

the Spectrum



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CAMP ROYALL
KICKS OFF
AFTERSCHOOL
PROGRAM

ANNUAL CONFERENCE:
PLANNING FOR SUCCESS

WANDERING:
HOW CAN WE KEEP OUR KIDS SAFE?

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MISSION STATEMENT

The Autism Society of North Carolina is committed to providing support and promoting opportunities which enhance the lives of individuals within the autism spectrum and their families.

VISION STATEMENT

The Autism Society of North Carolina strives to create a community where people within the autism spectrum and their families receive respect, services, and support based on individual differences, needs, and preferences.

PRIVACY POLICY

The Autism Society of North Carolina respects the privacy of its members and those who receive our publications. We do not sell or otherwise share our mailing list, email notification list, or any other personal information with other businesses or organizations.

THE SPECTRUM

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Editor: [Amy Seeley](#)

Reader input, photographs, and articles are welcome. Articles can be emailed (preferred), faxed, or mailed.

Please send any correspondence regarding this publication to Amy Seeley, Autism Society of North Carolina, 505 Oberlin Road, Suite 230, Raleigh, NC 27605 or fax 919-743-0208 or email editor@autismsociety-nc.org.

The deadline for submissions for the Summer 2014 Edition is June 3, 2014.



ASNC is also supported by:



MESSAGE FROM THE CEO



What a year of change 2013 was in North Carolina!

Here at the Autism Society of North Carolina, we continued to advocate on behalf of individuals and families affected by autism as the state expanded its use of managed care to deliver Medicaid services, going from 22 Local Management Entities (LMEs) to 10 Managed Care Organizations (MCOs). As the leading statewide resource organization for the autism community, ASNC kept you informed through advocacy alerts, blogs, email newsletters, and this magazine as autism insurance passed one chamber of the NC General Assembly after years of work by many autism advocates. And we appreciate all of your efforts to support us on these issues. We fully expect the autism insurance bill to come up in the NC Senate this spring, and we will be calling on you again to help us.

In 2014, we pledge to keep working to educate our community through those same channels as well as workshops by our Autism Resource Specialists, formerly known as Parent Advocates. (For more about this resource, please see page 7.)

A major part of our educational efforts each year is our annual conference, and this year is no exception. "Autism: Planning for Success" is our theme for the February conference. What is success? We realize it looks different for each individual, but we encourage you to come and learn from award-winning author Dr. Jed Baker as well as ASNC trainers, a family therapist, and ASNC Board member Dave Spicer, a father who was diagnosed with autism after his son was. (For more about the conference, please see pages 4-6.) The conference is also a great time to network with others in the autism community, whether they are parents, service providers, or supportive businesses. We hope you can join us on February 21 and 22 in Charlotte.

Once the conference is over, our spring Run/Walk for Autism events are not far behind. If you're looking for a spirit-filled day and a way to support ASNC and families affected by autism, check the dates on the back cover. Last fall, our participants raised an amazing \$420,000 to help individuals and families. You made a difference, and we thank you! (For more, please see pages 20-22.)

In the middle of race season, we will celebrate World Autism Awareness and Acceptance Day (WAAAD) on April 2. We hope you will join us for this fun and educational event at Camp Royall, which always has something great going on for families year round. (For more on WAAAD and Camp Royall, please see pages 10-11 and 24.)

In continuing with our provision of exemplary service to those on the autism spectrum, we added a Charlotte services office this year. We look forward to expanding our high-quality services to families in that part of our state in 2014 as well as continuing our many direct services to individuals with ASD in our current locations. (For more about services, please see page 12.)

We know there is always a lot going on in your life. We thank you for letting us be a part of it and for joining us as we support those who are affected by autism. Please let us know how we can help you.

Best,



Tracey Sheriff
Chief Executive Officer

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ANNUAL CONFERENCE: PLANNING FOR SUCCESS

The Autism Society of North Carolina's Annual Conference, "Autism: Planning for Success," will take place February 21-22 in Charlotte. The conference will focus on strategies that provide self-advocates, families, and professionals an opportunity for successful outcomes in all aspects of life – from communication and social skills to family relationships and using technology to accomplish goals.

Tracey Sheriff, CEO of the Autism Society of North Carolina, said, "The number of children and adults diagnosed on the autism spectrum continues to increase. We recognize that success is defined differently for each person because their abilities and goals are unique. This conference will help people learn how to provide an environment and learning experience that promotes success and supports each family."

On Friday, February 21, Dr. Jed Baker will present **All Kids Can Succeed: Effective Interventions for Behavioral and Social Challenges**. Individuals on the autism spectrum and those with behavioral challenges often have difficulty regulating their feelings and interacting socially. Dr. Baker will describe how to handle meltdowns and design behavior plans to prevent them. He will also discuss strategies to motivate individuals to learn, ways to teach social skills, how to generalize skills, and how to increase acceptance from peers. Dr. Baker is director of the Social Skills Training Project, which serves individuals with autism and social communication problems. He also serves on the professional advisory boards of several autism organizations, lectures, and provides training internationally. He is an award-winning author of five books.



On Saturday, February 22, participants will learn from training experts, therapists, parents, and a self-advocate. Topics will include:

Functional Communication Across the Spectrum, by Leica Anzaldo and Louise Southern, ASNC trainers: Communication impairments vary widely among individuals with Autism Spectrum Disorder, but one feature that often underlies these challenges is the difficulty in consistently initiating communication of needs and wants. This presentation will provide strategies and systems

to teach individuals with ASD the power of communication. (See page 6 for more on this topic.)

Autism: Is There an App For That? by Amy Perry, ASNC Autism Resource Specialist: The lives of countless people with autism have been revolutionized by iPads and other mobile technologies, but how do you know whether an iPad is right for your child? How can you use an iPad as an effective teaching tool rather than a toy? Which apps work well for people with autism?

Family Success: Keeping Your Balance and Balancing the Needs of Your ASD Child, by Kat North, LPA: The stresses and joys of raising a child with an ASD are many. You may be dealing with a child's challenging behavior, sleep disruption, difficulty in accessing treatment, financial strain, and concerns about siblings' needs. Learn ways to regain your balance, strengthen your relationships, and support your child.

Living Your life: Defining Success on Your Own Terms, by Dave Spicer, self-advocate: "It's been said that 'The unexamined life is not worth living.' Well, autistic folks' lives are certainly examined by others ... how can we on the autism spectrum examine our own lives in pursuit of meaning, fulfillment, and whatever is meant by 'success'?" (See next page for a Q&A with Spicer.)

The conference, which is the largest autism gathering in the state, also provides a unique opportunity to share with and learn from others in the autism community, professionals, and a variety of businesses and organizations that support families affected by autism. The largest nonprofit autism-specific bookstore in the country will also be present, offering discounts, and there will be an art gallery of pieces by individuals with ASD.

The event will be held at the Hilton University Place in Charlotte. Continuing education units (CEUs) will be awarded to professionals, and discounts are offered to groups of six or more.

For discounted conference and hotel room fees, register now through January 31. For more information or to register, please visit www.autismsociety-nc.org or call 800-442-2762. ♦

Get to Know Conference Speaker Dave Spicer

Dave Spicer was diagnosed with autism in 1994 at age 46, shortly after his son was diagnosed at age 8. Spicer's own diagnosis "came as quite a relief," he says. "My life, past and present, began making much more sense then." Since being diagnosed, Spicer has been examining his life with moderate diligence, he says. Spicer often speaks and writes about the experience of living with autism, and he serves on the Autism Society of North Carolina's Board of Directors. He will be our final speaker at this year's annual conference in Charlotte. Here he shares some of what he has learned.

What are some of the challenges you face because of autism?

The primary one is that my perceptions of situations, and my responses to them, are sometimes very different from those of most other people. Some of these differences occur at the sensory-input level (such as tactile and auditory defensiveness), some at the input-processing level (such as facial recognition), and some at higher levels (evaluating nonverbal communication, understanding nuanced social situations, dealing with others' imprecision or vacillation).



While I can compensate more or less successfully for these much of the time, another challenge is that I tend to decompensate under stress. My "functioning level" is far from constant and is dependent on a lot of behind-the-scenes effort which others are generally unaware of. This compensation is a lot of work – and success at it is sometimes rewarded by others raising their expectations beyond what I can handle. So in some circumstances, I can seem to be doing okay for a while, but then fall apart pretty quickly for no apparent-to-others reason.

How have you overcome some of those challenges?

Well, in the "defeat or conquer" sense of overcome, I have not. What I have is the daily opportunity to engage life on its terms and find a way to work with or around my built-in challenges when they interfere with my enjoyment and sense of fulfillment with life (or on difficult days, my ability to just cope and get through it).

In more practical terms, I work hard to do what I can when I can, try to take care of myself by managing fatigue and stress, and try to remember to ask for help when I need it.

What advice can you provide families on how best to help their children with autism succeed?

