

The Post CARD

A Publication of the Center for Autism and Related Disabilities Spring 2002

April is Autism Awareness Month!

What Can You Do to Educate Others About Autism?

1. Write a letter to your local newspaper.
2. Pass out autism information bookmarks.*
3. Give a presentation on autism at your child's school.*
4. Ask your local library to set up a display of available autism books and resources.

* CARD UF/Gainesville can provide you with bookmarks and other materials to help with presentations. Please contact Leannis Maxwell by phone at 352/846-3455 or 800/754-5891 or by email at maxwell@mbi.ufl.edu to request materials be sent to you.

Autism Facts You Can Share with Others:

- ⇒ Autism is a lifelong developmental disability resulting from a neurological disorder that affects the way the brain functions.
- ⇒ People with autism have difficulties interacting with others, behaving in socially appropriate ways, using language and communicating. They tend to develop narrow interests, repetitive behaviors, and intense attachments to routines. They can seem too sensitive to sights, sounds, smells, or physical contact - or not sensitive enough.
- ⇒ The Autism Society of America estimates that as many as 1 in every 500 children is born with autism. It affects more people than Down's Syndrome, Muscular Dystrophy, or Multiple Sclerosis.
- ⇒ Autism is more common in boys than in girls.
- ⇒ Autism affects people of all races, religions, ethnicities, and social backgrounds.

2002 Autism Awareness Auction/Benefit Race a Success!



Bryan Garlin hangs out with motocross participants.



Earl H., a CARD constituent wins the grand prize!

It was remarkable to listen to stories from nation-wide participants about their contact with individuals with autism in their communities. There was unbelievable interest in learning about and supporting individuals with autism...

--Art Wallen

The most unforgettable thing about the event was watching the tears well up in the eyes of a bunch of big "biker dudes" when the motorcycle raffle was won by an individual with autism. It was clear to all what this fundraiser was really about.

--Jennifer Nye

The event was very family oriented and fun for all--even with the rain! I had a great time and will do my best to be there next year.

--Donna Gilles



Lucy Garlin helps out by painting faces.

FOCUS ON THE CLASSROOM

Jan Seebeck Makes a Place for Aaron McCormac at Littlewood Elementary

By John Murchek



Looking around Jan Seebeck's kindergarten classroom at Littlewood Elementary School after her students have left for the day, you can see that care and order and imagination hold sway there. A quiet little barn full of books nestles in one corner; in another, well-used computers rest for the day. A child-sized kitchen promises play that mimics life. There's a vivid display of students' drawings of themselves as they imagine they would look with all their veins and arteries exposed to view. And, most magical of all, cotton wool clouds trailing construction paper rainbows hang suspended from the ceiling all across the room. Apparently, the students have been learning the colors of the spectrum, but the rainbows remind me of *The Wizard of Oz*. Hovering above the students' heads, they seem to speak of all the dreams the students dare to dream.

Under this canopy of rainbows, I sit down at a children's worktable to talk with Seebeck, Littlewood Principal Glenda Good, and CARD Associate Director Art Wallen about how six-year old CARD constituent Aaron McCormac came gradually to be included in Seebeck's class in the fall of 2001.

When Seebeck first observed Aaron in Barbara Scott's summer school pre-K classroom, she had her doubts about successfully including him in her class. He suddenly ran at breakneck speed across the classroom and behaved in self-injurious ways outside. "It was very scary to me," Seebeck recalls. "I was worried about Aaron's safety and the safety of the other children. I wondered how the parents of the other children would react." She laughingly admits she considered flight: "For awhile, I thought I'd just sell my condo!" Still, she stayed.

Especially given Seebeck's worries, everyone agreed to proceed by "baby steps" in the beginning so that Aaron could find success. To start with, he joined the class for 30 minutes a day when the students were free to choose what they wanted to do. Aaron could do things he liked—such as playing with letters and working at the computers. Then, he was allowed to stay for snacks and could eat lunch with the other children. Slowly, he joined the class for free play, and, after free play, would come in for one table rotation. "He got to know the routine," Seebeck recalls. "He was very regulated." In the end, it was Seebeck's idea to include Aaron in the classroom full-time. Good underlines the importance of the gradual approach: "It is important for the teachers that the process be gradual. That way they see that it has been successful."

If Seebeck decided when to include Aaron in her classroom and for how long, her other students were also exerting a powerful influence on the process. "The other children in the class have really embraced Aaron," says Seebeck. They look out for him and root for him. For example, if Aaron picks up a pair of scissors when he shouldn't, a cry goes up among the other children: "Ms. Seebeck, Aaron has scissors!" By contrast, when Aaron spells difficult words, the other kids will encourage him, saying, "Look what Aaron spelled! Isn't that good!" The significance of the interest the other children have taken in Aaron has not been lost on Aaron's aid, Fatima Needell. According to Seebeck, one of the girls in the class walked up to Needell, and asked, "How does he [Aaron] learn?" She responded, "He really learns a lot from you all."

Good reinforces this last point, insisting on the importance of building responsive classrooms. "Children are very compassionate. They learn to be receptive, and they are ready to have a child [such as Aaron] move along with them from grade to grade." Good notes that other children with disabilities have advanced in this way at Littlewood.

