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Spring
2004

South Carolina Autism Society

Together We Can Solve The Puzzle

It's Autism Awareness Month: Golf, Bowling, a Cruise, Hockey and More!

April is Autism Awareness Month across the U.S. In South Carolina, Gov. Mark Sanford has issued a proclamation (see it on the web at scautism.org). The S.C. Autism Society will sponsor a bowling fundraiser Saturday, April 17 in Columbia, and a golf benefit in Garden City on Saturday, April 24.

SCAS is pleased to announce these and other events to support South Carolinians with autism spectrum disorders. To benefit SCAS, motorcyclists will ride from the Aiken area to Columbia on April 3, and a silent auction will be held April 7 at a law

enforcement officers' conference.

To support Camp Good Times for children with autism, there will be a cruise of the Charleston Harbor on Sunday, April 4. On Sunday, April 18 in Augusta, Ga., a Canada vs. USA Charity Hockey Game will benefit Autism Ability Advocates.

Details of these events are provided in this article. If you can't participate, there are other ways you can get involved during Autism Awareness Month. You can help to sponsor the golf outing (see box), make a pledge to honor a bowler or golfer, or stop by SCAS's offices for the annual "drop-in" from 4 to 6 p.m., on Wednesday, April 28.

Information and registration for bowling or golf can be found on the SCAS website, www.scautism.org, or by calling 750-6988 in Columbia or 800-438-4790.

Bowl in N.E. Columbia April 17

Rolling for Autism Awareness will be held Saturday, April 17 at Royal Z Lanes, located at 8512 Two Notch Road in northeast Columbia. The fee is \$15 per person, which includes two games, shoes, a t-shirt and snacks. Families of five can bowl for \$55.

Call SCAS at 750-6988 to sign up for either the noon or 2:30 p.m. start time. Remember, prizes will be awarded for top pledges and donations, so talk to your family and friends today to enlist their support.

Hit the greens April 24

You don't have to be a winning golfer to play in the "Fun in the Sun" tournament, set for Saturday, April 24, at the Indian Wells

cont. on p. 3 — see Fundraisers

Be a golf sponsor

Families and employers can support SCAS by sponsoring a hole at the golf outing or becoming an event sponsor. Each sponsor is acknowledged on an individual sign that SCAS provides. Family sponsors who have a loved one with autism can have his or her name put on the sign. All for just \$50, the minimum gift. Call 750-6988 for more information about becoming a sponsor. Here are the categories:

Hole Sponsors

Family - \$50
Corporate - \$100

Event Sponsors

Platinum* - \$1,000
Diamond** - \$750
Gold - \$500
Silver - \$400
Bronze - \$300

* plus 4 players

** plus 2 players

From the Desk of the President

Dear Friends:

As you can easily see from our newsletters, the South Carolina Autism Society is going through a lot of changes. I'd like to go over some of them and share our vision of the future.

Service Coordination

As you read just before the holidays, SCAS was approved by the Department of Disabilities and Special Needs as a qualified provider for service coordination. We have begun providing this service in the Midlands. Cecilia Williamson is our service coordinator and program coordinator. The program is moving forward and we plan to expand across the state. SCAS will be able to facilitate the best services by managing the growth and expansion of our caseloads to ensure a smooth transition for individuals with autism and their families.

Our service coordination program can offer everything that your family member is getting from your current provider. The difference is that we will specialize in children and adults with autism. SCAS has a strong sense of "person centeredness," which means we believe the individual and/or their family must have choice and control in making decisions about their lives. This is why we suggest that families choose an independent facilitator for the person-centered plan, so that people with different perspectives are involved in developing the plan. Cecilia will work from that plan with you and your loved one to see that it is fulfilled. If you would like to switch to SCAS for service coordination, please call us.

Tax-Exempt Status

SCAS has received the final determination by the IRS granting us tax-exempt status as an independent nonprofit organization. For the last 30 years or more, SCAS has been a part of a group ruling issued to the Autism Society of America (ASA). Having our own exemption will allow us more independence and freedom to address the needs of individuals with autism spectrum disorders here in South Carolina. This is mostly a technical change, but it will allow us to do things that are needed in our state — like offering specialized service coordination.

SCAS Dues

Last quarter we announced we would no longer collect ASA dues after Jan. 1, 2004. We made this change partly due to confusion over membership expiration dates, which were different for ASA than for SCAS. ASA has agreed to send its own dues notices to members, and we will send you a separate renewal notice for ours. This may seem a little confusing now, but we believe it will work out better once we've all become used to the change. In the meantime, we encourage members of SCAS to continue as members of ASA, one reason being that ASA advocates for improvements in the lives of people with autism on the national level.

As SCAS moves forward, I project that we will continue to grow. Already we are looking for more parent mentors for our Parent School Partnership program. I am confident that service coordination will grow and our service area expand. But we can only move forward and expand with your help. SCAS needs you to become a member or renew your membership. We also need your support in promoting and participating in our special events, like those for Autism Awareness Month. Further, we need your financial support. Contributions are our lifeline. Thank you for continuing to support our important activities.



Craig C. Stoxen
President and CEO

Autism Awareness Month fundraisers

cont. from p. 1

Golf Course, Highway 17 Bypass, in Garden City. Amateurs and even beginners have had a good time at past outings and have helped the cause at the same time.

The staggered starts will be at 7 a.m. at holes 1 and 10. Individual players can register for \$75 (four-person team, \$300) by the extended deadline of April 8; \$85 (team, \$340) up to the day of the event; and \$100 (team, \$400) on the 24th. The fees include a cart and greens fees, plus lunch. You can register on-line. Another great way to support people with autism in our state is to become a golf sponsor (see box on page one).