The words I would suggest are understanding and support. Especially in my earlier years, the most distress I felt was from not understanding what was happening around me and not feeling understood when I was having trouble dealing with something. I often just could not do what was expected of me, and no one knew why. This can be very isolating, for the family as well as the autistic individual.

Suppose instead there was an atmosphere of seeking to learn more about each other and from each other, and seeking a way to journey through life together that works for everyone. Suppose there were allies – others in the same situation – and that you could help support each other and share what you have worked so hard to learn and understand ... and suppose that children on the autism spectrum had those same resources available, and could even become each others' allies.

Wouldn't this improve everyone's quality of life? And isn't that as good a measure of success as any?

What advice would you share with those who have autism?

I believe these things – see if believing them helps you: Not everyone will listen to me, but enough important people will. Not everyone will understand me, but enough important people will. Not everyone will want to help me, but enough important people will. Not every door will open for me, but enough important ones will. Not all of my wants will be met, but enough of my important needs will. Not every happy ending will come, but enough of the important ones will. Not every day will be wonderful, but there is always the chance that today will.

How can self-advocates better connect with each other and support one another?

By being given support and opportunities to connect. A recent ASNC Board meeting was held at IGNITE in Davidson, described as "a peer-to-peer community center." Before the meeting started, I was sitting with tears in my eyes thinking about how cool, and how wonderful, the place was. I felt a very strong sense of affirmation – that there was a place for me, that it was okay to be me, that the path led forward. There are many ways and many settings in which that message can be conveyed, given the opportunity.

How do you think life has changed for those with autism, as far as awareness, acceptance, etc.?

Here in Asheville where I live, there is sometimes morning fog. It's hard to see much of anything for a while, but then the fog starts to dissipate in the sunlight. We can see more clearly, we can see farther, we can appreciate what has been there all the time ... and we can see that we are not alone. There are a bunch of others like us, and support and understanding is growing, just as we are continuing to grow inside ourselves. The change over the years seems like that to me.

What do you see as the future for people with autism?

My hope is that we will be seen as a societal asset, as well as a population sometimes needing extra help. In a number of areas such as sensory environment, clarity of instruction, and perhaps even reasonableness of behavior, we can serve as the "canary in the coal mine" to help indicate where improvements could be made that would benefit everyone. Even our occasional distress can help nonautistic folks re-evaluate what is really meaningful and important in both daily life and its overall path.

We can help. We can work together. We can grow together. We can serve others together. Let's do this! ♦



BEHAVIOR THROUGH THE LENS OF COMMUNICATION

By Leica Anzaldo, MPA, BCBA, and Louise Southern, M.Ed., BCBA

Professionals working in the field of Autism Spectrum Disorder intervention and parents of individuals with ASD are all likely to have experienced challenging and persistent behaviors. These behaviors come in many forms, including noncompliance, aggression, elopement, and self-injurious acts. When we see these behaviors, one of the first questions we should ask ourselves is, “What is the individual trying to communicate with this behavior?” What need, want, confusion, pain, or fear is the individual trying to express? As one individual with ASD astutely stated, “You can’t not communicate. Everything you say and do or don’t say and don’t do sends a message to others.”

As we develop behavior support plans in clinical or school contexts, we find that a key consideration must be communication. In such cases, the individual is using a less appropriate behavior to communicate a message. Thus, our goal is not merely to reduce or eliminate the “bad,” but also to increase the “good.” In other words, a primary objective is to identify and teach more appropriate forms of communication that enable the individual to convey his or her message more effectively.

Sounds simple, right? In some ways it is, and in other ways, it is not. As we know, some individuals with ASD are not able to verbally communicate. Consider “Jane.” She has limited ways to communicate her wants and needs using a few basic gestures (e.g., reaching), a few gross approximations of signs (e.g., “more” “eat”), and she will also sometimes physically lead people to what she wants. While these communication behaviors are promising, they are so vague that anyone who doesn’t know Jane might have no idea what she wants. Jane also struggles to use those more appropriate communication strategies when she is anxious or upset, so she quickly resorts to tantrums, hitting, biting, and kicking to communicate her message.

For Jane, one initial approach would be to offer options at a higher frequency and present choices in a concrete and visual mode that meets her communication needs and level of understanding – via objects, pictures, or written words, for example. In addition, a likely next step is to identify a functional communication system that we will systematically teach her to use, so that she has a way to *initiate*

communication of her wants and needs. Can we teach her to communicate via a tool such as the Picture Exchange Communication System (PECS), by touching an icon on a handheld or tablet device, or by giving an object to someone?

And just because an individual can verbalize his needs and choices, is he actually doing this? For example, some people script language they have heard from TV shows or repeat what they hear rather than actually responding. Some individuals are nonresponsive to anyone other than people with whom they are very familiar. Others use language that does not seem to make sense given the context. Some individuals label everything but don’t use language to express wants or needs, or to respond to questions and statements. In all of these examples, while the individual is “verbal,” what does he do when agitated? What happens to the verbal communication then?

We have worked with a number of children and adults who are characterized as having high-functioning autism or Asperger’s Syndrome who do not self-advocate even to get their basic wants and needs met. Consider the high school student who never tells his teacher that he does not understand how to start the assignment. He sits and does nothing; some perceive this as noncompliance or even laziness. Among other strategies, what communication scripts might such individuals need to help them initiate appropriate communication?

Of course, a key to effective functional communication training lies within the teaching procedures. So often the system or script is developed and presented to the individual, but then never truly taught. Effective instruction is systematic and consistent across contexts and includes ongoing assessment of motivation, repeated practice, and reinforcement. As we support individuals across the spectrum, the strategies will vary, but the underlying principle is the same: promote self-determination by empowering the individual with ways to communicate more effectively.

These principles and instructional strategies, along with some success stories and lessons learned, are central to the “Functional Communication across the Spectrum” workshop that we will present at this year’s annual conference with ASNC Clinical Director Dr. Aleck Myers. ♦



ARE YOU TAKING ADVANTAGE OF ASNC WORKSHOPS?

Parents who contact the Autism Society of North Carolina are often looking for help with school issues. Sometimes children with autism need to receive specially designed educational services through an Individualized Education Program (IEP). Our Autism Resource Specialists help parents to understand the IEP process, educating parents about their rights and how to navigate the often confusing world of special education.

- Did you know there is a federal law that guarantees a free, appropriate public education for all children with disabilities who need special education?
- Did you know that just because your child has autism that does not mean they are eligible to receive these services?

If your child receives special education instruction:

- Do you know how to prepare for an IEP meeting? Our recommendations include talking with your child about his or her vision for the future and making a list of your top concerns to share.
- Do you understand the difference between accommodations and modification? With accommodations, the student is doing the same assignment as classmates but is supported by measures such as extended time to complete it. A modification in requirements might change what the student is expected to learn or the instructional level.
- Do you know what school staff members mean when they say “least restrictive environment”? Do you know the factors to be considered when deciding placement for your child?
- Do you know who should attend an IEP meeting? Did you know you are allowed to bring a person who can support you during the meeting?
- Do you know what to do if you receive an invitation for an

IEP meeting and the date is not convenient for you?

- Do you understand all the jargon the school uses? DEC? LEA? Is it even English?!
- Do you know what to do if you disagree with the IEP team?

Our Autism Resource Specialists offer a workshop titled “Building Success for Your Child at School: It’s More than Just Knowing Your Rights.” The workshop answers all of the above questions in greater detail, plus many more. If you would like to learn more about IEPs, please check our online calendar for a workshop scheduled in your area or contact the Autism Resource Specialist in your region.

If you have questions about other topics, we encourage you to take advantage of workshops led by our Autism Resource Specialists. They are parents of children with autism themselves; they have been where you are and can share expertise as well as valuable experiences.

Some of our topics:

- After the Diagnosis: Get Answers, Get Help, Get Going!
- Taming the Paper Monster: Organizing Your IEP Notebook
- Taking Autism to the Doctor/Dentist
- Guardianship: What is It? Who Needs It?
- Journey to Adulthood
- Considering College? Prepare, Plan, Succeed
- Managing Stress: Taking Time to Breathe
- Staying Two Steps Ahead: Safety Considerations for Caregivers
- iPads, Mobile Technology, and Autism

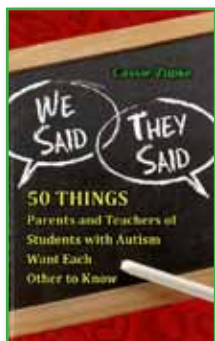
For more information and a schedule of all of our workshops, please visit <http://bit.ly/ASNCWorkshopCalendar>. ♦

Autism Resource Specialists: New Name, Proven Resource

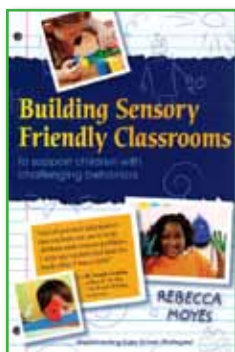
The Parent Advocates of the Autism Society of North Carolina are now called Autism Resource Specialists, better conveying the benefits they can provide to families seeking help for loved ones with autism. To find the Autism Resource Specialist who serves your area, please call 800-442-2762 or visit <http://bit.ly/AutismResourceSpecialists>.

