add to it, and we always invite you to contact an Autism Resource Specialist to discuss your specific journey.

As I said, it's been a busy year, but it's not too late to join us for an activity before 2024! The fall is a great time to connect with your local Support Group (formerly known as Chapters), attend a webinar or workshop, or speak with an Autism Resource Specialist. I also invite you to join us at one of the Fall Run/Walks for Autism! Our fall events take place in Asheville, Greensboro, and Raleigh, and a good time is guaranteed. Learn more and sign up at runwalkforautism.com.

Thank you, as always, for your support of the Autism Society of North Carolina. We are honored to work with all of you to improve lives, support families, and educate communities.

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Tracy Shuff

Tracey Sheriff, Chief Executive Officer

Board of Directors

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# Our New Logo

The Autism Society of North Carolina is proud to announce a new logo, featuring the state of North Carolina. This new logo represents our commitment to serving individuals, families, and communities across the entire state.

Previously, the logo was a three-dimensional puzzle piece. This logo reflected our ability to provide connections to services and resources and the collaborative relationship between autistic people, their families, professionals, and communities. With its three-dimensional shape, this image showed that there was more than one way to view autism, given that each person's experience is so different.

To ensure that everyone feels included, the Autism Society of North Carolina spends a lot of time listening to autistic individuals and families to truly understand the backgrounds, needs, and preferences of those we serve. We serve an incredibly diverse community, because each individual and family has unique needs. We believe our communities are their best when everyone can participate and everyone's lived experiences are

Autism Society
of North Carolina

considered and honored in decision making.

One important item of feedback that we have heard, particularly from autistic adults, is that the puzzle piece is no longer an appropriate image for our community. Autism is not the puzzle that it was considered to be in the 1960s when the puzzle piece became a widely recognized symbol for autism worldwide. A diagnosis of autism has nothing to do with a person's ability to "fit in" to a community, and there is not a missing piece to be found. Every person is unique, and every person deserves to build their best life.

Because we want to be as inclusive as possible, and because we want to reiterate our commitment to the entire state of North Carolina, our logo is changing from the puzzle piece to the silhouette of the state. We would not want anyone to see a symbol that they may find offensive and feel that they couldn't connect with us. The Autism Society of North Carolina is a lifelong partner, and we want everyone to feel welcomed when they access supports and services through our organization.

Our new logo will be implemented in phases, with changes happening online first at the end of August. Because our primary commitment is to providing services, programs, and resources, we will continue to focus on that work and use a phased approach to update our building and program signage across the state.

Our changing logo follows shifts we have made in the last year related to language and terminology. For many years, organizations recommended using person-first language (person with autism) rather than identity-first language (autistic person). Many in our community prefer identity-

first language because autism is such an important and inherent part of identity. We use both terms, and when we know a preference exists, we use the term preferred by the person being served.

We have also changed how we describe the spectrum and moved away from language related to functioning such as "low- functioning" or high-functioning." We have begun framing the spectrum by support needed. Support needs vary for everyone,

whether they are on the spectrum or not. One person may need little support with academics or work tasks but need a higher level of support for social skills and managing emotions. Another person may need more support with communication but less support for daily living activities. As all individuals work toward their unique goals, the levels of support needed will change, so this approach allows us to stay flexible with describing services and programs.

We want to thank all of the individuals, families, staff, and professionals who have shared the feedback and insights that have led to our more inclusive language and logo. We will continue to listen and adjust to ensure that we are meeting our community's needs. This logo change is exciting because it shows how far we as a community have come. There is no stronger community than the autism community, and we are honored to work together with all of you to improve lives, support families, and educate communities.

# Improving Health for Adults

In January, the Autism Society of North Carolina began offering the HealthMatters Program™ for adults. HealthMatters™ was piloted at the University of Illinois Chicago and aims to improve the health of people with intellectual and developmental disabilities. ASNC's program is facilitated by Felicia Williams Brown, ASNC's Resource and Connections Specialist.

The cohort of adults met via Zoom twice a week for 14 weeks. Classes focused on topics such as the effect of exercise on the body, how to identify sources of good nutrition, and how to make lifestyle changes safely. The group examined their own personal barriers to good health and developed personal exercise and nutrition plans. The group also had a chance to practice new fitness activities,

including dance, tai chi, yoga, kickboxing, and seated aerobics.



"The HealthMatters™ class had a very positive impact on [my daughter]," wrote one parent. "Prior to HealthMatters™, she didn't really have a strong understanding of healthy eating or the importance of exercise in her daily life. It's been a while since the class ended, and she has continued to make healthy choices with regards to food and exercise that she's proud of."

The parent continued: "One of the most important lessons to have come from HealthMatters™ was the importance of self-advocacy. This emphasis on self-advocacy started [my daughter] on a path of speaking up for herself not just at home but also at medical appointments, which has been so wonderful! I cannot overstate how much of an impact this part of the class has had. It really opened up her eyes to feeling like she can advocate for herself and that people will listen when she does."

The next HealthMatters™ class will begin September 25. To register, email Felicia Williams Brown at fwilliams@ autismsociety-nc.org. Class size is limited, but organizers will maintain an active waitlist.





# Whitney Sukonick Named New Clinical Director

The Autism Society of North Carolina is pleased to announce that Whitney Sukonick, MA, LPA, BCBA, has been named as the organization's new Clinical Director, following the

retirement of Dr. Aleck Myers. Sukonick has worked at the Autism Society of North Carolina since 2014 and previously served as the director of LifeLong Interventions, our Applied Behavior Analysis (ABA) program.

"I am thrilled that Whitney Sukonick will lead our Clinical team," said Tracey Sheriff, Chief Executive Officer of the Autism Society of North Carolina. "Whitney was instrumental in building LifeLong Interventions, and we all

benefit from her expertise, enthusiasm, and commitment to the individuals and families we serve."

Sukonick discovered her career path as an undergraduate at the University of North Carolina Wilmington. A psychology major, she knew she wanted to work directly with people but wasn't sure what form that would take until she worked in the research lab of Dr. Carol Pilgrim, a well-known behavior analyst. "Working in Dr. Pilgrim's lab crystallized my vision for what I wanted to do. I discovered behavior analysis and

realized it was a tangible way to help people," said Sukonick. "ABA was less well-known then, but it's an amazing program at UNCW and I was lucky to be there – in the right place, at the right time, with a really great mentor."

After receiving her master's degree and certification in behavior analysis at UNCW, Sukonick completed a clinical internship in pediatric feeding disorders at the Kennedy Krieger Institute in Baltimore. After the internship, she stayed on in a behavior analyst role where she provided a variety of support to the patients with feeding disorders outside of the mealtime context, including building communication skills and tolerating tube changes.

"My time at Kennedy Krieger set the bar really high for me in terms of what I wanted out of a team and out of an organization," said Sukonick. "I worked with a great interdisciplinary team that showed me the power of having a lot of different perspectives at the table. I saw how powerful integrated care can be as a wraparound for the people you're serving and their families. Because Kennedy Krieger is one of three programs in the country that specializes in pediatric feeding disorders, families traveled from all over the world to receive care there. It was a real privilege to help families at one of their most vulnerable points, and to see all the ways I could be part of a support system for them."

In 2013, Sukonick moved back to North Carolina, and the next year, she joined the Autism Society of North Carolina to help build the LifeLong Interventions program with Aleck Myers and Louise Southern. "It was an awesome opportunity to come in with leadership that wanted to build a good program," Sukonick said. "We got to dream big and say, 'this is what we think good ABA looks like,' and then we

figured out how to make it sustainable." Sukonick noted that good ABA involves soliciting ongoing feedback from autistic individuals and their families to continually refine the program's high standards: "We're committed to evaluating the work we do constantly. We learn from lived experience and hold each other accountable, but as an advocacy organization, we also work to disseminate the lessons we learn to the rest of our community and our fellow practitioners."