Indian Wells offers a blend of rolling terrain, sand, water and trees, and is one of the "Grand Strand's Dream 18" golf courses. Cheryl Bauerle, who chairs the SCAS Board of Directors, and Alex Holbert, a director and longtime golf organizer, are coordinating the outing.

Motorcycle run on April 3

Another annual event to benefit SCAS will be held Saturday, April 3, when motorcyclists ride from the Aiken-North Augusta area to the SCAS offices on Bush River Road in Columbia. Join us as we greet them in the SCAS parking lot. Please call 750-6988 if you would like to help welcome the riders, who collect money for our programs each year. The riders are always happy to show off their motorcycles too.

Cruise for Good Times April 4

Seating will be limited for the Sunday, April 4 cruise of Charleston harbor, so call now to reserve seats, 843-817-2221. Tickets are \$30 per person. Boarding will start at 5:30 p.m., with a 6 p.m. prompt departure. The event will raise funds for Camp Good Times, held in the Low Country each summer for children with autism spectrum disorders. The two-hour cruise will include food, beer and wine, and live island music.

Ice hockey benefit April 18 in Augusta

You'll have to cross the state line, but the \$5 per person ticket price is a winner for the Canada vs. USA Charity Hockey Game at the Augusta Ice Forum on Sunday, April 18. The game will benefit Autism Ability Advocates, which needs funds to continue its Building Bridges Workshops in the Aiken area. The game will start at 2 p.m. and last until 4 p.m. Children under 12 get in

free. For advance tickets, contact Denice Stout at 803-215-7593 or e-mail her at Dstout6@aol.com.

SCAS says "thank you"

The S.C. Autism Society expresses its appreciation to all the people who have helped to organize and support these events.

Joining a growing list of SCAS benefactors are two law enforcement groups, the S.C. Association of School Resource Officers and the State Association of Crime Prevention Officers. They have generously offered to give proceeds to SCAS from this year's silent auction, which will be held April 7 at their joint annual conference in Myrtle Beach.

Join us on April 28

SCAS will hold its annual Autism Awareness Month drop-in from 4 to 6 p.m. on Wednesday, April 28, in the offices at Suite 203, 652 Bush River Road, in Columbia. Join the staff for snacks and beverages and learn more about the growing programs SCAS offers, including service coordination for individuals with autism.

The Update

The Update is published four times a year by the South Carolina Autism Society, one of more than 200 nonprofit chapters of the Autism Society of America (ASA) and the only ASA chapter in South Carolina. Guest articles are welcome for possible publication. Information or points of view contained in the *Update* are not necessarily endorsed or held by SCAS, its directors or staff, but may be presented simply to keep readers informed about options. SCAS maintains offices in the Palmetto Office Building at 652 Bush River Road, Suite 203, Columbia, SC 29210. Call us at 803-750-6988 or 800-438-4790; fax us at 803-750-8121; or e-mail us at either scas@scautism.org or www.scautism.org.

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What's Going on at SCAS . . .

Society Now Offers Service Coordination

The S.C. Autism Society began providing service coordination to individuals with autism on Feb. 1. Cecilia Williamson was hired in January as the first SCAS service coordinator.

SCAS eventually plans to offer service coordination statewide but is beginning with residents of Richland, Lexington, Fairfield, Newberry and Kershaw counties.

Cecilia already is providing service coordination for several children and adults with autism who previously had service coordinators through their local Disabilities and Special Needs Boards. They are continuing to receive the same services as before; the only difference is that SCAS coordinates these services.

She has worked as a Department of Disabilities and Special Needs service coordinator for two years in Orangeburg and York counties. She is a native of Coward, a town near Florence, and has 10 years' experience in social work in South Carolina.

If you have a family member who is currently being served by DDSN through one of its boards, and you wish to transfer your case to the S.C. Autism Society, please contact your present service coordinator to tell her or him that you would like to transfer.

If you need assistance in this process, or you just want to talk over a possible change, call Cecilia at 803- 750-6988 or 800-438-4790. Her extension is 114. She will be glad to answer any questions.

The mission of service coordination is to enhance the life of individuals with autism by working with families to: (1) Identify and obtain needed services; (2) Monitor and evaluate services; (3) Construct lifelong plans; (4) Provide information and support; (5) Create and develop opportunities; (6) Assure plan achievement; and (7) Educate the broader community.

Service coordination is the newest program of SCAS and will build on existing programs of information and referral and advocacy. The program will fall in line with the organization's proactive approach in assisting our families.

"We have long taken the position that there should be more options for services for individuals with disabilities in our state," said Craig Stoxen, SCAS president and CEO.

"By offering service coordination, SCAS will provide an alternative to individuals and families who want a choice."

Get the Update by E-mail

The S.C. Autism Society is inviting *Update* readers to receive the newsletter electronically, via e-mail, instead of receiving a "hard" copy by mail every three months.

Receiving the newsletter electronically will cut SCAS's costs for the newsletter and get the information to you more quickly than before. There currently is at least a two-week "turnaround" on getting each edition printed and mailed to more than 2,000 addresses.

When you want to get the most up-to-date information on events like those set for Autism Awareness Month, two weeks can make a real difference.

The *Update* will be transmitted as a PDF file. E-mail users who cannot currently read PDF files will be able to download the software for free.