BOOKSTORE NEWS AND REVIEWS

As surprising as it sounds, the current school year is almost half over. Often, parents and teachers are looking for new resources to begin the new year after winter break. If you'd like to learn about teaching social skills, organization and executive function, dealing with bullying, or ending challenging behaviors, we have the books for you. We also have personal stories that will help you see the world through the eyes of those with autism.

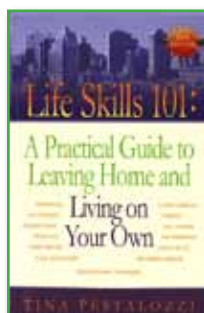


We Said, They Said: 50 Things Parents and Teachers of Students with Autism Want Each Other to Know gives voice to what parents and educators want to say to each other but don't. It explains why they do what they do and helps fill the chasms of misunderstanding that breed assumptions such as "They don't care about my child" and "They're just in denial." Educators and parents can gain the tools to build the relationships they need to help children. (BWES01, \$15.01)



Building Sensory Friendly Classrooms to Support Children with Challenging Behaviors walks any regular education or special education teacher through setting up a sensory-friendly classroom. This easy-to-use guide is currently the only book that discusses the importance of data-driven strategies and then helps teachers implement them. Sensory integration disorder often presents as a behavioral problem; thus, although it's an internal state, it must be addressed based on the child's observable behaviors. This book will help make any student's – and teacher's – life easier. (BBUI05, \$13.70)

Life Skills 101: A Practical Guide to Leaving Home and Living on Your Own (updated fifth edition) is a valuable guide to the

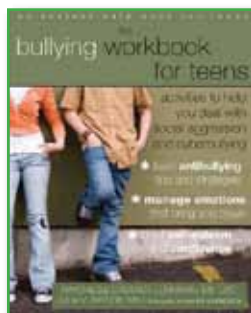


complete spectrum of skills required to successfully master the challenges of being a responsible adult, whether that means living alone, with roommates, or even with Mom and Dad. Subjects include financial know-how; job searches; interview, social, dining and workplace etiquette; home hunting; and lease negotiations. The guide provides essential advice on maintaining a home, car, time, and well-being. (BLIF07, \$11.80)



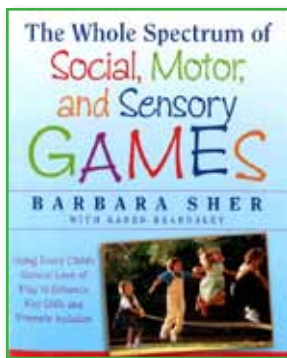
teens better understand and cope with their disorder. (BEXE01, \$12.80)

The Executive Functioning Workbook for Teens: Help for Unprepared, Late & Scattered Teens is an easy-to-use, practical workbook written by a licensed school counselor. The book will help you hone the skills needed to get organized, retain information, communicate effectively, and perform well in school as well as everyday life. Based on cognitive behavioral therapy that has been proven to be effective, the book offers activities that will help

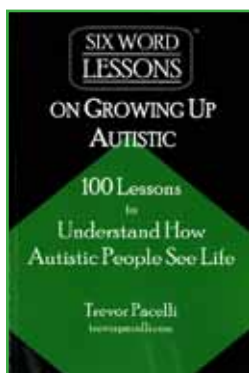


tion skills to help express feelings. (BBUL03, \$12.70)

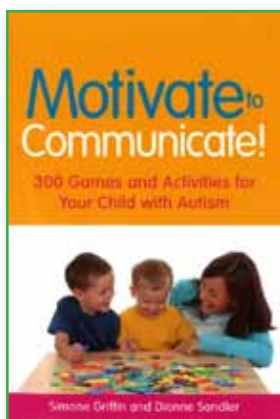
The Bullying Workbook for Teens: Activities to Help You Deal with Social Aggression and Cyberbullying incorporates cognitive behavioral therapy to help ease anxiety, fear, stress, and other emotions associated with being bullied. The 42 step-by-step self-help activities will help the reader learn anti-bullying tips and strategies; manage emotions such as anxiety, fear, anger, and depression; and learn constructive communication skills to help express feelings. (BBUL03, \$12.70)



success, and learning social skills. Step-by-step directions are provided for using children's natural interests at different stages of development to help them gain a wealth of sensory, motor, and social skills. (BWH003, \$11.60)



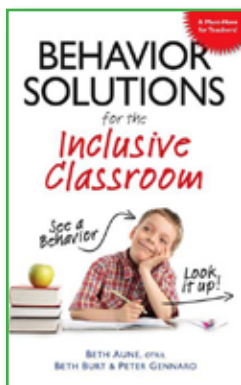
spectrum. (BSIX02, \$11.10)



The Whole Spectrum of Social, Motor, and Sensory Games: Using Every Child's Natural Love of Play to Enhance Key Skills and Promote Inclusion gives parents and teachers fun and easy ways to include all children in activities that engage all of their senses and promote important skills. Play is increasingly recognized by neuroscientists and educators as a vital component in brain development, academic suc-

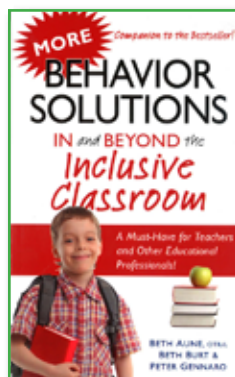
Six-Word Lessons on Growing Up Autistic: 100 Lessons to Understand How Autistic People See Life was written by Trevor Pacelli, who was diagnosed at age 5, in hopes that families could benefit from his experiences. As Trevor grew up, his autism presented difficulties not only for him, but for his parents and sister. The book includes 100 short, practical tips to help readers understand people with autism in their lives, told through insightful personal experiences by someone who has grown up on the

Motivate to Communicate!: 300 Games and Activities for Your Child with Autism is a practical resource brimming with exciting ideas and guidance for motivating children with autism and other communication difficulties. The clear, user-friendly format enables quick access to more than 300 practical, fun-filled games and activities for developing children's communication skills. This book supports parents, caregivers, and professionals. (BMOV02, \$14.85)

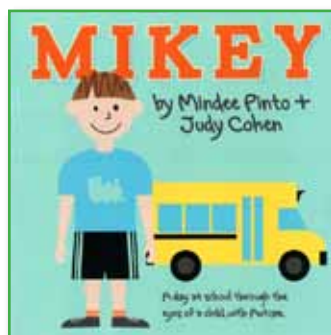


Behavior Solutions for the Inclusive Classroom: A Handy Reference Guide that Explains Behaviors Associated with Autism, Asperger's, ADHD, Sensory Processing Disorder, and Other Special Needs As inclusion becomes the norm in general education, teachers are faced with behaviors they have never before encountered. Special-needs educators may recognize the telltale symptom of a sensory need or a textbook case of an avoidance behavior, but this is all new

territory for many teachers. This book illuminates possible causes of those mysterious behaviors, and more importantly, provides solutions. Teachers can quickly look up an in-the-moment solution and learn about what the child is communicating, and why. It is possible to accommodate learning differences and sustain a positive learning environment for *all* students. This book is a must-have for every inclusive classroom. (BBEH04, \$12.58)

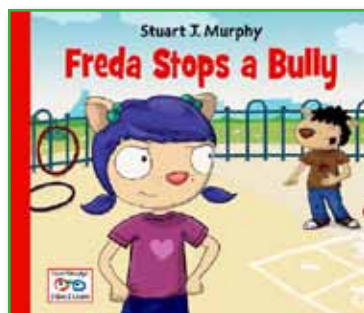


More Behavior Solutions In and Beyond the Inclusive Classroom: A Handy Reference Guide that Explains Behaviors Associated with Autism, Asperger's, ADHD, Sensory Processing Disorder, and Other Special Needs builds on the success of the first one by expanding the focus from within the classroom to all areas of the school environment – in the hallways, cafeteria, and auditorium; on the playground; and in therapy sessions during the school day. (BMOR04, \$12.58)



Mikey explains how a young child with autism sees, hears, and feels the world around him in his school environment. The book is perfect for teachers to read to their classes. It is intended to educate adults as well as young children to increase their awareness and understanding of the child with autism. *Mikey* was inspired by the author's vast experiences as a teacher working

with children with autism. (BMIK01, \$9.95)



Freda Stops a Bully Freda loves her new pink shoes. But when she wears them, a boy at school teases and makes fun of her. What can Freda do to make the bully stop? *Freda Stops a Bully* addresses emotional skills and dealing with bullying. With the support of her friends, parents, and teachers, Freda

learns how to stand up for herself. Visual learning strategies are used to help young children see and learn how to deal with bullying, a key emotional skill. (BFRE04, \$6.15)

You can find these books and many other resources online at www.autismbookstore.com. Let us help you find something to meet your needs. Call Dawn Eberwein at 919-743-0204, ext. 1132, send a fax to 919-743-0208, or send an email to books@autismsociety-nc.org. We employ adults with Autism Spectrum Disorder; your purchase supports them as they gain valuable job skills and increased independence. ♦



CAMP ROYALL INTRODUCES AFTERSCHOOL PROGRAM

Christopher comes running back into the fenced playground area after a restroom break. The 10-year-old looks around, eyes combing the swings, benches, and slide. He does not see what he is looking for and is momentarily still. “Christopher!” the call comes from the fort at the top of the slide. And he’s off, running up the steps toward his friend.