For Sukonick, it was also an opportunity to work with the kind of collaborative, interdisciplinary team she had seen at her internship. "I am wholly convinced that we have the best clinicians in the state," she said. "Everyone in our department has different educational backgrounds and clinical backgrounds. We build in time to collaborate so that every family we serve has a team of 30 clinicians behind

In addition to working directly with families and expanding LifeLong Interventions so that it now serves Asheville, the Triangle, and Wilmington, Sukonick appreciates that the Autism Society of North Carolina has offered her opportunities to provide training in the community, such as with school systems. "Empowering teachers and school teams with the knowledge of best practice strategies means we can multiply our impact exponentially," she said. "The kind of training we offer wouldn't be possible without

them. That's unmatched anywhere else."

"I am wholly convinced that we have the best clinicians in the state."



clinicians with the right skill sets disseminating that information."

As Sukonick assumes leadership of the Clinical Department, she looks forward to diversifying the department's service lines and addressing disparities in service that exist for autistic adults, people of color, and people in rural areas. "We'll look at all the ways we can support the needs of our community, whether that's directly, with programs like LifeLong Interventions, trainings, and consultations, or by supporting other departments at the Autism Society of North Carolina, such as our Autism Resource Specialists, Support Groups, and direct support professionals," she said. "Our team is nimble enough to adapt and meet families where they are. We know there are many ways to help individuals and families and make them feel like they're less alone in this journey."

Supporting individuals and families will remain paramount to Sukonick: "The best part of this job, without a doubt, is making someone's life a little better, a little easier," she said. "Working with our families has taught me a lot about the parent I want to be, and I'm grateful for all those lessons. I think on a professional and a personal level, it will always be the families that keep me going."

### LifeLong Interventions

# The Autism Society of North Carolina's ABA Program

Applied Behavior Analysis can increase self-advocacy and social communication skills, improve organization, attention and focus across settings, teach self-care and safety skills, and build stronger behavior regulation skills. ASNC's ABA program works to enhance quality of life and overall happiness for clients and families. We want to help every client identify and reach their goals.

We accept ABA clients of any age and skill level.

Our ABA program is available in:

- Apex
- Asheville
- Cary
- Chapel Hill
- Durham
- Raleigh
- Wilmington

Immediate availability in some areas for morning and afternoon clients!



ASNC is an in-network provider for many insurers and for Medicaid. We also accept private pay.

autismsociety-nc.org/clinical



# Applied Behavior Analysis: Misconceptions & Quality Indicators

By Whitney Sukonick, MA, LPA, BCBA, Clinical Director, and Louise Southern, PhD, BCBA, Associate Director



At the Autism Society of North Carolina, we believe that every autistic individual and their family has the right to high quality, person-centered, autism-informed services that recognize and value the individual's neurodiversity.

For individuals and families who pursue applied behavior analysis (ABA), we encourage you to advocate for a provider offering modern ABA. ABA represents a range of systematically implemented strategies developed from the science of learning and behavior. When it is at its best, ABA is person-centered instruction and support with the aim of improving quality of life for the individual.

Like any other field, ABA has evolved in recent decades. And like any other field, some professionals are evolving faster than others. There have been – and are – ongoing challenges with ABA. Some families and autistic individuals have experienced or heard of "ABA" treatments that do not follow modern best practices. This article addresses some misconceptions about ABA, red flags to look out for, and indicators of a quality program.

#### **Common Misconceptions**

#### Misconception:

ABA is only used as an autism intervention.

Behavior analysis is a science that goes far beyond autism intervention, and the origins of ABA were not in autism.

ABA strategies and principles have been demonstrated to be effective with an array of issues, including education, addiction, mental health, gambling, exercise, organizational behavior management, environmental sustainability, memory impairment, physical health, and more.

#### Misconception:

ABA is only for children.

Behavior analysis can be used to support the development of critical skills for learners of any age. Some insurance funders, including Medicaid, are recognizing this, as they now authorize ABA services for adults.

#### Misconception:

ABA is incompatible with other therapies.

ABA is compatible with other treatments, including speech therapy, occupational therapy, and other evidence-based practices. Evidence-based practices in autism such as visual supports, modeling, and naturalistic teaching, can and in many cases should be integrated into an ABA program. One evidence-based approach does not have to be chosen over another.

Providers who insist that individuals and their families only receive ABA treatment and disregard the value of other treatment options should be avoided. If an individual is fortunate enough to have an interdisciplinary team of providers in their corner, clinicians should embrace this as an opportunity for collaboration rather than a roadblock to care.

#### Misconception:

### ABA happens at a table with repetitive learning drills.

Sitting at a table, learning through flash card drills using materials unrelated to the skill they are learning is not high quality, modern ABA practice. Instead, you should see teaching occur through play-based interactions or in the context of functional routines. Quality ABA programs emphasize the most important skills for that person, in the environments that matter, using materials and activities that are most relevant for that person. Behavioral principles and strategies can be applied in schools, at the grocery store, in the workplace, at the coffee shop, at the swimming pool, in the kitchen, and so on. Teaching in the right context — one that makes sense for the skill and for the learner — is an important key to long-term success.

#### Misconception:

### ABA is just about behavior reduction or challenging behavior.

ABA has evolved towards a more client-centered approach that is focused on building the skills that will help the individual become their own best self-advocate, to live with dignity and safely while achieving a quality of life as defined by the individual and their family. When challenging behavior is happening, it is communicating a message to us; it expresses an unmet need. The goal is to teach the individual better ways to get those needs met.

Treatment plans that emphasize compliance are to be avoided. In order to celebrate neurodiversity and to affirm the perspectives and opinions of our autistic clients, it's important that ABA programs emphasize empowerment and self-advocacy. Teaching compliance as a focal point of ABA treatment is not only irresponsible and unethical but can also be dangerous to the individual receiving services and can lead to long term negative outcomes. It's important that we view treatment as an opportunity to teach skills that give members of the autism community more of a voice, with effective ways to express their opinions and preferences. Learning to protest, to say "no," and even to question authority in safe and effective ways is a safety skill that is important in both childhood and adulthood.



On that note, individuals learn best when they feel empowered rather than intimidated. Programs that emphasize only instructor-led goals, activities, and ideas are to be avoided because the autistic individual is not affirmed through that model of teaching, and the outcomes will not be person-centered or as meaningful as those that result from a client-led, individualized approach.

#### Misconception:

Only BCBAs can use behavior analytic strategies.
For autism treatment and support, Board Certified Behavior Analysts (BCBAs) are master's and PhD-level professionals who oversee the intervention program. But BCBAs and the registered behavior technicians (RBTs) that they supervise are not the only people who can apply behavior analytic strategies. Caregivers can use these strategies in their natural routines and interactions with their child. Effective classroom teachers use many tools and strategies that are drawn from the science of behavior analysis.

The time spent in ABA sessions working directly with BCBAs and RBTs is obviously a crucial component of the treatment package. However, your treatment team's primary goal from the onset of services should be to teach not only the individual receiving services but also to collaborate with their primary caregivers and support systems to ensure that the strategies that have been found to be successful in sessions can be carried over and used outside of sessions

#### Misconception:

Everyone needs many hours of ABA each week for it to be effective.

Not all individuals need a high number of treatment hours per week to make progress. In fact, this can often be contraindicated and harmful to progress if the number of sessions prescribed is higher than the actual need. One major red flag when searching for an ABA provider is a blanket dosage recommendation or service hour minimum. High quality providers will first conduct an assessment

and seek to understand the routines and schedules of your family. Then, they will make a recommendation based on need and the stamina/engagement level of the individual. Recommendations should be individually tailored, just like other aspects of treatment planning.

#### **Quality Indicators**

Though ABA services can (and should) look different from person to person, there are several indicators of well done, modern ABA that families and individuals should look for in evaluating the quality of a program. What is quite possibly the most important element of high-quality services is the person-centered nature of the treatment plan, goals, and teaching procedures. When ABA is done well, the clinician takes the time to truly learn about the preferences and personal goals of the individuals they are serving. This starts with the assessment process and can be done by spending time with the individual and the people who are most important to them, including family members and teachers. It should be clear in reading the treatment plan that the clinician has incorporated information provided by the individual receiving services and their family to develop goals that truly matter to the individual.

This person-centered approach should be carried through treatment in intentional ways, such as using child-led play to teach young learners or activities that incorporate interests and preferences for adolescents and adults. It is also important that ABA practitioners strive to be trauma-informed and culturally responsive in their teaching approaches and strategies. High quality, modern ABA upholds the values of the individual and their family at all times.