Please let us know if you want to receive the newsletter by e-mail, and SCAS will send it to you electronically each quarter. E-mail your request to: scas@scautism.org. Your name will then be removed from our USPS newsletter mail list.

Find SCAS, Other QP Listings on DDSN Site

To take a look at all of the organizations currently providing services under the S.C. Department of Disabilities and Special Needs, look up the department's Qualified Provider List (QPL) on the website, www.state.sc.us/ddsn/.

As more organizations (like the S.C. Autism Society) begin serving the DDSN population, the QPL will grow.

The QPL shows providers, services offered, disabilities served, and in which counties services are provided. You can search by county or by service (housing, service coordination, early intervention are a few examples). By offering choices of providers, DDSN is moving closer to its goal of person-centered services for its clients in our state.

What's Going on at SCAS . . .

Parents Needed for Interviews about Marriage

Married parents of children with autism are needed for interviews to aid in the development of couples training. The training will be designed to help parents of these children to strengthen their marriages as well as their overall family functioning.

Susan Marciano, a Ph.D. candidate in the University of S.C. College of Social Work, is conducting the interviews in cooperation with the S.C. Autism Society. SCAS has been sending letters to parents to find volunteers, but more are still needed.

In her letter, Susan notes that several studies have indicated that parents of children with autism are at even greater risk for marital problems than parents who have children with other special needs. For the study, she is seeking interviews with the natural parents of children with autism who are married and living together in South Carolina. She will not be interviewing single parents for this study.

The interviews can take as little as one hour, and only one parent is required to be present. Susan is doing the interviews in the parents' homes.

The parents are being asked to identify their needs and concerns relating to their marriage and family in view of having a child with autism.

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Online Forum Opens

SCAS has opened an online forum for higher functioning individuals with autism or Asperger's syndrome, and their families.

Membership will be monitored, which means forum members will need to complete an easy application process. Content will not be monitored. Members may not attach files because of potential viruses.

To join, send an e-mail message to: schighfunctioningasd-subscribe@yahoo.com.

A New Arrival!

Congratulations to Anjeanette (AJ) Cheshire, one of the S.C. Autism Society's parent mentors, on the birth of Luke Benjamin in December.

He weighed in at 7 pounds, 6 oz., and joins brother Ryan and sister Katie.

Debbie Howard helped out with AJ's families while she was on leave.

"It was painless," said one mother who was interviewed. "It took only 45 minutes and we did some talking."

"The interviews and training are a great idea, and we're happy to be collaborating on it," said Craig Stoxen, SCAS president and CEO.

If you are willing to be interviewed, Susan can be contacted at her office, 803-776-1736. If you prefer you can call the SCAS toll-free number, 800-438-4790, and leave a message at ext. 108.

"I know from talking to many parents over the years that marriages are affected, sometimes profoundly so, by having a child with an autism spectrum disorder," Craig said. "But there aren't many studies, materials or programs available at this time in this area, which means the help some families need is just not out there. This is a positive step, so we hope parents will call Susan to be interviewed."

Wanted: Parent Mentors

The S. C. Autism Society's Parent-School Partnership is looking for two parent mentors, which are paid positions. One parent is needed to work with parents in Horry, Georgetown and Williamsburg counties; another is needed for Orangeburg, Bamberg and Barnwell counties.

The mentor must be the parent of a student with an autism spectrum disorder and an active participant in the student's educational program; have some training in autism and the Individuals with Disabilities Education Act; have reliable transportation and be willing to travel within the assigned counties; and be willing to work a flexible schedule.

Duties include, but are not limited to, phone work, attending IEP meetings with assigned families, speaking to schools and other groups about issues relating to autism spectrum disorders, attending workshops relating to autism spectrum disorders and IDEA, and maintaining data and other pertinent information relating to the job.

If you have questions regarding this position please call Program Coordinator Melanie Marquis at 803-750-6988 or 800-438-4790, ext. 101.

Send your resume to: S.C. Autism Society, 652 Bush River Rd., Suite 203, Columbia, SC 29210, to the attention of Melanie Marquis.

Spring Calendar of Events

April

3	Linking Families with Special Education, Mullins	Peggy Bryant 843-423-4623 ext.125
3	SCAS Fundraiser, Bimini's Oyster Bar, Myrtle Beach	SCAS at 800-438-4790, 750-6988
4	Charleston Harbor Cruise for Camp Good Times (Benefit)	Mary Buty 843-813-3200
6	Roles, Rights and Responsibilities, Mauldin	PRO-Parents 800-759-4776 803-772-5688
13	Roles, Rights and Responsibilities, Greenwood	Michelle/Ashley/Tina 864-942-4982
14-15	SLEPA Training, Midlands Autism Division	803-898-9609
15	Supporting Adults with Autism, Piedmont Autism Division	803-898-9609
16	Roles, Rights and Responsibilities, Easley	Lyle Jacks 864-859-5416
16-18	DAN 2004 Spring Conference, Washington, D.C.	Tanya@newhopetravel.com
18	Canada-USA Hockey, Augusta (Building Bridges benefit)	Denice Stout 803-215-7593
17	SCAS Bowling Fundraiser in Columbia at Royal Z Lanes	SCAS at 800-438-4790, 750-6988
20	Roles, Rights and Responsibilities, Gaffney	Lori Covington 864-487-2139
21-23	Power of 1.5 Conference, Washington, D.C.	www.unlockingautism.org
22	Roles, Rights and Responsibilities, Spartanburg	Paula White 864-596-2207
22	Supporting Adults with Autism, Piedmont Autism Division	803-898-9609
22-23	PECS Workshop, Atlanta GA	Sarah Moore 302-368-2515
24	SCAS Golf Fundraiser in Garden City	SCAS 803-750-6988
27	Autism-Service Coordination, Coastal Autism Division	803-898-9609
28	Drop-In for Autism Awareness, SCAS Office, 4-6 p.m.	803-750-6988
29	Supporting Adults with Autism, Piedmont Autism Division	803-898-9609
29	Section 504 Workshop, Sumter	PRO-Parents 803-772-5688