Making friends at an afterschool program might seem like no big deal to many children, but parents of children with autism know that several challenges can stand in their children’s way. First, they must find an afterschool program with staff members who know how to work with children with autism. Then, their children must feel safe and accepted enough to open up to others.

Camp Royall, part of the Autism Society of North Carolina, started just such a program this year. Director Sara Gage said they wanted to offer quality care by people who understand children with autism and accept them the way they are, so their parents can work with less stress.

Christopher’s mother, Krystal Pister, says the afterschool program has changed her son, who was diagnosed with autism at age 2. “From Day 1, he came home and his eyes were lit up, and he was engaged with us. I feel like it’s wakened him.” Pister said that having more than two hours a day of intense interaction with others and movement helps her son be calmer at home. Christopher had been receiving occupational therapy once a week, but it just wasn’t enough, she said. The family had also tried activities such as martial arts, but Christopher always had trouble with the noise, or the chaos, or managing the expectations of those in charge.

So they signed him up for two days a week in the Camp Royall afterschool program. After a couple of weeks, Christopher – who previ-

ously did not enjoy outdoor activities and had to be torn away from electronic toys – told his parents he wanted to go to the afterschool program every day. “He loves it more than anything,” Pister said.

The afterschool program follows a structured schedule; staff members use a visual board to help campers transition to the next activity. They try to keep the children active and moving – no video games here. On a recent afternoon, six boys with a range of abilities and challenges convened in the camp’s gym for free time during the

first half hour of the program. Christopher and one of his friends raced across the floor, kneeling on roller racers as a 7-year-old bounced a huge pink ball. Along the wall, a 4-year-old climbed the bleachers as a volunteer held his hand, repeating the words “up” and “down.”

Gage said that the afterschool program is not meant to be therapy, but participants do make advances such as increasing their self-confidence. “We don’t have set goals for the kids, but it happens naturally,” she said.

Staff members are constantly guiding the children, challenging them to use words if they don’t, and giving them feedback. The staff is made up of local college students who have worked at summer camp, so they have been through the Camp Royall training. Coming from different towns, they also help with the program’s biggest challenge: getting the children to the remote location in Moncure, near Pittsboro.

Seven children attend the afterschool program now, for three or more days a week. “We’d love to see it really grow and thrive,” Gage said.

For more information about the afterschool program or to sign up, contact Camp Royall at camproyall@autismsociety-nc.org or 919-542-1033. ♦



Time to Register for Summer Camp

It's hard to believe, but the time is already here for Summer Camp registration. Applicants are selected to attend camp through a random lottery. We will accept applications for the camp lottery at www.camproyall.org from January 13 to February 24. Our website also has all the latest information about Summer Camp, including dates and rates for 2014. Our fees have held steady since 2010, but revenues have not kept pace with increased costs, which necessitates a slight increase this year. Please call the camp office at 919-542-1033 if you need help with the registration process or do not have access to the Internet to complete the application.



Year-Round Programs

2013 was another incredible year at Camp Royall! Our year-round programs have grown tremendously, and our new afterschool program has been a great success. All of these programs have enabled us to serve over 1,200 individuals and their families in 2013. If you have not been to camp in a while, we encourage you to visit again! Check out the website to learn more about all of the happenings throughout the year. You can print out our flyer of 2014 events at <http://bit.ly/CampRoyallPrograms2014> so you won't miss anything.



Afterschool Program: Our afterschool care is offered each day during the school year at Camp Royall. We have been able to provide transportation for some children and are open to siblings of those on the spectrum as well.

Mini-Camp Weekends: Campers arrive Friday evening and stay through Sunday for a weekend of fun, providing a needed break for both campers and families.

Adult Retreat Weekends: Adults 18 years of age and older with high-functioning autism/Asperger's can come and spend a weekend with friends, enjoying camp and community activities.

Family Fun Days: Bring your family to enjoy an afternoon at camp filled with recreation and leisure activities in a fun and safe setting.

Family Overnight Camping: Come for Family Fun Day and stay overnight!

Winter Camp: A day camp program held during the winter break. This is a great resource for families during the hectic holiday season.

Help More Campers Experience the Joy of Camp

The Autism Society of North Carolina has been offering summer camp for over 40 years for individuals with autism of all ages. Camp Royall is the oldest and largest camp exclusively for individuals with autism in the United States. We work year round to raise money to give campers who are unable to afford camp the opportunity to learn new skills, have fun, and make friends at camp. Each year, the demand for scholarships exceeds the funds we have available.

We hope you will consider giving to provide life-changing experiences for campers with autism. Please contact Kristy White, Development Director, at kwhite@autismsociety-nc.org or 919-865-5086 if you are interested in donating to camp, learning about named scholarships, or helping with fundraising. We look forward to working with you to help campers from across North Carolina.



DIRECT CARE SERVICES: FULFILLING POTENTIAL

The past year and a half has included big changes to services delivery in our state. North Carolina completed the transition from a network of 22 Local Management Entities to 10 Managed Care Organizations (MCOs). With the changeover complete, families and professionals have a better understanding of what assistance is available and where to go to get it. In addition to providing support through the Autism Resource Specialists (formerly called Parent Advocates), the Autism Society of North Carolina is a licensed service provider with the state and MCO network, specializing in high quality services for individuals with autism and their families.

ASNC provides services throughout the lifespan. We provide help through Medicaid Innovations, state-funded (formerly known as IPRS), and Vocational Rehabilitation services. If you do not qualify for any government programs, we also can contract directly with you. Our staff members are trained on research-based best practices for working with individuals with autism. Employee training exceeds the state mandates. We want our staff to help each person we serve to reach his or her highest potential.

Services are coordinated through offices in Raleigh, Asheville, Charlotte, Greensboro, Greenville, and Fayetteville. The types of services that ASNC provides include:

Skill Building: Each individual with ASD is unique, with challenges to be addressed and strengths to be nurtured. We offer one-on-one tutoring or group training to bolster the following skills:

- Personal care, including eating, bathing, dressing, daily hygiene, and mobility.
- Socialization, including the development or maintenance of self-awareness and self-control, responsiveness, interpersonal skills, and the ability to maintain personal relationships.
- Community integration, including recreation, employment, and leisure activities.

Family Consultation: We work with families to provide specific recommendations for appropriate home supports, opportunities for community participation, and coping strategies. We can help you provide maximum support to your loved one with autism while maintaining balance for the other family members.

Afterschool Programs: We offer trained supervision after the school day ends. Children practice social skills and enjoy extra-curricular activities in a structured environment. Availability of afterschool programming is limited. Check with the services office nearest to you.

Respite: We provide families and caregivers a break from the demands of caring for an individual with autism, offering you the opportunity to recharge physically and emotionally. Our qualified staff provides respite in the individual's home or in an out-of-home setting, either one on one or in a group.

Recreational Opportunities: We offer a variety of social skills groups for adults and teenagers. These informal

groups allow participants to bond over common interests and practice interpersonal skills.

Employment Support: We can offer assistance with finding, keeping, and thriving in a job as your loved one makes the difficult transition to adulthood. We provide an initial vocational assessment, resume and interview preparation, job search support, placement, on-the-job coaching, specialized job training, and individually tailored supervision.

To locate your nearest ASNC services office, visit our website at http://bit.ly/ASNC_ServiceOffices. From this page, you can click on the office nearest to you and learn more about specific options offered where you live. ♦

“*The staff were well-informed about autism and trained to handle every situation... and so respectful of our son and his wishes!*”

– Parent of a 21-year-old who received services from ASNC

Denise Ferguson Retires After Two Decades of Service

Denise Ferguson, Director of Services, retired from the Autism Society of North Carolina on December 31, 2013. She worked for ASNC for nearly 20 years in all areas of services delivery.

“Denise has been a friend, trusted confidant, and leader within the Autism Society of North Carolina for many years. Denise has been instrumental in establishing our services across the state, and I know that countless staff, parents, and individuals with autism have benefitted from her many contributions. She will be sorely missed,” said Tracey Sheriff, CEO.