And of course, in order to provide both person-centered and values-based care, clinicians must acknowledge

neurodiversity as part of their practice and design programs that affirm the unique perspectives and characteristics of each of their autistic clients. This means that clinicians ensure that their primary goal is not to change the person with autism or to promote conformity to neurotypical standards or perspectives. High quality, modern ABA does not promote masking (or hiding characteristics of autism). Instead, it should highlight self-advocacy and empowerment so that autistic individuals learn new skills that get them closer to their individually determined goals.

These elements come together to create treatment sessions that look and feel natural and enjoyable for the individual. ABA sessions will look different from individual to individual based on their age, goals, and treatment setting. However, there is one common thread with high quality ABA programs – the individual receiving services should be happy, relaxed, and engaged with their treatment team. This doesn't mean that the sessions aren't challenging at times as the individual learns new skills. But learning cannot happen through stress, tears, or power struggles.

In essence, ABA treatment programs and all interactions that occur within ABA sessions should uphold various fundamental rights of individuals with autism. These include, but are not limited to: the right to be valued and heard, to express their opinions and interests, to say "no," to protest, and to negotiate. The right to safety and privacy. The right to move one's body to feel calm and relaxed. To explore meaningful vocational and social opportunities. And the right to receive accommodations, supports, and validation.

For more information about high quality ABA, including a list of questions to ask potential ABA providers, please scan the QR code.



### We're Hiring!

Do you know someone who is passionate about helping individuals on the autism spectrum and their families? Let them know that the Autism Society of North Carolina is always looking for qualified candidates to join us as we improve lives.

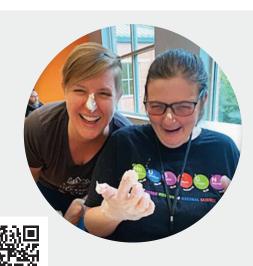
Why work for ASNC? We offer:

- · Extensive training and education
- Full- and part-time positions across the state
- Flexible hours & customized schedules
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We are always looking for candidates or referrals for the following positions:

- Autism Support Professionals
- Employment Support Professionals
- Autism Services Coordinators
- Social Recreation & Camp Counselors
- Behavior Technicians

autismsociety-nc.org/careers



# Lessons Learned from ASNC's Annual Conference



On March 10-11, autistic adults, caregivers of people with autism, and professionals who serve the autism community met in Charlotte for the Autism Society of North Carolina's annual educational conference. This year's theme was "The Autism Experience: Brain, Body, and Behavior," and panels focused on best practices for understanding and improving physical and mental health, medical and behavior issues, and the needs of autistic people. This article presents some of the highlights of the conference:

### James Bedford, M.D. Medical Issues & Autism

Dr. Bedford explained the ways in which autism can make healthcare more difficult, including stigma from providers, lack of access to autism-informed providers, difficult sensory environments, and the many changes that take place in the healthcare environment. He urged individuals and families to find a primary doctor who is willing to learn about autism and who is caring and flexible and to postpone medical care because it seems to difficult to obtain. Visits with a provider can be made easier by adequately preparing the autistic patient in what to expect and by coming to the appointment with data, questions, and goals.

Dr. Bedford reviewed common co-occurring medical conditions for autistic patients, including seizure disorders, asthma, allergies, eczema, gastrointestinal problems, injuries from accidents, dental problems, and infections, as well as co-occurring psychiatric issues for people with autism, including ADHD, anxiety, trauma, insomnia, depression, bipolar disorder, OCD, Tourette's syndrome, psychosis, self-injury, and aggression.

For many autistic people, these medical problems may be missed because of diagnostic overshadowing, or the tendency to attribute any symptom, behavior, or concern to a person's developmental differences, rather than investigating them as separate issues. When this occurs, providers may advocate for a behavioral treatment rather than treating the problem medically (for example, if someone is incontinent due to the side effect of a medication, it's not appropriate and is actually harmful to begin a system of rewards to change behavior). Because these conditions have many overlapping factors, it's important to find providers who are willing to change one variable at a time and consider the data to determine the causes and appropriate treatment for the individual.

# Peter Gerhardt, Ed.D. Shanna Bahry, Ph.D., BCBA-D, LABA/LBA Autism & Better Adult Outcomes

Individuals are adults much longer than they are children, so Dr. Gerhardt and Dr. Bahry advocate planning accordingly. Currently, supports and services drop off dramatically after high school; and studies show that autistic adults struggle as



a result, with data indicating more limited independence than neurotypical peers, lack of post-secondary education, limited employment opportunities, limited social support, absence of specialized support services, all contributing to a reduced quality of life.

Dr. Gerhardt and Dr. Bahry discussed how Applied Behavior Analysis can be adapted to help adults enjoy good outcomes, including choice, control, competence, freedom from harm, and respect. They noted the skills that adults need in today's world are rapidly changing, and that behavior analysts must constantly adapt to ensure they are teaching the most relevant skills. For example, for many years, an adult might have focused on learning how to count money to make a purchase in a store, but with the rapid rise of credit cards and Apple Pay, budgeting and shopping skills need to be taught differently. Certain skills that were once taught may not be necessary at all, or it might not be necessary to learn them at a level of "mastery" if the skill is only used occasionally. Instead, professionals should work with individuals and families to develop individualized, meaningful goals in critical skill areas, such as those related to self-care, problem solving, physical safety, and communication of wants and needs. That work can start when individuals are children; while families may be focused on how certain skills will assist a child in school, behavior analysts should also be thinking long-term about how those very same skills can one day increase independence for the adult.

# Kim Carpenter, Ph.D. Jill Howard, Ph.D. Autism & Anxiety

Dr. Carpenter and Dr. Howard defined anxiety as an emotion associated with anticipated danger, which may be characterized by worry or a sense of uneasiness with accompanying physical symptoms, such as muscle tension, rapid breathing, and an increased heart rate. Sometimes, anxiety is adaptive, as it helps individuals recognize danger and take action, and it is developmentally appropriate at times, such as when infants experience stranger anxiety. However, when it's no longer adaptive or developmentally appropriate, it causes challenges and may meet the criteria of an anxiety disorder or phobia.

Dr. Carpenter and Dr. Howard reviewed common anxiety disorders and phobias, noting that anxiety disorders are more prevalent in children with autism and may present differently in autistic patients. Anxiety is also associated with increased challenges in autistic children, such as sleep problems, gastrointestinal issues, picky eating, irritability, social difficulties, and repetitive behavior. It's thought that autistic individuals may have some precursors to anxiety, including intolerance of uncertainty, emotion dysregulation, and sensory over-responsivity.

Studies show support for the use of cognitive behavioral therapy (CBT) techniques for anxiety disorders. CBT can help an individual to improve emotion identification and identify a plan for calming oneself and regulating emotions. Visuals, role-playing, explaining abstract concepts, and incorporating lessons into play can also help children with autism practice calming themselves in situations that cause anxiety. Seeking a diagnostic assessment and working with a professional mental health provider is recommended.

#### Lisa Morgan, M.Ed., CAS Brenna Maddox, Ph.D. Mental Well-being & Suicide Prevention

Suicide is a leading cause of premature death in autistic people, and autistic individuals are significantly more likely to think about, attempt, and die by suicide than the general population. However, for many years, there were very limited tools to help providers identify and support autistic people in crisis. Morgan and Maddox spoke on risk factors for suicide in the autistic population, including co-occurring psychiatric conditions, lack of social support, unmet support needs, camouflaging or masking, late diagnosis, and autistic burnout. Prevention is complicated by the fact that autistic distress/crisis may not look like neurotypical distress/crisis. Warning signs of suicide in autistic people might include sudden or increased withdrawal; an inability to communicate acute distress; current traumatic event; marked increase in rate and/or severity of self-harm; worsening of anxiety and/or depression; new focus on death-related topics that are not a known special interest; perseverative suicidal thoughts and ruminations; seeking means or making plans for suicide, or suicide rehearsal; statements about lacking a reason for living or feeling no sense of purpose in life; and hopelessness. Morgan and Maddox urged people to consider how they spoke to autistic people in crisis, noting that as of now, there are no clinical guidelines or published studies on effective, autisminformed interventions. Everyone can help by learning more about autism: "Understanding autism and the culture of autistic people, so autistic people do not have to mask/camouflage their autism, is suicide prevention," Morgan said.