May

4-6	Autism-Basic Treatment Strategies, Midlands Autism Division	803-898-9609
14	Autism-Parent Training, Midlands Autism Division	803-898-9609
22	ADD/ADHD & Behavioral Intervention, Laurens	Tammy Guthrie 864-862-7435
27-30	Autism One 2004 Conference, Chicago, IL	www.AutismOne.org

June

7-8	PECS Workshop, Greensboro, NC	Sarah Moore 302-368-2515
10	Autism-Basic Treatment Strategies, Piedmont Autism Division	803-898-9609
16-17	Carol Gray Workshop, Columbia	SCAS 803-750-6988
17	Autism-Basic Treatment Strategies, Piedmont Autism Division	803-898-9609
24	Autism-Basic Treatment Strategies, Piedmont Autism Division	803-898-9609

Congratulations, Latest Bravo Winners

Bravo awards are given during the school year to deserving school personnel who serve students with autism spectrum disorders (ASDs).

They are nominated by parent mentors working in the S.C. Autism Society's Parent-School Partnership, and are chosen for their dedication to, and love of, students with ASDs. SCAS gives winners a certificate and sends a letter about the recipient's accomplishments to the appropriate school superintendent.

Congratulations, Bravo winners!

Mrs. Margaret Thomason, Principal, Crestview Elementary School
Greenville County School District

Nominated by Debbie Howard

Mrs. Thompson was nominated for her positive attitude and interpretation skills, as well as her management style in serving students with autism.

Mrs. White, Ms. Crall and Mrs. Jarmaill, Resource Teachers
Fort Johnson Middle School

Charleston County School District

Nominated by Dandrea Woolridge

This is the team every student with autism needs if inclusion is to be successful in the middle school years.

Ms. Carla Gambrell, Special Education Teacher
McKissik Elementary School

Pickens County School District

Nominated by AJ Cheshire

Ms. Gambrell is a wonderful teacher whose love and dedication run deep. She ensures that her students learn skills that are functional and teaches them in the way they each learn.

Ms. Claire Sturkey, Speech Therapist
York County School Districts 1 and 2

Nominated by Tammy Ruiz

Ms. Sturkey is determined that her students will be able to communicate in some way, shape or form. She will stop at nothing to provide students the opportunity to communicate with the world around them.

Ms. Lynette Brigman, Special Education Teacher
Cheraw Primary School

Chesterfield County School District

Nominated by Lissa Waring

Ms. Brigman is warm and loving to students and families, helping both with the first-time school experience.

Alice Williams, Special Education Teacher
Fullmer Middle School

Lexington District 2

Nominated by Melanie Marquis

Ms. Williams is extremely dedicated to her student's needs in the classroom, home and community, even helping the family to access services outside of school.

Ms. Lisa Hill, Paraprofessional
Speers Street Elementary

Newberry County School District

Nominated by Brande Smalley

Ms. Hill is compassionate and really wants her student to be successful. She has even taken it upon herself to watch videos and read information on autism. She has asked to attend her student's IEP meeting.

Caregiver Sleep Loss Needs to be Addressed Too

by Ruth K. Abramson, Ph.D.

Department of Neuropsychiatry and Behavioral Science, USC School of Medicine

Editor's note: Ruth is a Fellow of the American College of Medical Genetics and a regular contributor to the Update. She is part of the USC-Duke University team that is researching the genetics of autism spectrum disorders.

Welcome to the spring edition of the New Research Report. Before I go into the topic of sleep research and autism, I'd like to mention the ice storm of late January because I have wondered what the experience was like for our younger children with autism or Asperger's syndrome. I would love to hear about how children and adolescents reacted to the slippery cold ice fairy land and the cold, not to mention power outages if your family experienced that. Please send your interesting stories to the Autism Society and I will include a few in my next column.

For this edition of the New Research Report, I would like to report on two articles that deal with something that is important to all of us: SLEEP. Whether we have autism or Asperger's or whether we are a parent, the impact of sleep on our lives is not insignificant.

Schreck and colleagues (2004) [Sleep problems as possible predictors of intensified symptoms of autism, *Research in Developmental Disabilities* 25:57-66] evaluated sleep as a something which might influence daytime behaviors and affect behavioral interventions for children with autism. Studies of normal adults and children have shown that sleep problems can negatively impact learning rate and cognitive, verbal, motor, visuospatial and creative performance. Not getting proper sleep can also alter emotional states, impair flexibility to change, and result in noncompliance, inattention to task, depression, hyperactivity, and aggressive behaviors in normal adults and children. Thus, if you are a parent of a child who has sleep problems and you have sleep problems because of your child's, then how you learn, react, and function may be very different from when you get good sleep on a daily basis. Sleep loss also means you won't be able to handle the world in which you live as well.