When she began working for ASNC, the organization had fewer than 24 employees statewide. Today, ASNC employs more than 1,000 people working with the autism community in a variety of roles. Because there was no ASNC office in the Fayetteville area, Denise literally worked out of the trunk of her small red convertible. She was instrumental in raising awareness in Cumberland County about the needs and provision of autism-specific services and supports for children and adults. She was and is a strong advocate for adult services such as housing and employment. Recognizing that effective service delivery is a collaborative process, Denise worked closely with the area Local Management Entities (LMEs) and decision-makers to ensure that

they understood the needs of the autism constituency. Throughout all discussions, Denise kept the needs of the families and individuals at the forefront. As service grew, she helped establish the Fayetteville area office and a Laurinburg satellite office.

While a regional services director, and later as Director of Services, Denise mentored countless others when they joined the organization, sharing her knowledge of the system and her values of respecting the dignity of each person and family she worked with as well as the professionals with whom she collaborated. ASNC now has six regional services offices throughout the state, and each of the regional directors was trained and mentored by her. Denise led not only by words but by her actions, including a willingness to speak face to face and work hand in hand to solve problems.

Denise set an example to fellow coworkers about what really mattered: the people we serve. We will miss her smile, laugh, and genuine concern for everyone she worked with.

We thank Denise for her tireless efforts to serve the autism community and to make the Autism Society of North Carolina into the organization that it is today. We wish her well in her retirement.



Alan Cohen Wins Direct Service Award

The Autism Society of North Carolina has named Alan Cohen of Raleigh as the 2013 winner of the John and Claudia Roman Direct Service Award. The annual award honors an ASNC direct service employee who has demonstrated outstanding dedication to individuals with autism and their families. Cohen is an employment supports professional who has worked for ASNC for four years.

“The award allows us the opportunity to honor an ASNC direct support professional and acknowledge the tremendous difference they make each day in the lives of the families and individuals we support. The award also raises public awareness about direct support professionals and the important work they do,” said Denise Ferguson, ASNC’s Director of Services.

The two parents who nominated Cohen for the award agreed that he truly understands individuals with autism, their challenges, and their needs. Cohen takes time to get to know his clients and helps them find careers, not just jobs.

“I have very much appreciated the respect and understanding that Alan has shown in working with Alex,” Linda Griffin said. “He could have more easily found Alex a job doing something that did not use Alex’s education and skill set. But rather

than just stick him in a job, check him off the list and move on, he considered what would be best for Alex in the long run.”

Griffin said Cohen has helped her son not just in job development, but in other areas of personal growth, such as building an exercise regimen. “None of these things are within Alan’s job description, I am sure, yet he does these things with a compassionate heart and such a generous spirit that I am moved beyond words. He is an unheralded hero, in my opinion – a secret treasure in the heart of the Autism Society.”

“Alan has become more than his job title. He is a trusted friend,” Griffin said.

Cohen received a cash award of \$1,000 during National Direct Care Appreciation Week. He also will be recognized at the Autism Society of North Carolina’s annual conference in February in Charlotte.

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



WANDERING: HOW CAN WE KEEP OUR KIDS SAFE?

The media reports leave us shaken. A 14-year-old boy with autism walks out of his New York City school, never to be seen again. A 3-year-old escapes her grandmother's home in Massachusetts and is quickly found in a nearby pond, but she is unresponsive and dies the next day. A 5-year-old is found drowned the day after he wandered from his grandparents' house in Missouri. According to a recent report by the Associated Press, 60 children with Autism Spectrum Disorder have died after wandering in the United States in the past four years.

Children with autism are more likely to run from caregivers than other children; so much so that the problem has been given many names: wandering, elopement, bolting. They might have phobias or sensitivities that make them likely to flee in certain situations. Once they have escaped supervision, their fascinations can prove deadly, drawing them to water, trains, construction vehicles, or traffic.

In a study published by the journal *Pediatrics* last year, 49 percent of children with autism had attempted to wander at least once after age 4. The families surveyed came from the Interactive Autism Network and included about 1,200 children with autism and 1,100 siblings without autism. The study found that from ages 4 to 7, children with autism were four times as likely to wander as siblings without autism. Twenty-six percent were missing long enough to cause concern. Of those who wandered, 24 percent were in danger of drowning and 65 percent were at risk of injury in traffic. (You can read more about the study online, at <http://bit.ly/WanderingStudy>.)

Once they have wandered, children on the autism spectrum also are likely to have characteristics that make it difficult for them to return to safety. Their special interests and sensory issues might cause them to run toward something that fascinates them, such as a train or water, or away from something that is

overwhelming, such as loud sounds or lights. They may have poor judgment, not recognizing where or from whom to seek help. Their problem-solving skills may be impaired by rigid thinking, lack of perspective, or anxiety. They may not be able to speak at all or communicate effectively to tell those who find them where they belong.

Given this very real risk to our children, what can parents and caregivers do to keep children with autism safe?

Do not isolate yourself: Talk to neighbors about children or family members with ASD and their challenges, in case they wander out of your home or yard. Give them your contact information. Consider asking them, and any other friends and family who live nearby, whether they would be willing to help you search for your child in an emergency situation. Keep a list handy of names and phone numbers for those who agree.



Contact first responders: Go to your local police station, fire station, and EMS to talk about your loved one with autism and give them a current photo and a personal information handout. If possible, bring children with autism so they can see people from whom it would be safe to seek help. Adults with ASD and those with high-functioning autism or Asperger's Syndrome may have sophisticated spoken language but still not respond properly to officers. It is important to teach these individuals what to say if they are lost or hurt and to self-advocate.



In your home: Consider putting safety items in place such as a home security alarm system, window locks, and alarms on windows and doors to alert you if someone is trying to open them. Sometimes putting a "stop" sign on doors and windows can prevent a person with ASD from going any farther. Consider putting a fence around your home with locked gates. If you have a pool, make sure the pool is not

accessible without supervision. Teaching children to swim is important, but it isn't a guarantee that it will save them from drowning.

At school/day care: Discuss with teachers your concerns about your child's safety. Make sure they and any other caregivers know what to do if your child wanders. Make safety part of IEP goals.

Teaching your loved one: Teach your child how to safely cross the street; the meaning of street signs, such as "STOP"; and who is a safe person and who is a stranger. Talk to your child about safe places to go if they are lost or hurt: police stations, fire stations, schools, etc. Consider using social stories or picture schedules to teach them what to do in dangerous situations that they might encounter once they wander.

Identification information: Consider a wearable ID such as a bracelet, tags in their clothing or on their shoes, or even electronic tracking devices.

Attend one of our workshops: For more information about keeping your loved one with ASD safe, attend one of the Autism Society of North Carolina's workshops, "Staying Two Steps Ahead: Safety Considerations for Caregivers." The workshop covers general community safety considerations for parents, family members, and community caregivers of children and adults with autism. How autism can affect safety, how to be proactive, and safety-related resources are discussed. Find the schedule for all of our workshops at <http://bit.ly/ASNCWorkshopCalendar>. Our trainers also conduct workshops for first responders across the state, teaching them how to interact with individuals with autism.

The Autism Society of North Carolina is introducing a new safety kit. The kit is available on our website, www.autismsociety-nc.org, and includes printable forms for you to fill out and share with first responders, examples of social stories, an informative tips sheet, and links to other resources and products such as ID labels.

Let's work together to keep our loved ones safe. If we can help you in any way, please contact us at 919-743-0204 or info@autismsociety-nc.org. ♦

New Safety Kits Online

The Autism Society of North Carolina is introducing a safety kit on our website, www.autismsociety-nc.org.

The kit includes:

- printable forms for you to fill out and share with first responders
- examples of social stories
- an informative tips sheet
- links to other resources and products such as ID labels.



Want one or more of these decals? Request them on our website.

Other safety issues

Driving: Do you have a new driver in your household? Individuals with autism might not respond properly to officials in a situation such as a car accident. A decal on the car can alert first responders. We offer free decals in our online safety kits; these could also be used on windows of your home in case of fire or other emergency.

Fire: Does your loved one with ASD know what to do in case of a home fire? The National Fire Protection Association website can help your family be prepared. The website, www.nfpa.org, has activities for children and a social story that can be individualized. Teach your child when and how to call 911.

Bathroom etiquette: Does your child go to the bathroom in public places by himself? Most women do not realize that there is different bathroom etiquette for men than for women. Women frequently make conversation with others they may not know in a public restroom. This is not true for men. Children, especially boys, need to know not to talk to strangers in public restrooms and what to do if a stranger approaches them.

Internet: For individuals who lack social skills or judgment, safety measures should be put in place to manage Internet access – whether at home, at school, or in the workplace. If you have a child or young adult who is visual, place instructional picture cards directly on the computer. If they can read and understand written language, keep those rules right next to the computer and negotiate an Internet use contract. Check with your ISP on safeguards. The NC Department of Justice website, www.ncdoj.gov, contains several safeguards.