#### Jenna Flynn, MSW, LCSW, NADD-DDS Team-Based Care

Flynn, ASNC's Integrated Care Professional, explained the values of team-based care and the way it can help address the variety of health issues discussed at the conference. Historically, all healthcare was delivered by one provider in a community; as more providers specialized, silos sprung up that made it hard for one provider to know what another was doing. There is now a move toward integrated care, or team-based care, as research has shown that no single provider can meet every need a patient has.

Team-based care works by putting the patient at the center, with all professionals, from physicians to counselors to social workers and more, in a circle around that patient. All the professionals would be expected to share information, and all should be working to meet the goals and needs identified by the person at the center. With this approach, clients, families, and the providers themselves benefit from a diversity of knowledge and experience, and clients are more engaged in their care, understand their needs, feel trust in providers, and advocate for themselves.

### Autistic Adults Panel Personal Perspectives & Insights

The conference ended with autistic adults Krysten and Gerald providing insights into their own experiences with autism. Here are some selected quotes:

"It's important to understand and teach your child what their strengths are, and how to seek help when they need



it. Sometimes I need people to drive me, but there's no shame in needing help. I want others to get to know the whole me, not just what's on the outside."

"When I look distracted, it doesn't mean I am distracted. I'm more likely to

be listening when I'm slouching than if I'm worried about sitting up straight. This hurt me at work, when I got dinged on evaluations for slouching and my lack of "business acumen."

"I need people to follow through on what they say — whether it's a schedule or a reward. If you say you're going to do something, do it. If you don't do it, then I hyperfocus on that. Also, it helps if others initiate the plan. I can say if I don't want to do something, but it's too hard to initiate. I also need to know the steps of the plan. I'm going to meltdown if I don't know the next step.

"We grow up hearing something's wrong with us because of autism. That's why it's so important for caregivers and family members to teach the importance of autistic identity. There is nothing wrong with you. There's something wrong with how neurotypical folks treat you."

Save the date for the next conference: March 8 in Raleigh.

# Ascend, Day Program for Adults, Opens in Asheville







The Autism Society of North Carolina's newest day program for adults, Ascend, opened in Asheville in February.

For Michael LePage, Regional Services Director, a day program for the Asheville area is a long-held dream. "Every year, people are graduating and falling off the services cliff," he said. "It's tough without those supports and natural structures. But we can offer a meaningful program. Participants can contribute to the community in a meaningful way and families will have a meaningful alternative for respite."

In the earliest days of the program, participants were already engaged in volunteer projects to help their community. With

the help of local high schoolers Ben LePage and Samantha Harrell, who designed a service project to help people experiencing homelessness in Asheville, Ascend participants prepared care packages of supplies for people in need. The bags included food and drink, toiletries and personal care items, and new socks. LePage and Harrell provided visual instructions, helped to pack the bags, and explained the

importance of these bags to participants: "We're working to make people feel good about themselves," Harrell said.

#### A Meaningful Day: Skill-Building & Community Engagement

After the Ascend participants finished preparing care packages, they played word games and practiced sign language to build communication skills, engaged in an art activity, and then they went to the park to play games.

Ascend Program Director Jordan Hall said this mix of skillbuilding, creative expression, wellness activities, community

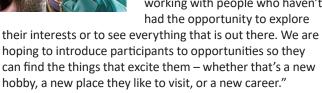
exploration, and volunteerism will be typical for participants, and she emphasizes that the participants will play a major role in identifying the activities and outings that are relevant to their interests and goals.

"We will listen to what our participants want out of this experience," Hall said. "We'll always be asking what they want to do and what they want to learn. Our goal is to present meaningful learning opportunities and fun activities and have a well-rounded program."

While Ascend's program space is vibrant – the walls are already covered with participants' artwork, informational sheets on job searching, and shelves full of games – Hall

> envisions that participants will spend about half their day in that space and the other half of their day in the community, volunteering, enjoying a community excursion, or exercising in a local park.

"One of our main goals is to expand our participants' view of the world," said Hall. "We may be working with people who haven't



#### A Diverse & Committed Staff

When Hall started at the Autism Society of North Carolina's Asheville office in 2021, LePage showed her where the Ascend program would eventually be. Hall says that seeing the space inspired her and motivated her to work towards

leadership in the program. After immersing herself in Asheville's services, Hall was promoted to program director.

"Jordan is absolutely the best person to lead Ascend," LePage said. "She has a real concern for the best outcomes for our participants."

Joining Hall is a staff of committed and caring staff, including several staff members on the autism spectrum.

Andrew Claire said that his neurodiversity provides him with a unique point of view and understanding of Ascend participants.

"A big part is learning to listen to the variety of ways our participants communicate," said Claire. "Everyone expresses themselves differently, and we as staff learn how to respond to what they tell us."

Claire enjoys helping participants work on a variety of skills, from communication to wellness. "We're working on things that will make life easier, both for the participant and their caregiver," he said. "But we're also having a lot of fun – playing games in the park and exploring the Nature Center." Claire is excited about expanding opportunities for participants to volunteer at local non-profits and planting a community garden. "Every participant can choose things they want to work on," he said.

#### **Acknowledging History**

Ascend will be officially dedicated to Sara Handlan and Galene Fraley, who LePage called "the original autism experts in town." Both worked in Asheville's UNC TEACCH program and helped parents, teachers, and professionals understand autism at a time when few resources were available and knowledge was limited.

Catherine Faherty, a colleague of Handlan's and Fraley's, wrote that the women were "architects of a new paradigm of attitudes and practices for professionals in their relationships with autistic people and their families. This attitude, simply put, is the unequivocal understanding that all autistic people are to be respected, that there is a reason for any and all behavior, and that our teaching strategies and responses must be based on a deep listening and learning from the individual with autism."

LePage said that ethos drives the Asheville office and its offerings today. "It's important to recognize our history and all the work in the autism community that came before ours. We're all standing on someone's shoulders, and in Asheville, we especially stand on Sara and Galene's shoulders. These two did so much for our community and we don't want that to be forgotten."

If you're interested in Ascend, scan the QR code to fill out an interest form, and staff will be in touch.





### Recognize Your ASNC Direct Support Professional

Join us in celebrating all support staff during Direct Support Professional Recognition Week, September 10-16.

Do you have an ASNC direct support professional who regularly goes above and beyond? Have they had a significant impact on you, your loved one, your family, and the community?

Recognize their excellence by nominating them for the John and Claudia Roman Direct Service Award. This award honors an Autism Society of North Carolina direct support professional who has demonstrated outstanding dedication to individuals with autism and their families.

Please complete the nomination form at *autismsociety-nc.org/RomanAward* by September 1.

The John and Claudia Roman Direct Service Award was endowed by Lori and Gregg Ireland to honor Christine Roman, the direct support professional who worked with their son, Vinnie. It was named for her parents, John and Claudia Roman.

# Gratitude for Gifts



We just finished another wonderful summer at Camp Royall, with hundreds of overnight campers enjoying fun activities and making new friends, and we're looking forward to an amazing fall of new adult programs, teen and adult retreats, mini camps, and more. So many people work extremely hard to make camp a reality, including facility staff, lifeguards, activity directors, and counselors. We also work hard year-round to raise money for scholarships for campers and programs that support campers, and we're thankful to everyone who gives to make an amazing camp experience possible. We'd especially like to thank two donors who provided key grants this year:

#### Women's Giving Network of Wake County

In December 2022 and February 2023, Camp Royall hosted a special new event – a weekend for moms and their children on the spectrum. These weekends were made possible with a grant from the Women's Giving Network of Wake County

Gift Fund, a component fund of the North Carolina Community Foundation.

"Women's Giving Network of Wake County (WGN) was thrilled to support the Autism Society of North Carolina's first-ever Women's Weekend at Camp Royall," said Sarah

Décarpentrie, WGN Grants Chair. "The WGN members felt that this was an exciting and impactful opportunity to support not only local children with autism through a fully-supported weekend at camp, but this was also an opportunity to support and empower their moms."