Given the impact of sleep problems on normal adults and children, Schreck and colleagues wanted to examine the question, "Are the fundamental diagnostic characteristics of autism exacerbated by sleep problems?" and evaluate whether specific sleep problems might be related to the expression of specific behavioral features of autism. A few general studies of sleep problems for children with autism indicated that sleep problems affected daytime behavior including overactivity (Hoshino et al, 1984), disruptive behavior (Patzold et al, 1998), communication difficulties (Segawa et al 1992), social difficulties (Segawa et al, 1992), and difficulties breaking routines (Segawa et al, 1992). All are problems that could significantly affect how a child learns during the day.

For this study information was taken from a database (Schreck & Mulick, 2000) which examined types of sleep problems in children with autism. For this study, information from 55 parents on their child with autism (ages 5-12 years) was included. Inclusion in the study required that the parent report that the child had previously been diagnosed with autism spectrum disorder and that a Gilliam Autism Rating Scale (GARS: Gilliam 1995) be completed indicating a high probability that autism was an accurate diagnosis. Parents completed three forms: (1) a demographic form (informant, marital status, race, work shifts, developmental diagnoses of child, professionally diagnosed sleep disorders, current medication, location of sleeping arrangements and educational placement); (2) the BEDS [Schreck, 1997/98; 2003, a sleep problem questionnaire consisting of a 22-item, four factor scale – Factor 1- Expressive sleep disturbances (9 items), Factor 2 - Sensitivity to environment (7 items), Factor 3 - Disoriented Awakenings (4 items) and Factor 4 - Apnea (2 items)] and (3) the Gilliam Autism Rating Scale. Information on hours of sleep per night and hours of naps during the day was collected as part of BEDS. The BEDS can discriminate between children with no sleep problems and those without sleep problems and correlations between professionally diagnosed sleep disorders and parent reports of sleep problems.

The reports of sleep problems from the BEDS were related to the GARS communication, developmental, stereotypic, social skills, and Autism Quotient domains. Daytime communication problems (GARS communication domain) were significantly related to increased sensitivity to stimuli in the sleeping environment (BEDS Factor 2:sensitivity to Environment) and by periods of screaming during the night (BEDS Factor 1: Expressive Awakening). **Thus, children with a strong response to the environment at night and who tend to awaken at night have higher abnormal communication scores on the GARS.**

Sensitivity to environmental stimuli and screaming during the night were also related to worsening of other diagnostic characteristics of autism. Screaming during the night in combination with fewer hours of sleep per night predicted increased stereotypic behavior. Children with autism were not so different from adults with sleep problems. Fewer hours of sleep per night predicted difficulties with social interactions (GARS Social Skills) and a

higher GARS overall score. In addition, sensitivity to the environment was also found to be a significant predictor of fewer disturbances during development (GARS developmental domain). Although these sleep problems contributed only a small amount of the variance in daytime behaviors, this was a significant finding.

Thus, this study continues to support the hypothesis that sleep problems and day behavior are directly connected. This study predicts that sleep problems predicted more intense symptoms of autism. This highlights the need for families where a child with autism has sleep problems to work with professionals to try to treat the sleep problems, both for the effect on daytime behaviors and learning ability in the child and also for the parent, who will not function as well because of their own sleep deprivation. We want the best daytime performance we can provide so that the learning curve in the child with autism is optimal. Making small changes can make a difference!

The second article by Tani et al, (2003) examines sleep problems in young adults with Asperger's syndrome. [Insomnia is a frequent finding in adults with Asperger's syndrome, BMC Psychiatry 3: 12-22]. In children with autism spectrum disorders, initiation and continuity of sleep are disturbed to a greater degree than in children with other developmental disabilities. Children with Asperger's syndrome have previously reported more sleep problems, specifically problems in initiating sleep (going to sleep or sleep latency) and maintaining sleep than age matched controls. The question exists, does this persist as the child with Asperger's syndrome becomes an adult.

Insomnia is defined as difficulty initiating or maintaining sleep, or nonrestorative sleep lasting at least one month and causing significant dysfunction during daytime. It can be primary or secondary (caused by mental disorder, substance abuse, other sleep disorder, or a general medical condition). Insomnia in normal individuals causes emotional distress, daytime fatigue and loss of productivity.

Individuals with Asperger's also may be diagnosed with a mood or anxiety disorder. Mood and anxiety disorders by themselves can influence sleep. This study evaluated sleep quality and comorbid psychiatric disorders in 20 adults with Asperger's matched with 10 normal adults for education, Body Mass Index, and IQ. Subjects were drug free. The autism spectrum screening questionnaire was completed by a parent. The Wechsler Adult Intelligence Scale was administered to all participants by a psychologist. Four of the Asperger's subjects had no psychiatric diagnosis. The most common psychiatric diagnoses among the 18 other adults were anxiety disorders, mild to moderate depression, and obsessive personality disorder or traits. Subjects filled out the Beck Depression Inventory, sleep questionnaire and sleep diary. Sleep latency (how long it took to get to sleep) and sleep efficiency (time in bed-sleep latency-length of time awake after falling asleep or sleep awakening) were calculated.

The Beck Depression Inventory scores were significantly higher for adults with Asperger's than for normal controls, but only two individuals with Asperger's met criteria for moderate depression. The results of the study were the same for individuals with Asperger's and a comorbid psychiatric disorder and those without any psychiatric diagnosis. Individuals with Asperger's had more sleep problems on the sleep questionnaire, including initial insomnia (n=11) [problems falling asleep or sleep latency of greater than 30 minutes], middle insomnia (n=2) [waking up in the middle of the night], and terminal insomnia (n=14) [waking up early in the morning and being unable to get back to sleep]. Poor sleep quality was rated by 5/20 individuals with Asperger's. Only 3 controls displayed insomnia with no daytime consequences and no report of poor sleep quality. The same problems persisted whether it was a work day or a free day. More frequent sleepiness in the morning after awakening and during the day was also reported and was not dependent on whether it was a work day or a free day. Sleep diaries indicated that 15/20 individuals with Asperger's and 3 controls were poor sleepers, with prolonged sleep latency, (n=13); prolonged awakening after being asleep (n=6), and low sleep efficiency (n=9).