CHAPTERS AND SUPPORT GROUPS

ASNC's 50 Chapters/Support Groups across the state – all as unique as the communities they serve – have something very special in common. Members all work hard, and they all play hard. As families geared up for the often challenging transition back to school this fall, our Chapters provided much-needed support and information. Popular topics at Chapter meetings included addressing student anxiety, keeping loved ones safe, using effective communication, sensory and behavioral strategies, and navigating the ever-confusing world of community services.

Our **Surry County Chapter** took on a very special educational project this fall. After discussing the needs in their community with each other and with

their ASNC Regional Chapter Coordinator, Judy Smithmyer, members decided that their priority for the year was to use Chapter funds to offer autism education for their school system. With Smithmyer's help, they brought together Leica Anzaldo, ASNC Training Manager, and Surry County Schools EC Director Emily Summey to arrange the training and consultation for teachers and teacher assistants.

Anzaldo conducted two in-depth

workshops on communication and behavioral strategies that build effective learning environments for students with Autism Spectrum Disorder. She also visited classrooms to listen, share ideas, and offer specific suggestions.

“*Having Leica Anzaldo from the Autism Society of NC spend a day in my classroom gave me many significant insights into my students and provided me useful suggestions to making my instruction and classroom management the most effective it could be.*”

– Mark Fuhrmann,
North Surry High School

Right on the heels of back-to-school education and support came the season of fall fun. For families everywhere, October typically ushers in spooky events, autumn outings, and Halloween goodies. But for many of our kids with autism and their families, this can be a difficult month, triggering sensory issues, feelings of anxiety, and disconnectedness with peers. In response, several of our groups offered their own fall fun opportunities.

Our **Onslow County Chapter** kicked things off on a Saturday in September with an incredibly successful and fun-spirited Zombie Walk for Autism. Drawing an impressive 500-plus zombies, the event featured a “dead walk,” local rock bands, and even professional zombie makeup artists for folks who wanted costume enhancements. The walk not only raised awareness of autism but also brought in proceeds to support the Chapter's goals in the Onslow community. Members hope to make it an annual event.



In October, the **Wake County Chapter** held its annual costumes-optional Halloween party with more than 200 ghouls and goblins of every size in attendance. The evening featured face painters, games, crafts, a bouncy house and giant slide, photos, treats, and gluten-free and regular pizza. The much-anticipated finale was a “Trunk or Treat,” during which children trick-or-treated out of festively decorated car trunks. This event, besides being the largest the Chapter has had in several years, was also its inaugural event with the Autism Angels from Meredith College. The students worked hard as event co-chairwomen and volunteers, contributing to the event’s success with their enthusiasm and heart.



Our **Jackson/Swain/Qualla Boundary Chapter** folks participated for a second year in the annual Cherokee Fair held on the Qualla Boundary. The event featured multiple days of fun that included games, rides, animal exhibits, food, concerts, traditional dance, storytelling, and art. Community groups were invited to host awareness tables.

Pictured at left: Chapter co-leaders Amy Welch and Jody Miller, who also serves at the local Family Support Network, staffed an awareness table displaying services and supports that the organizations offer to the families of individuals with autism and other disabilities.



Pictured at right: Alyssa, daughter of Amy Welch, smiles in appreciation of a huge parade, a Cherokee Fair main event. Alyssa enjoys helping at the fair every year by setting up and conversing with folks.

The **Mecklenburg County Chapter** offered group trips to a local museum and Renaissance Fair as part of its recreational group formed this fall. Kimberly Green, who is a Mecklenburg Chapter volunteer, often brings her family on the outings. “My son has truly enjoyed it because he has a sense of friendship now,” Green said. “He feels that he has a group of friends that accept him just the way he is. He looks forward to the outings to hang out and meet new people. The parents love it because we network and share information in a social setting. The siblings love it because they meet new friends with other siblings.”



Robeson County Chapter members enjoyed a monthly night of bowling, compliments of Lumberton Bowling Center and owner Scott McLean. Pictured at left: Jennie Lee, Robeson County Chapter Treasurer, and Monica Graham and their families pose with manager Richard Chmura.

In the holiday months of November and December, many of our groups held a variety of gatherings for members: museum outings, sensory-friendly movies, potluck gatherings, parties with Santa, workshops on avoiding stress, and dining-out fundraisers. We’re ever-thankful for our Chapters and all they do to enrich the holiday experience for our families.

Be sure to check out our calendar at www.autismsociety-nc.org regularly for the Chapter/Support Group event closest to you. ♦



PUBLIC POLICY IN 2014

By Jennifer Mahan

Is our bill dead? This is probably the most common question about public policy asked before, during, and after a legislative session. The public policy process can be frustrating: introducing bills, getting our hopes up, and then not seeing anything happen. The legislative process can be confusing, so here are a couple of quick facts about bills and the North Carolina General Assembly that we hope will clear up some common misconceptions.

The General Assembly runs on a two-year cycle. During odd-numbered years, they are “in session” (i.e. working on laws) from January until the end of June. In even-numbered years, they are in session for only six weeks from mid-May to the end of June. Sometimes the session goes longer, or special sessions are called, but this is unusual. Bills are introduced in the long session during odd years. A bill must be introduced, receive a yes vote in a couple of committees, go to the floor of the House or Senate, get two more yes votes on the floor, then go to the other legislative chamber, where it goes through the same process. A bill that receives a yes vote in all those committees and on the floor of *both* chambers goes to the governor for a signature and then becomes law. It can be more complicated, but this describes the basic process from bill to law.

There are many points in the process where a bill can get stuck or be revived. In the long session, bills must meet a legislative deadline in mid-May to pass one chamber or the other. This deadline helps the legislators determine their priorities and which bills have support. If the bill does not pass one chamber, it is usually not eligible to become law for the rest of that session or the short session the next year.

Legislative committees do not have to hear a bill and give it a thumbs up or down. Sometimes bills sit in committee and are never heard. Because bills are amended during the committee hearings and on the floor of the chamber, sometimes the language from one bill will show up in other bills later. There are many legislative oversight and study committees that meet between sessions. These committees can make recommendations that can be introduced as bills in the following session. This is a big exception to the bill deadlines and one way to keep a bill moving. There are many exceptions to these basic rules – more than we can go over in a short article. You can find more information about legislative rules at www.ncleg.net.

ASNC will continue working on our legislative targets in 2014’s short session, which begins May 14. During the sessions, even short ones, ASNC works on many issues in our legislative targets, which you can read on our website at <http://bit.ly/ASNCLegislativePriorities>. But not all targets will be achieved in a year or two; many take much longer or require many small steps. Here are some of the main public policy issues ASNC will be working on in 2014:

Insurance Coverage for Autism: House Bill 498, which requires insurance plans to provide coverage for treatment for autism, has passed the NC House, but not the NC Senate. It has the support of the governor. ASNC continues to work with the leaders of the Senate so they understand the need for the bill and how it would work in our state. The Senate as a whole is supportive, and we will be working to make sure the bill comes up for a vote in the short session.

Retaining Voting Rights: During the last session, legislators had a lot of questions about voting rights for people with intellectual and developmental disabilities (IDD), and we expect that trend to continue. Individuals with IDD can retain voting rights under NC’s guardianship laws, and ASNC will continue our work to educate lawmakers and retain people’s rights.

Managed Care and Medicaid Reform: North Carolina intends to expand the use of managed care across its Medicaid system. Because so many people with autism and other long-term disabilities receive health care and supports through Medicaid, ASNC is working to ensure that managed care is used to help people be healthy and live as independently as possible. ASNC continues to push for the inclusion of case management in Medicaid managed care, the input of families and individuals on the spectrum in the development of managed care in NC, and the expansion of quality services and supports.

Developing a positive relationship with your elected officials is an important part of creating change in public policy. ASNC encourages you to stay informed by signing up for our email notices at <http://bit.ly/NCAutismAdvocacy>, by telling your elected officials your story of autism, and by responding to our public policy alerts. For more information, contact Jennifer Mahan, Director of Advocacy and Public Policy, at 919-865-5068 or jmahan@autismsociety-nc.org. ♦



HEALTH CARE NEWS

By Jennifer Mahan

People in North Carolina, in particular those with disabilities and other health conditions, have two new options for getting health-care insurance: Medicaid “buy-in” and insurance purchased through the health-care marketplace under the Affordable Care Act.

Medicaid Buy-In: North Carolina will begin implementing a requirement to the state’s Medicaid program that allows people with disabilities – including those on Innovations/CAP – to keep their Medicaid coverage or to purchase Medicaid health coverage if they have earned income. To qualify for Medicaid in NC, people must be at 100% of the federal poverty level, \$958 per month.