While the children enjoyed all of Camp Royall's activities, the mothers had time to relax and recharge on their own. The mothers also had time to network with each other

and attend trainings with staff from the Autism Society of North Carolina.

"My 11-year-old son stated that the weekend was one of his happiest moments," said one mom. "I gained resources, a break from my hectic normal environment, a network

of relatable people to reach out to for support, and my will to parent a child with special needs has been strengthened. Meeting other moms and guardians of special needs children made me more confident as a mom. The experience opened my eyes to my own capabilities and my son's."



#### **Duke Health**

For many campers, their counselor is their favorite part of the Camp Royall experience. Counselors are not required to have any knowledge of or experience with autism before working at Camp Royall; instead, we look for staff members who have a willingness to learn and a lot of enthusiasm. Once hired, counselors complete an on-site intensive professional training. This year, the counselor training was



made possible with a grant from Duke Health's Building Healthy Communities Goodwill Grant Fund.

Training includes presentations on autism, preventing challenging behaviors, communication strategies, and personal care for campers from senior camp leadership, ASNC's Clinical Department, and an occupational therapist. Staffers also hear from panels of autistic adults and parents, who share what Camp Royall means for them and their families.

For many counselors, a summer at Camp Royall is the first step in a career in healthcare or human services, with former counselors now working as doctors, psychologists, teachers, and behavioral therapists. Counselors who receive our training early in their careers have a head start in implementing strategies that improve health outcomes for autistic people, meaning that Duke Health's funding will make an impact beyond Camp Royall.

"I use a lot of Camp's structure when I work with students - the visuals, the schedules," said one counselor working as a speech pathologist. "It's instinctive for me to use those supports because Camp Royall taught me how to use them."

#### **Help Send Kids to Camp**

If you would like to provide life-improving experiences for campers with autism, please consider making a gift at autismsociety-nc.org/donate. You can also contact Kristy White, Chief Development Officer, at kwhite@autismsociety-nc.org or 919-865-5086 to learn more about donating to camp, named scholarships, or helping with fundraising.

#### **Registration for 2024 Programs**

Online registration for the Camp Royall Summer Camp lottery will run from November 1 to January 15. This schedule allows us to notify you about placement and

scholarship awards in early February. We hope this will help you make your summer plans!

Registration for all other 2024 programs will also open on November 1, but that registration closes on December 15, so that families can be notified in early January. After the registration period, you can apply for waitlists.

This year, prices for Camp Royall's programs are increasing. We offer financial assistance so that children and adults of all income levels can participate in camp. If you are unable to pay the full cost, please complete the Scholarship Assistance Application on our registration website. Partial scholarships are awarded according to available funds and are based on income as well as family and financial circumstances. We also offer payment plans over six months.

As always, we are honored to provide a caring, accepting place for campers on the autism spectrum. Please contact Camp Royall staff if you have any questions at 919-542-1033 or camproyall@autismsociety-nc.org. You can also learn more on our website, www.camproyall.org.

#### Supplies

Camp Royall always needs supplies to keep camp operating smoothly. If you are interested in giving supplies to Camp Royall, we have an Amazon wish list: bit.ly/CampRoyallWishlist

#### Spread the Word about Working at Camp

We are looking for hard-working, passionate people who are looking to provide service. Working at Camp Royall is a life-changing experience filled with fun, friendships, and an amazing feeling of accomplishment. We provide training and support to our staff so they are prepared to work with individuals with autism. If you or someone you know is interested in working at Camp Royall, please direct them to our website, www.camproyall.org, to learn more. Full job descriptions are available at







# **Building Partnerships with Police**

At IGNITE, the Autism Society of North Carolina's community centers for young adults, members have focused on building strong relationships with their local police departments. These regular and positive interactions between police and neurodiverse communities have helped to build trust, improve relationships, and increase effective communication. IGNITE members have gotten to know the people who help keep them safe, and officers are learning how to assist those with autism better.

#### Davidson -

Since its founding, IGNITE has cultivated a strong and trusted relationship with the Davidson Police Department. Before the holidays, Davidson Police Department came to IGNITE for a special fraud prevention workshop to teach IGNITE members how to identify, prevent, and protect themselves from scams. The Davidson Police Department has also visited IGNITE for meetand-greets. Members practiced their self-advocacy skills by sharing more information about autism and their own individual characteristics. "Your members are amazing young people," said Police Chief Kimber Davidson of the Davidson Police Department.

This past year, IGNITE members attended a Mecklenburg County community engagement luncheon. Local police departments from around the Charlotte metro area were all in attendance. This was extremely beneficial to our members that live in neighboring communities. Members paired up with an officer and participated in a variety of activities such as kickball, art

projects, and trivia. Mooresville Police Department also hosted a pizza and ice cream event where members were able to share information about themselves and interactions they have had with law enforcement.

#### Raleigh -

In April, IGNITE partnered with the Cary Police Department to challenge fears and work on teamwork at Bond Park's ropes course. Over the course of the day, members and officers shared laughs, pizza, and a great feeling of accomplishment in completing the course. In May, the Cary Police Department came to the IGNITE space. Officer Patrick Fox discussed what to do if you're pulled over by police while driving. Members learned tips on mutually safe and respectful interactions with police if pulled over. One member even got hands-on experience of being behind the wheel as Officer Fox demonstrated what he does when he pulls someone over. The day ended with a friendly game of Mario Kart; thankfully, none of the characters got pulled over!

#### Greensboro -

The safety group has completed activities including filling out autism cards to keep in wallets, making crisis plans, and communicating safety needs. In April, officers from the Greensboro Police Department and members of the Behavioral Health Response Team (BHRT) visited IGNITE Greensboro. The BHRT is specially trained to handle incidents involving people with intellectual and developmental disabilities and those in crisis with care, ensuring that they receive appropriate responses based on their needs.

During the presentation, IGNITE members engaged with the officers, asking them questions and role-playing scenarios involving police encounters. The afternoon ended with laughs and all our members trying to fit in a police car! Afterwards, one parent said, "I wanted to share with you that my son really liked the event. He came home saying how important it was for police officers to get to know special needs people and vice versa."

## Summer Fun in Eastern NC

Social Recreation in Eastern NC serves individuals residing in the Trillium Health Resources service area. Our locations in Newport, Wilmington, and Winterville support individuals and their families with afterschool programs, adult programs, and summer day camp. Program activities are designed to increase social relationships, communication, physical wellness, and independence, all while having fun! Enjoy some recent summer camp highlights from each location:



#### Newport -

Newport campers have been busy exploring their community and having fun on field trips! Some favorite outings have included the aquarium, the children's museum, and the petting zoo. Campers

also loved field trips where they got to be active and play, including the local splash pad, an indoor jungle gym, and a trampoline park.

Campers in Newport also love to escape the summer heat by attending the weekly free children's movie at a local theater. Some campers saw their first movie in a theater this summer! The wonderful summer culminated in the annual talent show, which is always a favorite activity for staff and parents, who love to see the campers shine!



#### Wilmington -

Wilmington campers are exploring the animal kingdom! They welcomed an engagement specialist from the Wildlife Resource Commission, who brought reptiles for campers to touch, hold, and learn about. Campers also toured the training facility of paws4people, a local foundation that trains service

dogs, and had the opportunity to play with puppies and help staff with training.

Members of the Wilmington Fire Department visited to talk to campers about safety in the community, and campers had a blast exploring the fire truck! They also enjoyed visits from the Kona Ice food truck and trips to the pool Many campers said their favorite activity this summer was bowling, and staffers agreed, saying that they'd never seen so many high fives!



#### Winterville-

What's summer without ice cream? Winterville campers loved their field trip to Simply Natural Creamery in Ayden, where they got to pet baby cows, play on a blow-up jump "blob," go down giant slides, and eat local ice cream!

"My favorite field trip was the creamery because I got to eat ice cream with my friends, and jumping on the blob made me feel like a superhero!" said one camper.