The main finding of this study, using three methods, is that adults with Asperger's Disorder have frequent complaints of insomnia (getting to sleep, staying asleep) and daytime sleepiness. This is true whether the individual with Asperger's had a psychiatric diagnosis or not. Subjects complained most often of hypersensitivity to external noise, forgetting oneself at the computer, ruminating on things that happened during the day and most often, just unexplained difficulty in falling asleep. Formal sleep studies (Godboldt et al, 2000) found decreased sleep time in the first 2/3 of the night, REM sleep disruption, and a few individuals with periodic leg movements during sleep. These features predispose to low sleep quality and to the subjective complaint of insomnia. Thus it appears that the sleep problems identified in children with Asperger's persist into adulthood. Some of the problems may be worsened by anxiety and depression, but may still be present in those without these comorbid diagnoses. The authors question whether there is a problem with a defective sleep control system in individuals with Asperger's Disorder.

Once again, it's important to seek help for sleep problems, as they truly affect our functioning!

We would like to thank all the participants in our Autism/Asperger's genetic study and invite new families with a child with autism or Asperger's to participate. We are completing intelligence testing on all children in our families, and results will be available to parents. Sarah Ravan, Dr. Alicia Hall, and I will be happy to answer any questions. Reach us at 803-898-2343. Together we can make a difference in finding the causes.

Autism Division Announces ABBIS Teacher Training

by Bruce A. Braswell, M.Ed.

Director of Training and Quality Assurance

Autism Division of the S.C. Department of Disabilities and Special Needs

Editor's note: This is the second of two articles about new training for teachers that has been developed by the Autism Division of DDSN. In the last Update, Bruce addressed the history of Autism Division training.

The Autism Division of the Department of Disabilities and Special Needs is offering new training for classroom teachers, Autism: Behavior Based Instructional Strategies (ABBIS). ABBIS will be offered for the first time in the 2004-2005 school year and is designed for teachers of students with autism. This article will look at the (1) Autism Division approach to training; (2) ABBIS competencies; and (3) major features of ABBIS.

T&D vs. Academia

The Autism Division uses an approach to designing training that is promoted by Training and Development (T&D) professionals, who are represented by the American Society of Training and Development (ASTD). The approach targets the *skills* people need to do a particular job.

Think about the people trained to work in a bank or to be on an EMS team. Their training is typically based on principles of T&D. Simply stated, the T&D steps of training design are to determine: the skills needed to do a job, the knowledge or information needed to learn the skills, and the minimum time and most cost effective way to train people so that they will have the skills. In the world of business and industry, the T&D approach is a dynamic and ever improving system of training.

The T&D approach is different than course development in the world of academia, or in colleges and universities. College courses usually focus on a body of knowledge, with the goal of learning that knowledge. Skills that people learn in a college course are based on, and flow out of, that body of knowledge. To maintain accreditation standards, college courses have to be a certain number of hours long over so many weeks. Typically for three hours of credit students attend a class for 45 hours over 15 weeks. The academic approach to training involves *knowledge-based* instruction conducted in standard time periods such as semesters. A T&D approach to training is *skill-based* instruction conducted in as short a time as possible. In both approaches mastery of the skills is the goal. How we get there, however, is done in a different manner.

Why the Autism Division Uses the T&D Approach

Part of the Autism Division's mission is to train people in order to positively impact the lives of people who have autism in South Carolina. We use the T&D approach to accomplish this mission for several reasons. First, a T&D approach is best suited to the large number of people we train. Over the past three fiscal years, the number of people attending our training each year has ranged from 1,500 to 1,900.

Second, a T&D approach will allow us to see positive effects on individuals with autism more quickly. Training such as Designing Visual Supports and Designing Social Skills Training provide tools and train skills that people can use the next day after training. These two examples relate to simple assessment and program forms. Third, the T&D model saves time for those who are trained. Family members and professionals simply don't have the time necessary to take formal academic course. Most of the new training will last one to three days.

While T&D focuses on skills, there is a place for training that is informational. There is also a place for training that addresses attitudes, values and personal philosophies. Within the T&D method these types of trainings utilize adult learning principles through meaningful activities and discussion. Some of the Autism Division training is mainly informational, such as our *Introduction to Autism*. And in various trainings we address the importance of values and attitudes in serving people with autism and other disabilities.

ABBIS Competencies and Their Sources

In keeping with the T&D approach the Autism Division spent a significant amount of time identifying the key skills classroom teachers need to instruct students with autism. First we surveyed teachers who serve autistic students in various types of classes. Then we reviewed the (1) Judevine Teacher Training Curriculum, 1972; (2) Results of the PIA (now the Autism Division) Training Retreat, 1991; (3) Indiana Resource Center for Autism's Teacher Competencies, 1993; (4) Applied Behavior Therapy Services Guidelines by SCDOE, July

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2000; and 5) Autism Program Quality Indicators, New York University and New York State Education Department, 2001.