Under the buy-in option, people with disabilities can go back to work, earn money, and keep their Medicaid coverage. To be eligible, the person must:

- be between the ages of 16 and 64
- have a disability (as defined by the Social Security Administration)
- be working
- have unearned income (e.g. SSDI, SSI, alimony) under 150% of the federal poverty level. *There is no earned income limit.*

Some fees or premiums may be charged based on the person’s countable income from both employment and unearned sources. The application process is the same as regular Medicaid application. It may be useful to specifically mention Health Coverage for Workers with Disabilities in your communications with your case worker, as some DSS offices may not be as familiar with the program. If you meet the requirements above and have applied but are having difficulties accessing the program, please contact Disability Rights NC at 877-235-4210.

Affordable Care Act: People can now purchase health-care coverage, regardless of any pre-existing condition, through the health-care exchange or private insurance companies. Most people will be required to get health-care coverage by March 31 or pay penalties. People who already have coverage through an employer, Medicaid, or Medicare do not need to purchase it through the ACA. Many of those who need coverage will qualify for subsidies to make the insurance plans more affordable. Coverage plans began January 1.

Why should people with autism and their families sign up for health-care coverage?

- The old saying goes “an ounce of prevention is worth a pound of cure.” Healthy people get regular checkups and routine tests to look for treatable problems. Many preventive health care visits, including autism screening for children at 18 and 24 months, are covered free or at low cost under the ACA. People with disabilities may die sooner than others, not because of their disability but because of other treatable conditions. Individuals with autism sometimes have difficulty communicating, so may not be able to tell caregivers about physical problems they are experiencing.
- A health-care crisis can be expensive: insurance coverage can be a measure of security that you can get help paying for major medical expenses such as an emergency room visit, a hospital stay, or treatment for illnesses such as cancer. Insurance companies are no longer allowed to impose dollar limits – annual or lifetime – on coverage.
- The ACA requires health plans to have some coverage of habilitative services that people with autism may need such as speech therapy, occupational therapy, and physical therapy. State law does apply limits to some benefits, however, and it remains to be seen which are affected. Applied Behavioral Analysis is not included in the ACA list of “essential” benefits.
- Health plans may also help with the cost of medications and some behavioral health care (i.e. mental health care) even if services like ABA are not yet covered.
- Young adults can be covered under their parents’ plan until they are 26 years old.

There are several ways to learn about coverage options and enroll:

- Use www.healthcare.gov. The site has basic info about the Affordable Care Act as well as a place to sign up online.
- Call 800-318-2596. Assistance is available 24 hours a day.
- Make an appointment with a health-care navigator. These are people trained to provide one-on-one help in understanding and signing up for health-care coverage. Call 855-733-3511 for an in-person appointment in your area.
- Contact a private health insurance agent to ask about coverage options. ♦



CAMERON'S CREW

It started out as one mom's idea to help her son's cross-country teammates understand more about him and autism. Just a few weeks later, "Cameron's Crew" brought together 120 walkers and runners for the Triangle Run/Walk for Autism.

In the early hours of that Saturday morning, dozens of students boarded a charter bus in Goldsboro for the 50-mile trip. A former teacher drove with her family all the way from Georgia. Alumni, guidance counselors, his sister's field hockey team – all of them traveled to Raleigh to support Cameron Carlyle and the Autism Society of North Carolina.

"It was so overwhelming, and I was just so excited for him," said the 13-year-old's mother, Holly Carlyle. "I never thought I would see something like that, so many people that would be so caring." Cameron, too, said, "I'm kind of surprised about how many people joined my team... It made me feel happy and special."

The team name "Cameron's Crew" was a reference to the seventh-grader's love for all things pirate, and some carried props or donned pirate garb as they ran or marched through the downtown Raleigh streets. A coach from his school, Wayne Country Day School, even wore the mascot outfit of Pee Dee the Pirate from East Carolina University, keeping it on throughout the race. The students cheered, hugged, and posed for smartphones, cameras, and a videographer.

Cameron's aide, Rob Glass, said the experience was more than just a fun field trip. "It was life-changing for a lot of them. Autism was just a word before."

"I think it opened their eyes that there's nothing different about Cameron compared to everyone else. He just does things different. He's just like any other 13-year-old boy; he likes video games."

Cameron was diagnosed with pervasive developmental disorder not otherwise specified (PDD-NOS) at 18 months, and his diagnosis was changed to autism when he was 2½. His family started him in therapies when he was young, but he struggled with sensory processing, fine motor skills, and gross motor skills.

Last spring, when Cameron was having trouble in school, his parents moved him to Wayne Country Day. His mother said the small school has a positive atmosphere, and she can tell the students are happy. "No one has teased him since he has been there," Carlyle said. "They don't tolerate stuff like that."



Cameron has also benefitted greatly from the influence of Glass, who shadows him throughout the school day, helps him stay organized, and makes sure he is progressing toward goals. Cameron said Glass "is also a good mentor and friend who has taught me not to be afraid to try new things."

Cameron joined the cross country team this fall when his family was looking for a way to keep

him active outdoors – away from video games – and interacting with peers. When Holly Carlyle suggested the race as a bonding activity, the team quickly got on board. Cameron's parents came to the school to speak at an assembly and hand out autism awareness items; by the end of the day, 70 students had signed up. "The more the team got excited about doing the walk, the more Cameron did," Carlyle said. "All of a sudden, kids are starting to high-five him in the hall."

All of that excitement translated into more than \$7,400 in donations for the Autism Society of North Carolina.

But Carlyle and Glass said the best things to come out of the team's participation were the kids' unity and awareness about autism. They learned "we're not a bunch of individuals, we're all one," Glass said. ♦



FALL RUN/WALKS

The Autism Society of North Carolina's Run/Walks create awareness about autism while raising funds throughout the state. Last fall, more than 4,600 participants raised \$420,000 to improve the lives of individuals with autism, support families affected by autism, and educate their communities. We are so appreciative of all the individuals, families, and businesses that participated, donated, volunteered, or sponsored this year! Here are some highlights from the fall of 2013:

Triangle Run/Walk for Autism

An autumnal morning in downtown Raleigh set the tone for the 15th annual Triangle Run/Walk for Autism, which raised more than \$320,000. A record-breaking number of participants – over 3,500 – and 230 teams signed up for the October 12 event to raise money in honor of a loved one with autism or to promote awareness in the community. Many of the teams showed their team spirit and creativity with customized t-shirts, banners, costumes, and even a Team Declan flash mob! Shades of Gray and Pediatric Possibilities were the top two fundraising teams, while Walking with Grace signed up a Run/Walk record number of team members: 256.

WNC Run/Walk for Autism

The eighth annual WNC Run/Walk for Autism on September 14 raised more than \$61,000. More than 600 runners and walkers, 100 volunteers, and a variety of businesses participated in the family event to raise awareness and change lives in the community. UNC-Asheville hosted the run with its challenging course full of hills. The event had over 100 more participants this year, with Team Marlowe having the largest team.



Greensboro Run/Walk for Autism



The fifth annual Greensboro Run/Walk for Autism was held September 28 at UNC-Greensboro. This year, the event raised more than \$39,000 with over 400 participants. In addition to the competitive and noncompetitive 5K events, a one-mile Family Fun Walk was added that brought out

families of all abilities. The Alamance All Stars once again were a top fundraising team, with Burlington-based Quest for Quay coming in a close second.

Help Plan Upcoming Run/Walks

Our families, friends, supporters, committees, and volunteers work very hard year round to make these events successful. We hope you will consider joining us next year for one of our signature Run/Walks. We currently have events planned in Asheville, Beaufort, Concord, Greensboro, Greenville, Mount Airy, Raleigh, and Wilmington. All of the Run/Walks are looking for new committee members to help the events continue to grow.

For more information, please contact Macy Russell at mrussell@autismsociety-nc.org or 919-865-5051. All of the proceeds from our fundraisers stay in our state to help North Carolinians affected by autism. Your contribution makes a difference!

Run Sponsors Many thanks to the following sponsors of our fall Run/Walks for Autism. These events would not be possible without our sponsors. Please support these businesses and thank them for their support of the Autism Society of North Carolina. ♦

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FUNDRAISERS AND EVENTS

What Can Your Gift Make Possible?

\$50 gives a parent an evening of respite so they are better able to care for their child.

\$100 sends an Autism Resource Specialist to an Individualized Education Program meeting at school so a family doesn't have to go alone.

\$250 allows a child to build social skills in an enriching afterschool program for a week.

\$500 delivers an educational workshop to families, teachers, or first responders.

\$1,700 sends a child for a week to Camp Royall to have fun, learn new things, and make friends.

\$5,000 provides four adults with autism the necessary job skills training to gain meaningful employment.

Visit www.autismsociety-nc.org to make an online donation or mail your contribution to:

ASNC, Attn: Beverly Gill
505 Oberlin Road, Suite 230
Raleigh, NC 27605.

Does Your Company Match Gifts?

Many companies will match donations by their employees. Check with your human resources department to see whether your company offers this option; it will double the impact of your gift!