Other field trips included the community pool, local parks, the splash pad, a water park, a frozen yogurt parlor, a bowling alley, and a farm to pick strawberries. Campers also enjoyed arts and crafts, gym games, music and motion, and outside water play.

For parents, the highlight is always the annual talent show. One parent said, "I am so excited to watch my kids perform in a talent show where they can pick their own unique talent, we are surrounded by families like ours, and they have staff that just 'get it'! It is my favorite day of the year!"



# New Services for People with I/DD on Medicaid in North Carolina

Medicaid in North Carolina is now offering new services to people with Medicaid who have an intellectual and/or developmental disability (I/DD), including autism, as well as those with mental health issues and substance use disorders. These "1915(i)" services will eventually replace 1915(b)(3) services over the next year. Unlike (b)(3), 1915(i) services are an entitlement. This means that the program does not run out of funds to help people and does not keep waiting lists (like the waiver). The same set of 1915(i)services will be offered across the state, unlike (b)(3) which may be different from place to place.

These 1915(i) services include:

- Community Living and Support
- Community Transition
- Respite
- Supported Employment
- Plus other services to support those with a primary diagnosis of mental illness or substance use disorders.

You or your family member with I/DD must be eligible for Medicaid, as well as be determined to be in need of these types of services, in order to get them. Your Tailored Care Manager or your Care Coordinator at the Local Management Entity Managed Care Organization (LME MCO) will use a standardized assessment tool to determine your eligibility for 1915(i). The North Carolina Department of Health and Human Services will review the assessment and if you or your family member is eligible, your Care manager or Care Coordinator will develop an Individual Support Plan (ISP) or Person Centered Plan (PCP) for those services.

You do not need to meet the same criteria as for the Innovations waiver (a need for institutional level of care) so if you or your family member does not meet Innovations criteria, consider getting assessed for 1915(i) services eligibility. You do have to have a documented diagnosis of Autism Spectrum Disorder and or I/DD as well as financially qualify for Medicaid to be eligible. You can also use 1915(i) services and remain on the waiting list for an Innovations waiver slot. These services will be available through your LME MCO, through Medicaid Direct for those in pre-paid health insurance plans, and through the Specialized Foster Care Plan (when launched).

#### Next steps:

- Contact Medicaid or your local Department of Social Services office to get information on Medicaid eligibility: https://medicaid.ncdhhs.gov/
- Contact your Local Management Entity Managed Care Organization (LME MCO) for information on local, state, and federal funded I/DD services you may be eligible for, including 1915(i) services: https://www.ncdhhs.gov/ providers/lme-mco-directory
- Ask your Tailored Care Management Provider/Care
   Manager to be assessed for 1915(i) services eligibility. If
   you do not have a care manager, contact your LME MCO
   and ask for your Care Coordinator to assess you or your
   family member for 1915(i) services, and if eligible, to
   develop an ISP.
- Review the 1915(i) fact sheet from NC DHHS: https:// medicaid.ncdhhs.gov/north-carolinas-transition-1915b3benefits-1915i/download?attachment

ASNC continues to advocate for increased access to services for people with autism. We are interested in what you have to say about 1915(i) services. Please send any comments or questions on this or other public policy issues to Jennifer Mahan, ASNC Director of Public Policy, at jmahan@autismsociety-nc.org.



### Go Green: Receive the Spectrum electronically!

We send out over 30,000 printed copies of the magazine each year.

If you would like to help us save money on printing and postage – and have early access to the magazine and clickable links – sign up to receive your next Spectrum digitally.

Complete the form: www.autismsociety-nc.org/edelivery



# Achieve a Better Life Experience with the NC ABLE Program





by North Carolina Treasurer Dale R. Folwell, CPA



When I took office as the 28th Treasurer of the State of North Carolina in 2017, the NC ABLE Program was introduced. This unique program allows eligible individuals with disabilities — and those assisting them — to save and invest in taxadvantaged accounts which can fund essential disability services and qualified

expenses without endangering eligibility for means-tested, public benefits such as Medicaid and Supplemental Security Income (SSI).

Over the past six years, through grassroots efforts and working with organizations like the Autism Society of North Carolina, we have been spreading the word about NC ABLE to the population that would benefit most from the program.

Saving money can be difficult when you or a family member is living with a disability. This is only compounded if you rely on state or federal means-tested benefits.

NC ABLE changes everything.

The NC ABLE Program redefines saving for individuals with disabilities. Available to individuals of any age with the occurrence of disability prior to the age of 26, NC ABLE provides a path to financial freedom through checking and investment accounts. Additionally, earnings are tax-free when spent on qualified disability-related expenses like housing, food, special-education programs, healthcare, hearing and vision aids, laptops, financial planning, smart home technology, and even cell phones. Since 2017, the NC ABLE Program has distributed more than \$8.3 million. These are funds that have been used to help account holders Achieve a Better Life Experience.

However, NC ABLE accounts are not just for those people who are receiving means-tested benefits. It also serves as a tool for those who are employed or have benefits through work or family but do not qualify for public benefits. All NC ABLE account holders can save for current or future disability expenses and care.

Up to \$17,000 per year can be contributed into an NC ABLE account, and anyone can make contributions on behalf of the account holder. Through the ABLE-to-Work provision, working account holders can contribute even more than the annual limit and use direct deposit for their paycheck. SSI payments can also be directly deposited into an NC ABLE account.

Overseen by a six-member Board of Trustees, NC ABLE has grown to nearly 2,000 accounts and program assets of more than \$21 million. The age limit for the occurrence of disability is increasing to 46 in 2026 through the ABLE Age Adjustment Act. This means an additional 6 million people, including 1 million veterans, may become eligible for the NC ABLE Program.

I have seen firsthand how important it is to give people with disabilities a vehicle to save and spend to Achieve a Better Life Experience – but there is more work to be done. Many families and eligible individuals have not yet heard about NC ABLE. I encourage you all to join me in raising awareness of this important program, and together we can reach all of the eligible population in North Carolina.

Visit NCABLE.org for more information about the program, eligibility, and benefits.



# Finding Connection & Understanding

By Cindy Martin, Autism Resource Specialist & Person County Support Group Leader

Being an autism parent can be a challenge when you don't have a community of support and understanding. We are in a different phase of life than many of our friends who want to support us, but don't truly understand the joys, tribulations, extreme victories and moments of defeat. It can be a lonely journey, and we sometimes miss out on the invitations to social gatherings and the opportunities to share and belong without judgement.

How do we find folks who walk this journey? Sometimes we stumble across other parents and caregivers, but we need a place to feel safe, a place to find our circle of parents, and a place to meet people who "get it."

Five years ago, I reignited my local Support Group sponsored by the Autism Society of North Carolina. I had no idea when I held that first meeting, inviting families just like my own to come together, what an amazing transformation it would make, not just in my life, but in the lives of others in my community.

At our first gathering, we all had similar stories. Our kids were all on different ends of the spectrum, but we understood one another. We laughed, we cried, and we planned what we wanted to do to create our journey together as a united circle.

We began networking with local businesses and came up with sensory-friendly activities for our kids across the spectrum. We gathered, and they played. They started playing side-by-side, then over time we watched them form connections. We saw them gravitate closer to each other, communicating in whatever ways they could. Soon they were the guests at each other's birthday parties, they began to make requests for events they desired, and they looked forward to our monthly gatherings.

Meanwhile, as parents, we found the connections we had longed for. I will never forget one of our early events. A fellow mom and I had both had tough days with our children at occupational therapies. Both kids had been pushed out of their comfort zone and challenged. They had a hard time, and we had a hard









time as a result. We knew that look of exhaustion and defeat, and we sat beside each other while the kids were engaged. We just held hands and took a deep sigh together. We didn't say a word, but we released our emotions through our presence together. I left there feeling like I had the strength to continue with my night. In an odd sense, it revived me to just be able to sit together and be supported.



There is no judgement in our Support Group. There are no cliques. There are no stares when a child is having a difficult moment. It is a safe place in the best possible way.

If you've been hesitant to reach out to your local Support Group, stop hesitating. If you didn't know they existed, THEY DO! You will find comfort there. You'll find a space where you can ask other parents questions, hear ideas, connect, and fill your cup.