Some Examples

In April 2003, 39 competencies were identified as being essential for classroom teachers. A couple of these were succinct skills such as “delivery of reinforcement.” Others represented a cluster of sub-skills. One example is “Define and apply behavior principles.” One of the issues identified in the previous article about the history of the Autism Division is the growing importance of applied behavior analysis for treating students with autism. The behavior category has since been broken down into 15 sub-skills that are important for teachers. Of the 39 identified skills were six related to data taking and analysis. Skills related to data taking and analysis are also important in the correct implementation of applied behavior analysis principles.

Final Set

With the T&D approach one of the goals was to design training that would be realistic for teachers to attend. In order to be accommodating to teachers, not all of the 39 competencies will be covered in ABBIS. The examples above along with other skills that are judged as foundational will be included. Some of the other skills include designing functional group activities that promote socialization and communication, designing a daily schedule and designing visual supports.

Major features of ABBIS: Schedule

ABBIS is a nine-day training session, made up of a five-day Summer Institute and four one-day in-service training sessions. This summer two sessions of the five-day institute will be conducted in July and the four one-day in-service sessions will be conducted in September 2004, October 2004, January 2005 and February 2005 respectively. Both Summer Institutes will be conducted in Columbia.

Each of the four Autism Division offices (Columbia, Spartanburg, Florence and Charleston) will conduct each of the four in-service training sessions once during the designated month in their respective part of the state.

In other words, during September the Autism Division will conduct the first one-day workshop on four different days in or near the four cities I just listed. It is hoped that conducting in-service training in different parts of the state will make it easier for teachers to participate.

Individualization of Material

As part of their ABBIS training, participants will be given a Resource Notebook and a Student-Class Profile. The Resource Notebook will already contain some of the handouts and will serve as a way to organize the training information. The Student Profile will be a simple folder to help individualize some of the material over the nine days. Starting on day one, as we discuss traits of autism and how they affect a student’s learning, participants will enter details in the appropriate section of their Profile folder.

This will give them an individual picture of their student(s) with autism. As various instructional strategies are discussed and developed, teachers can tailor the information to their students in the folder.

Teacher Re-certification and College Credit (*Hey, I thought you said ...*)

The Autism Division is in the process of applying for ABBIS to be approved for Teacher Re-certification through the S.C. Department of Education, and for graduate credit through the College of Charleston.

Now, if you’re wondering about the comments at the beginning of this article about Training and Development and academia, here are a few points to consider. One, it was noted that while T&D has a different approach to designing training than does academia, both have the goal of students acquiring the skills. ABBIS was designed with T&D methodology. While developing the final phases of ABBIS, we considered the requirements for course approval by the Office of Professional Development with the College of Charleston. The application is in process. The Autism Division has received such approval in the past, and hopefully we will be able to make this option available to teachers for ABBIS.

New Brochure

Our new training brochure is scheduled to be out in March. It will give more details about dates. Be sure to contact the Autism Division office nearest you if you are not already on the Division’s mailing list. The Autism Division is excited about providing this new training for teachers in South Carolina.

A Final Footnote

For more information about the ASTD and its standards, visit the society’s website at: www.astd.org.

November - January Donors

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Please support
your local
United Way.

The South Carolina Autism Society is a participant in many United Way organizations across the state.

Allocations and designations are an important part of the SCAS budget.

United Way contributors who designate SCAS are listed as donors in the *Update* when this information is provided by the individual United Way organizations.

Thank you for giving
from SCAS and the United Way.

November - January Members

New

Benefactor

M/M LS Taylor

Basic

Dorothy Tucker
Deanna Dickson
KelLeigh Benfield
K. Alisa Lowrey
Patricia Lebel
Cynthia Caldwell
Sharon Scarlata
Full-Time Student
Jennifer Brucker
Katie Shannon

Renewing

Benefactor

Thomas Brandner
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Supporting

M/M John Stack
Grace Gifford
Gene Grace Holbert

Basic

M/M Neil Lowry
Rebecca Mussman
Emily Ridlehoover
Stephanie Burchfield
Gloria Grambling-Smith
Jane Charles
Lissa Waring

Helpers Needed for 2004 Silent Auction

Contact Johanna Nwanagu, SCAS development director, if you would like to help plan and secure items for the 2004 Silent Auction, held each year in October along with the Society's annual conference. Or give Johanna a call if you would like to donate an item. Reach her at ext. 104 at 800-438-4790 or 750-6988.

Annual Appeal to Begin in April Each Year

Beginning this year, the S.C. Autism Society will hold its annual fundraising campaign beginning the last week in April -- a change from holding year-end campaigns in December.

The change is being made because various United Ways in South Carolina restrict year-end fundraising until after Dec. 15. These fundraising "blackouts" give organizations like SCAS only two weeks to ask for contributions and for donors to respond by the end of the tax year.

Conducting the annual appeal at the end of April will also coincide with Autism Awareness Month activities, SCAS President and CEO Craig Stoxen said. "We will mail our request for support just as we are wrapping up Autism Awareness Month, which is appropriate.

"But I do want donors to rest assured that this will be the only time during the year that we will directly appeal to you for a contribution," he explained. "It will be the only time you will receive a letter asking for your financial support."

If you have not participated in the past, please consider doing so this year. Donations have allowed SCAS to go above and beyond what other funding sources have permitted. For example, SCAS can track activities at the Statehouse because of the annual appeal.

"We greatly appreciate the support we received in December 2003 from last year's appeal. We ask that you continue to support us this year, only in April and May," Craig said.

Link to ASNC Bookstore and SCAS will Benefit

Now you can purchase books from the Autism Society of North Carolina's bookstore using the S.C. Autism Society's website, scautism.org.