Host a Fundraiser to Help Families

Volunteers throughout our state host fundraisers to benefit the Autism Society of North Carolina. They rally friends, families, and colleagues to participate in restaurant nights, donate proceeds from the sale of various items, or create a unique event. It all starts with a fundraising idea. A few recent highlights include two golf tournaments – Keystone Insurers Group raised over \$10,000 and Vulcan Materials raised over \$15,000 – and a workout fundraiser by Forged Fitness that raised over \$12,000. (Pictured above from left, Paula Martin of Vulcan Materials, Macy Russell of ASNC, Jim Lafon of Tramac, and Beverly Gill of ASNC take time out for a photo during the Vulcan golf tournament.)

ASNC is grateful to the many individuals and businesses that host fundraisers to help families affected by autism. If you are interested in hosting your own fundraiser, please contact Heather Hargrave at hhargrave@autismsociety-nc.org or 919-865-5057. We would like to thank the following individuals and businesses for recently hosting a fundraiser:

Addy Miller
Asheville-Buncombe Adult Soccer Association
Burlington Royals Baseball Club
DeOnna Bryant/New Bern High School
Calvary Baptist Church
Chocolate 5K
Chuy's
Coddle Creek Elementary School
Jason Colmenero/Bailey's Fine Jewelry
"A Time to Give" Fundraiser
Durham Bulls Baseball Club
Dunn-Benson Ford
Forged Fitness
Full Throttle Car Club
Gannett Foundation/Cornhole Tournament
Genworth
Inman Park Community Neighborhood
Melissa Jacobs/Stella & Dot

Rev. Alexander Jones/AME Zion Church
Jordan Lake School of the Arts
Kenley Wood/Lemonade Stand
Keystone Insurers Group
Kiwanis Club of Lee County
Knights of the Fiat Lux
Helene and Bill Lane/Lake Park Kids Triathlon
Jennie Lee/Showing Off for Autism
NC Scrapbook Crops & Retreats, Inc.
Outer Banks Beach Ice, LLC
Kevin Smitherman/Vulcan Golf Tournament
Stangs-R-Us Car Club
Southwest Elementary School
The Tommy Foundation, Inc.
Whole Foods - Asheville
Williams Chiropractic

A photograph of three people in a canoe on a river. The person in the front is a woman in a green shirt and yellow life vest, holding an orange paddle. The person in the middle is a woman in a grey shirt and yellow life vest. The person in the back is a man in a purple shirt and yellow life vest. The canoe is dark grey and has "SEA ARK" written on its side. The background shows a riverbank with trees and grass.

WORLD AUTISM AWARENESS AND ACCEPTANCE DAY

On Wednesday, April 2, you are invited to join families, self-advocates, and other members of the autism community at Camp Royall to celebrate World Autism Awareness and Acceptance Day (WAAAD) 2014. Nearly 500 people attended the WAAAD celebration in 2013, and we hope to have even more people participate this year.

What is World Autism Awareness and Acceptance Day? In 2008, the United Nations General Assembly unanimously declared April 2 as World Autism Awareness Day to highlight the need to help children and adults with the disorder to lead full and meaningful lives. The Autism Society of North Carolina recognizes that acceptance of each person as an individual and of their ability to contribute to society is just as important, so we added "Acceptance" to the day's title.

Camp Royall, located in Moncure just south of Pittsboro, will be open from 10 a.m. until 4 p.m. for our celebration. Attendees will have a chance to participate in boating, fishing, hay rides, and many more kid-friendly activities. For those who are not familiar with Camp Royall, it is a great chance to check out everything it has to offer. Face-painters will also be on hand, and many sensory activities are planned. And of course, no trip to camp would be complete without a cookout! Plan to stay for lunch. ASNC staff, including Autism Resource Specialists, will also be available to answer questions.



“It’s wonderful. It means that there is a lot of awareness in the community. For my family personally, it’s great because it’s a chance to come out and enjoy camp.”

– A mother speaking about attendance at last year’s event

The activities and lunch are free; we will accept donations. To help us plan for staffing and food, please RSVP via email to camproyall@autismsociety-nc.org or by calling the camp at 919-542-1033.

Editor’s note: In the summer 2013 article about last year’s WAAAD event, we

stated that Betty Camp and Mary Lou (Bobo) Warren started the summer camp for children with autism that would become Camp Royall. Bobo was the camp’s first director and visionary. Later, as board president, Betty was instrumental in securing funding for Camp Royall. ♦

Join Us for World Autism Awareness and Acceptance Day!

When: 10 a.m. to 4 p.m. Wednesday, April 2

Where: Camp Royall, 250 Bill Ash Road, Moncure, NC 27559

To RSVP: Email camproyall@autismsociety-nc.org or call 919-542-1033

DONOR SPOTLIGHT: KEYSTONE INSURERS GROUP

Several years ago, the senior executives and board of Keystone Insurers Group wanted to designate a corporate cause. After about 25 years in business, their company was one of the largest privately held insurance agencies in the United States, and they thought it was time to give back to the community. Autism was a cause that had hit home. Joe Joyce, who had been with Keystone for more than a decade and was one of those senior executives, has a son who is severely affected by the development disorder.

“Everyone within Keystone knows of the challenges that our family has faced in raising David,” said Joyce, who lives in Harrisburg, PA, with his wife, Elise; son David, 15; and another son, Matt, who has Down Syndrome. David, who has never spoken and has self-injurious behaviors, lives at home but is constantly supervised by his mother and aides. “We have to have people with him at all times to keep him from injuring himself,” Joyce said.

When the company’s leaders committed to supporting organizations that help families affected by autism, Joyce was “completely overwhelmed,” he said. Keystone president David Boedker says the decision was easy. The effort would not only honor the son of his friend, whom Boedker calls “his personal hero in life,” but also help bring much-needed attention to an issue they thought wasn’t getting enough notice.

Since then, Keystone has donated nearly \$400,000 to autism groups in some of the nine states where it has partner agents and also na-

tionally. “David will never know all of the good that he has caused to come about,” Joyce said.

In North Carolina, the company has raised more than \$40,000 for the Autism Society of North Carolina through three golf tournaments held during their meetings of partner agencies every other year.

Eighty to 90 golfers participate in the Greensboro tournament, and donations come from both companies and individuals.

“It’s a humbling experience to be a part of it,” said Jim Trotter, vice president for the North Carolina region. Trotter serves as the “go-to guy” during the tournament, making sure participants are checked in, sponsor booths are set up, and everything goes smoothly. “For me, it’s extremely rewarding simply because of my observation of the Joyce family,” he said. “They’re just a great family.”

The tournament is capped by a dinner that evening, during which participants hear from Joyce as well as speakers from the Autism Society of North Carolina. Joyce said it

was difficult at first to share his personal story, but he knows it is important to help increase awareness about autism. Boedker said, “There’s rarely a dry eye in the room after Joe’s speech.”

Trotter said he is always inspired by the speakers. “It’s heart-wrenching as well as heart-warming.” ♦



“David will never know all of the good that he has caused to come about.”

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 July 1, 2013, and November 30, 2013. Please contact Beverly Gill if you have any questions or corrections at 800-442-2762, ext. 1105, or bgill@autismsociety-nc.org.

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Eric Anderson <i>Melonia and Randy Anderson</i>	Miles Jones <i>Suzanne and Daryl Jones</i>	Tracey Sheriff <i>ABC of NC</i>
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John Rex Endowment awards grant

The John Rex Endowment has awarded a capacity building grant of \$47,725 to the Autism Society of North Carolina to update our strategic plan to ensure the organization's sustainability and future growth. The implementation of the strategic plan will lead to greater access to quality care for children with autism to improve lives and reduce the overall costs associated with providing care.

The John Rex Endowment supports an environment where children and families in greater Wake County live healthy lives. Guided by the belief that all children should reach their full potential, the John Rex Endowment works with the community to support the physical, mental, and emotional well-being of children. For more information about the John Rex Endowment, call 919-838-1110 or visit www.rexendowment.org.



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SAVE THE DATES

January

- 13 – Camp Royall Summer Camp lottery opens (See page 11)
- 31 – Annual Conference early registration deadline (See pages 4-6)

February

- 21-22 – Annual Conference, “Autism: Planning for Success,” in Charlotte
- 24 – Camp Royall Summer Camp lottery closes

March

- 25 – Autism Awareness Night at the Carolina Hurricanes in Raleigh
- 29 – Coastal NC Run/Walk for Autism in Wilmington
- 29 – Cabarrus County Chapter Puzzle Run in Concord

April

- 2 – World Autism Awareness and Acceptance Day at Camp Royall (See page 24)
- 12 – Eastern Run/Walk for Autism in Greenville
- 26 – Surry County Chapter Walk for Autism in Mount Airy

May

- 17 – Crystal Coast Chapter Run/Walk for Autism in Beaufort

June

- 1 – Zipping for Autism in Asheville

To learn more about these and other upcoming events, please visit www.autismsociety-nc.org or contact Heather Hargrave at 919-865-5057 or hhargrave@autismsociety-nc.org.