Our Support Group Leaders are trained by the Autism Society of North Carolina, and all activities can be found on the calendar at the Autism Society of North Carolina's website. Once you click on the event, all the details will be provided, and if registration is needed, it will indicate that. You're welcome to attend any event, whether you live in that county or not.

If you're looking for your local support group, please visit *autismsociety-nc.org/supportgroups* and enter your county. Many groups have a private Facebook group, which is a great resource to ask for suggestions for pediatricians, dentists, and other professionals. It's a place to ask advice and opinions and feel 100% comfortable doing so.

If your county doesn't currently have a Support Group Leader, and you'd like to discuss how rewarding that role is, please reach out to Marty Kellogg, Support Groups Coordinator, at mkellogg@ autismsociety-nc.org. There are several options, even for parents who are not seeking to "lead" a group but would like to help organize social activities and build connections. We are always looking to expand our reach and unite families in all 100 counties, and we are happy to provide guidance and support on forming a group.

# Courtney Chavis Named New Support Groups Director



We are pleased to announce that Courtney Chavis is the new Support Groups Director. Chavis has worked at the Autism Society of North Carolina since 2017, most recently as the Lead Triage and Connections Specialist. In that role, she facilitated connections between Autism Resource Specialists

and individuals, families, and organizations. She also chairs ASNC's Diversity Committee and delivers presentations on autism and culturally relevant topics to service providers, families, and other partners. She has supported individuals with intellectual and developmental disabilities, their families, and community members since 1997.

"My journey with Support Groups began when my daughter was four," Chavis said. "I was reaching for a lifeline. I never would have guessed that some years later I would become a leader myself, planning and organizing with other parents."

Chavis said that in her previous role, when triaging calls, she would always encourage people to find their local Support Group. "The value of community means that much to me," she says. "It was lifesaving. Community answers isolation, and we know our lives would not be the same without Support Groups."

Chavis said she looks forward to working with others to strengthen and expand the "front porch" that Support Groups provide, as they often serve as individuals' and families' introduction to ASNC. "My daughters are now older than I was when I had them, and I find that Support Groups still meet me where I am as the mother of adults," she said. "Even just checking in on Facebook and seeing faces I know is enough on a busy day. As my family's needs change, Support Groups are there, and I realize the importance of the 'front porch' embrace our support groups strive to give. We are often the first impression for thousands of families like mine."



# Recursos y Eventos para las Familias Hispanas

El Departamento de Alcance Comunitario y Apoyo Hispano brinda asistencia en español. Ofrecemos recursos y ayuda para preguntas sobre la escuela, el sistema de servicios y terapias. También tenemos Grupos de Apoyo, Campañas de Sensibilización y Entrenamientos en línea. Las personas y sus familias pueden contactar a Mariela Maldonado, Senior de Alcance Comunitario y Apoyo Hispano, al 919-865-5066, o al correo electrónico mmaldonado@autismsociety-nc.org.

#### Sitio web en español

Nuestra Página de Recursos en español ofrece información sobre el autismo, Grupos de Apoyo, Servicios Clínicos, Campamentos de Verano, Artículos traducidos, Vídeos, Narrativas sociales, Kits de Herramientas, así como una lista de los próximos eventos. Visite nuestra página en *autismsociety-nc.org/recursos*.

Además, cualquiera de las páginas del sitio web de ASNC se puede traducir al español al hacer clic en el icono del globo terráqueo ubicado en la esquina superior derecha y seleccionar "Spanish/Español" en el menú.

#### Grupos de Apoyo Hispano

Ofrecemos reuniones en línea y presenciales en varias regiones del estado que son organizados por los facilitadores de los Grupos de Apoyo Hispano, junto con los líderes en cada región. Si le interesa liderar un Grupo de Apoyo en su área, comuníquese con Mariela Maldonado.

#### Consulte el calendario de ASNC para conocer nuestros próximos eventos:

Verano 2023

**Picnics Hispanos** 

Octubre 2023

**Baile Social** 

**Noviembre 2023** 

Celebración de Acción de Gracias

Diciembre 2023

Celebración de Navidad con

Santa Claus

Enero 2024

Desfiles de Reyes Magos

Febrero 2024

Celebración de la Amistad

Abril 2024

Mes de Sensibilización y Aceptación del Autismo

Mayo 2024

Celebración del Día de la Madre

#### Personal Bilingüe de ASNC

Nuestra organización cuenta con varios miembros bilingües entre su personal para ayudar a las familias hispanas:

#### **Denisse Avilez**

Facilitadora en el área del Triángulo

**Xóchilt Garcia** 

Facilitadora en el área de Triad

**Maria Laura Torres** 

Facilitadora en el área de Charlotte

Vanessa Vázquez

Especialista de Recursos Bilingüe en el área de la Triad

Eva Castro

Asistente Administrativa, Oficina central de ASNC

Mariela Maldonado

Senior de Alcance Comunitarios y Apoyo Hispano

#### Becas para la Conferencia Anual

Los Grupos de Apoyo Hispano ofrecen becas para la Conferencia Anual de Autism Society of NC con las actividades de recaudación de fondos como Zumba por el Autismo, Venta de Comida, Encuentros Sociales, entre otros. Cerca de 150 padres hispanos participaron en la conferencia del 2023 en Charlotte con traducción simultánea. La Conferencia del 2024 se llevará a cabo el 8 de marzo en Raleigh por lo que nuevamente se realizaran eventos para recaudar fondos. Contáctenos para participar en estos eventos y las becas.

### Donaciones para el Departamento de Asuntos Hispanos

Las donaciones para el Departamento Hispano ayudan a brindar servicios de traducción, eventos culturales hispanos y becas. Si desea hacer una donación, puede comunicarse con Mariela Maldonado al correo mmaldonado@autismsociety-nc.org.

### Inscríbase en la Carrera/Caminata por el Autismo de Otoño

La Carrera/Caminata por el Autismo es la mejor oportunidad para apoyar a las familias y a nuestra organización. ¡Arme un equipo con su familia y amigos y acompáñenos! La inscripción debe realizarse únicamente en línea, así que asegúrese de visitar el sitio web para inscribirse y recopilar donaciones. Todos los fondos recaudados se destinarán al apoyo de los programas locales de la ASNC.

#### 16 de septiembre—Asheville

WNC Carrera/Caminata por el Autismo wncrunwalkforautism.com

#### 24 de septiembre—Greesboro

Tríada en Greensboro Carrera/Caminata por el Autismo triadrunwalkforautism.com

#### 14 de octubre-Raleigh

Triangle Carrera/Caminata del Triángulo por el Autismo trianglerunwalkforautism.com



## ¡Inicie pronto la Transición a la Adultez!

Es importante iniciar pronto la preparación para la vida adulta de su hijo. Estos son algunos pasos:

- Conozca las capacidades y limitaciones de su hijo en cada año de su crecimiento.
- Participe en el Componente de Transición en la reunión del Programa de Educación Individualizado (IEP, por sus siglas en inglés).
- Hable con el Consejero Escolar sobre las posibilidades universitarias u otros programas de preparación.
- Busque recursos o servicios en su Organización Administrativa del Cuidado (MCO, por sus siglas en inglés).
- Considere la posibilidad de conectarse con los Servicios de Rehabilitación Vocacional, Programa Diurno, Hogares de Residencia, Habilidades Sociales y otros programas de acuerdo con las necesidades.
- Antes de que su hijo cumpla 18 años, solicite la Custodia Legal de su hijo, si es necesario.

ASNC puede ayudarle a prepararse para esta transición. Tenemos muchos seminarios web, blogs y kits de herramientas en nuestro sitio web que puede consultar, y nuestro personal bilingüe puede ofrecerle orientación. Visite *autismsociety-nc.org/recursos* para obtener más información.