There is a link to the bookstore on the website. If you purchase books this way a portion of the purchase price will be given to SCAS.

The North Carolina bookstore has an extensive collection. It is one of the two or three largest such collections in the country.

Adolescent Support Group to Meet at Coastal Office

A meeting will be held Saturday, April 27, at the Autism Division's Coastal Office in Charleston about starting a support group for adolescents with high functioning autism and Asperger's syndrome.

The group will be for adolescents only. A non-family member is being sought to facilitate the members' discussions.

For more information, contact Dandrea Woolridge at 843-762-2713, or the Coastal Autism Division Office at 843-852-4120.

Camp Good Times Announces June Dates

Camp Good Times, a summer day camp in Charleston for children with autism, has announced its camp dates for this summer.

The camp will be held four days, Monday through Thursday, in the weeks beginning June 14, 21, and 28. It will be held at Ashley River Creative Arts.

For more information or to register your child, call Beth Weiner at 843-817-2221 or 843-588-6253.

See page 3 for information on the April 4 Charleston Harbor cruise to benefit the camp.

Attention, Food Lion Shoppers

If you are a Food Lion shopper and you have an MVP card, you can designate SCAS to receive a percentage of your purchases in their stores.

On the web, go to www.foodlion.com. Click on fundraising, then click on register MVP card, and enter your information.

If you have questions, call Mary Bennett at SCAS, 750-6988 or 800-438-4790, ext. 105.

SCAS Offers 4 Options for Membership

There are four types of memberships available for you to join the S.C. Autism Society, if you aren't already a member.

Because of space limitations the entire membership form does not appear here. But you can select the option you like best and either call us at 800-438-4790 or 750-6988, ext. 100, or join us on our website, www.scautism.org.

For membership in the Autism Society of America, which is not included with SCAS membership, try the website www.autism-society.org, or call 1-800-3AUTISM.

BASIC:

Individual \$10 Family \$20

- Receive the *Update*, the SCAS quarterly newsletter
- Free shipment of SCAS products purchased by phone
- Personalized membership card
- SCAS membership decal
- Voting privileges during annual meeting (Family level gets two votes)

SUPPORTING:

Individual \$35 Family \$50

- Basic benefits *plus*
- 10% discount on all SCAS promotional items (travel mugs, t-shirts, etc.)
- Exclusive limited edition member coffee mug (Family level receives two mugs)

BENEFACTOR:

Individual \$75 Family \$100

- Basic and Supporting benefits *plus*
- Exclusive "Solving the Puzzle" ribbon lapel pin (Family level receives two pins)
- Personal invitation to special events

FULL-TIME STUDENT:

Individual \$10

- Basic benefits

SCAS Programs

- **Information and Referral:** Information for parents and professionals about autism spectrum disorders and available services.
- **Advocacy:** Advocacy on many levels, from individual to systems change.
- **Autism and Informed Response:** Training for emergency responders (law enforcement, EMS, firefighters) on autism and risk factors.
- **Awareness Training for Dept. of Social Services Caseworkers:** Training on autism and other developmental disabilities, their effects on families, and what professionals can do to help. Funded by the S.C. Developmental Disabilities Council (DDC).
- **People with Disabilities and 9-1-1 Assistance — Bringing the Two Together:** Funded by the S.C. Developmental Disabilities Council, this project is designed to increase awareness about the availability of informed response across the state, so as to better protect citizens who are at higher than normal risk in emergencies.
- **Parent-School Partnership:** Assists families and schools by building relationships between the two. Goal is the best education possible for children with autism spectrum disorders.

Mission Statement

South Carolina Autism Society

The Purpose of the South Carolina Autism Society is to enable all individuals with autism spectrum disorders in South Carolina to reach their maximum potential.

SCAS is a chapter of the Autism Society of America.

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Reach us at 803-750-6988 or 800-438-4790. Extensions are listed below. Our fax number is 803-750-8121. Our website is www.scautism.org. E-mail us at scas@scautism.org.

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Debbie Howard (303)

Tammy Ruiz*

Lissa Waring* (302)

Brande Smalley*(103)

* *parent of child with an autism spectrum disorder*

Applications Due Soon for Partners in Policymaking

Partners in Policymaking, an advocacy class for family members and self-advocates, is seeking applications for its next session in fall 2004.

The program is sponsored by the S.C. Partnership of Disability Organizations, of which SCAS is a member. The training is administered by the Arc of the Midlands.

Applications must be turned in by June 30. For an application or more information, call the Arc at 935-5266 or toll-free at 866-300-9331.

Partners in Policymaking teaches parents and self-advocates to be community leaders and obtain the best available services for themselves and others. Two-day training sessions are held once a month in Columbia for eight months.

There is no cost to participate, and lodging and meals are provided. Two adults with autism have completed the program, as well as numerous parents.

Mildred Lilley Receives Order of the Palmetto

Mildred Lilley, chairperson of the S.C. Developmental Disabilities Council, has received the state's highest civilian honor, the Order of the Palmetto, for more than 20 years of working on behalf of individuals with disabilities in South Carolina.

Mildred is the parent of an adult son who has autism, and is a longtime member and former officer of the S.C. Autism Society.

During the first round of state government restructuring, Mildred worked to have an Autism Division created in the Department of Disabilities and Special Needs. She has been named Parent of the Year by the Autism Society of America, served on the Olmstead Task Force, and is a founding member of the Partnership of S.C.

The award was presented to her by DDC Executive Director Charles Lang on behalf of Gov. Mark Sanford.

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South Carolina Autism Society

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