# **Fundraisers & Events**

#### Spring Run/Walks for Autism a Great Success!

A big thank you to all the participants, volunteers, and sponsors who made the Spring Run/Walks for Autism a great success! More than 1,800 people stepped out to improve lives at the Run/Walk events in Beaufort, Greenville, and Wilmington, and together, they raised more than \$116,000 to support local programs of the Autism Society of North Carolina. To see photos, please visit our Flickr page: flickr.com/photos/autismsocietync

#### Join us for the Fall Run/Walks - In-Person or Virtually!

Make plans to join us for a Fall Run/Walk for Autism! These events improve the lives of children and adults with autism while providing an amazing feeling of community. For each event, we're offering the opportunity to participate virtually, which is a great option for friends and family across the country who want to be part of your team and help fundraise. Proceeds will support local programs of the Autism Society of North Carolina.

Registration is online only: RunWalkforAutism.com

#### WNC Run/Walk for Autism

September 16 Bill Moore Community Park, Fletcher wncrunwalkforautism.com

Triad Run/Walk for Autism September 23 Jaycee Park, Greensboro triadrunwalkforautism.com

Triangle Run/Walk for Autism October 14 Halifax Mall, Raleigh trianglerunwalkforautism.com



#### **Spring Event Sponsors**

We thank the following sponsors of our spring events; these events would not be possible without them. Please support these businesses and thank them for helping to improve the lives of individuals with autism and their loved ones. Thank You!





#### **Gold Level**











Bridget Harrell & Carr Bender

**Middleton Family** 



#### **Champion Level**







**McCumbee Family** 



**Selby Family** 







#### **Partner Level**

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#### **Advocate Level**

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#### **Friend Level**

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Starbucks
Synergies Consulting Services
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Trent Cadillac Buick
Wirth Chiropractic



#### **Camp Royall Classic Golf Tournament**

On May 1, golfers came out for the Camp Royall Classic at Governors Club in Chapel Hill. The teams enjoyed a beautiful day on the Jack Nicklaus Signature Golf Course and raised more than \$32,000 to send children and adults to Camp Royall. Our thanks to local McDonald's franchise owners Paul, Pat, Rex, and Kelli Willoughby as well as Jeff Woodlief and Premiere Communications and Consulting, a Kane Company, for their continued support of Camp Royall.



#### **Catwalk to Camp**

This year's Catwalk to Camp on March 30 in Raleigh was an incredible night of talent, stories, and generosity. Keynote speaker Carrie Cariello, an author and blogger, shared her experience parenting her autistic son Jack and preparing him for adulthood. Guests enjoyed a favorite Camp Royall tradition – the talent show – with campers showed off an immense array of talent, including dance, music, video production, and baking. The evening included an exciting live auction, with guests showing their support for Camp Royall and its ability to help children and adults build their best life. More than \$250,000 was raised for scholarships to Camp Royall, ensuring an amazing summer of friendships and connections for campers.



#### **Wilmington Gala**

This year's Wilmington Gala, held on May 11, featured speaker Adrian Wood, PhD, entertainment by The Hatch Brothers, and a live auction. In her speech, Wood, who writes the blog Tales of an Educated Debutante, asked the audience to consider what version of themselves they present to the world – a sanitized perfect version, ready for social media, or a messier and more authentic one. Wood spoke about finding greater connection and comfort once she was honest with her following about raising a son with autism. The event raised more than \$130,000 to support the Autism Society of North Carolina's Wilmington programs.



# Thank You!

The Autism Society of North Carolina would like to extend a heartfelt thank you to all of our donors. While we appreciate every gift, we have limited the donation list to Honorarium/Memorial gifts in the interest of space and printing costs. Thank you for your tremendous support.

This list reflects donations received on or between January 1 and June 30, 2023. Please contact Beverly Gill if you have any questions or corrections at 919-865-5056 or bgill@autismsociety-nc.org.

#### **Honorariums**

**ASNC Greenville Goal Getters** 

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**Sherri Brown** 

Maureen & Douglas Murray

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**Nolan Child** 

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Diane Keenan

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# Call on Us!

The Autism Society of North Carolina improves the lives of individuals with autism, supports families affected by autism, and educates communities.

Autism Resource Specialists connect families to resources and provide training to help you become your child's best advocate. As parents of children with autism themselves, they understand your concerns. Find yours: autismsociety-nc.org/ARS

Workshops and conferences with our Autism Resource Specialists or Clinical staff will help you learn more about topics that concern you, such as early intervention, evidence-based practices, IEPs, transitioning to adulthood, and residential options.

autismsociety-nc.org/workshops

**Online resources**, including toolkits, webinars, a blog, and a Staying Safe section, provide opportunities to learn on your own time from your home.

**Support Groups** provide a place for families who face similar challenges to feel welcomed and understood as they offer each other encouragement. Find one near you: *autismsociety-nc.org/supportgroups* 

Skill-building and support services provide children and adults with autism the skills to increase self-sufficiency and participate in the community in a fulfilling way. ASNC's services across the state include skill-building in areas such as communication, socialization, community integration, and personal care; family consultation; respite; and adult day programs. Services are provided through the NC Innovations waiver, state funding, B3, and private pay. autismsociety-nc.org/skillbuilding

**Clinical Services** offer a variety of supports for individuals with autism and their families to increase

independence and empower children and adults. The Autism Society of North Carolina provides Applied Behavior Analysis (ABA) through LifeLong Interventions. LifeLong Interventions is available in Asheville, the Triangle (Raleigh, Durham, and Chapel Hill), and Wilmington. We accept ABA clients of any age and any skill level. We use proven, individualized strategies to meet each person's unique needs. Short-Term Clinical Consultation (STCC) is for children and adults with a diagnosis of autism spectrum disorder. STCC is available throughout all 100 North Carolina counties, as the service is delivered via telehealth. This service typically lasts 3-4 months. Areas addressed may include enhancing structure, promoting independence, building self-advocacy, social communication, or emotional regulation skills, and positive behavior support strategies. **Behavior consultations** provided by our psychologists and Board Certified Behavior Analysts (BCBAs) can help explain why behaviors are occurring, develop comprehensive behavior plans, and coach caregivers on effective strategies.

autismsociety-nc.org/clinical

Employment Supports helps individuals with autism explore their skills and interests, then assists them in finding, keeping, and thriving in a job. Services are funded through the state Division of Vocational Rehabilitation. autismsociety-nc.org/jobservices

**Adult programs** serve individuals ages 16 to 28 with a focus on job readiness, development, placement, and training, as well as financial literacy, daily living

and independence skills, and social skills. The year-round programming includes small group instruction in centers and one-on-one support in the community.

autismsociety-nc.org/adults

IGNITE community centers in Davidson, Raleigh, and Greensboro offer activities, skills training, and educational workshops that foster social, financial, educational, and employment independence for young adults with low support needs. autismsociety-nc.org/ignite

**Camp Royall** is the nation's oldest and largest camp for individuals with autism. Located near Pittsboro, Camp Royall serves all ages and offers yearround programming. *camproyall.org* 

Social Recreation programs provide opportunities for participants to bond over common interests, practice social skills, and try new activities. In Newport, Wilmington, and Winterville, social recreation programs include summer day camp, afterschool programs, and adult programs, with support from Trillium Health Resources. In other areas, summer camp and group activities may be available. Contact us to learn which services are available in your area. autismsociety-nc.org/socialrec

ASNC's public policy efforts aim to advocate for the needs of individuals with autism and their families by maintaining a wide range of ties with the executive and legislative branches of state government. You can get involved and make your voice heard. autismsociety-nc.org/policy

#### www.autismsociety-nc.org

We have regional offices in Asheville, Charlotte, Fayetteville, Greensboro, Greenville, Newport, Raleigh, and Wilmington. Contact our state office to be connected to resources. State Office: 800-442-2762 5121 Kingdom Way, Suite 100, Raleigh, NC 27607 Sign up online to receive our email updates: autismsociety-nc.org/contact-us



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### Join us this fall. Register today!

**Sept. 16**WNC Run/Walk
Fletcher

**Sept. 23**Triad Run/Walk *Greensboro* 

Oct. 14
Triangle Run/Walk
Raleigh

RunWalkforAutism.com

#### Save the Date!



November 25 | Davidson

11th annual car show to benefit IGNITE

americarnalive.com

**Autism Awareness Football Game** 

UNC vs. Appalachian State **September 9** 

Learn more at www.teamautismnc.com

Thank you to our sponsor again this year!

#### Save the Date!



Annual Conference March 8, 2024 Raleigh