Both Seebeck and Good stress how essential it has been to have the support of the parents of Aaron's classmates, and how indispensable it has been to be able to work with a family as collaboratively involved as the McCormacs have been. "Any time there was a difficult situation, Virginia [McCormac] was there," Seebeck observes of Aaron's mother. "Mrs. McCormac is always so positive. There's always a smile on her face."

McCormac (cont.)

Seebeck plainly treasures "seeing the celebration" in Virginia McCormac's face when Aaron has made a step forward. She remembers the first day Aaron could go to car pick-up, and wait with the other children for his mother to pick him up. "There were tears in Mrs. McCormac's eyes."

Virginia McCormac is thrilled by the progress Aaron has made. "Watching Aaron grow this year in this supportive environment has been so beautiful, like watching a flower unfold: his smile, his confidence, and his little John Wayne swagger as he strolls down the hallway to class, waving over his shoulder."

The day before our conversation at Littlewood, Art Wallen had been faxed copies of Certificates of Recognition Aaron and his older brother David had both received the previous week from the Littlewood Leaders Program. Seebeck explains that each month teachers at Littlewood nominate students to become Littlewood Leaders. She had nominated Aaron because of all the progress he had made. It was simply a wonderful coincidence that another teacher had put forward David's name at the same time.

When I ask Seebeck what kind of progress she'd like Aaron to make before the end of the year, she says, "I'd love to see more eye contact, more spontaneous speech." It is difficult to imagine a parent, sibling, teacher or schoolmate of a child with autism who doesn't sometimes share this wish. As I tuck my notepad into my folder, I glance up again at the rainbows. Maybe it's a dream that really will come true.

What are the Benefits of Receiving the CARD UF/Gainesville Newsletter by Email?

- ◆ Cut Down on Paper Clutter in Your Home or Office
- ◆ Receive Information Faster
- ◆ Receive Periodic Updates About Our Trainings

Please Note: We do not include attachments with our emails. In addition to the text of our emails we include links to websites where you can find our current newsletter or more information about trainings.

If you are interested in switching over to email delivery contact Leannis Maxwell at maxwell@mbi.ufl.edu. Please be sure to give her your current delivery address.

Sibshop Update

The first sibshop of this year was held on Saturday, February 23rd, 2002 at Sun Country Sports Center (West Facility). Twelve siblings participated and we had a lot of fun. Some of the activities included gymnastics, climbing a rock wall, playing silly games, and making ice cream sundaes.

CARD would like to thank **Sun Country** and **Hungry Howie's Pizza (Jonesville)** for helping make this event a success.

CARD plans to offer sibshops for a variety of ages bimonthly.

April 8-12 year olds

June 5-8 year olds

August 12-16 year olds

If you would like more information about sibshops please contact Karin Marsh by phone at 352/392-4171 or by email at kmarsh@mbi.ufl.edu.

CARD UF/Gainesville is now a United Way benefiting agency!

STAFF HIGHLIGHT: JENNIFER NYE

By John Murchek



Popular stereotypes about health science and health care typically pit the aloof "ivory tower" research scientist shut up in a lab against the sensitive caseworker devoted to individuals. CARD Support Specialist Jennifer Nye, however, gives the lie to the stereotypes by bringing together the questioning temperament of the researcher and the compassion of the caseworker.

Jennifer, who has worked at CARD since June of 2000, has a background in research—as do other members of the CARD staff. She holds both a B.S. and an M.S. in Psychology from the University of Florida, and had completed all the work for a Ph.D. except her dissertation before joining the CARD staff. She participated in research that examined children's movement in home videos for early signs of autism. The results were presented at various conferences and published in the Proceedings of the National Academy of Science.

At the same time, Jennifer's reasons for working with people with autism have everything to do with personal history and attachments. At age twelve, she suffered a seizure doctors could not explain. She was put on anti-seizure medication for five years. The experience left her wanting to know more about what causes such episodes. Later, while studying at UF, Jennifer responded to an advertisement that former CARD Assistant Director Emily Savarese had posted for someone to spend time with her son DJ, who has autism. Jennifer ended up working with DJ for a number of years—and his picture has pride of place on a shelf above her desk at the CARD office.

It's not surprising that Jennifer should baffle stereotypes given how she describes her interests and guiding principles. To begin with, she's always looking for the "big picture." She was drawn to study physiological psychology because, rather than focusing on any single aspect of the psyche, it explores the dynamic relations between the brain, the body, and behavior. Similarly, autism fascinates her because it affects not only sensation and movement, but also social skills, language and communication. At CARD, she enjoys the challenge of focusing on the constituent's total situation. She explains, "You have to take in seemingly disparate kinds of information—psychological, medical, and educational—in order to make sense of the constituent's condition."

Jennifer also says she approaches her work guided by the principle that "you can't make assumptions." She insists, "You have to deny everything you think you know." Time after time she's had this lesson brought home to her.

For example, there's the assumption that children with autism don't interact with others. Jennifer explains that many of the videos she viewed of children in the research study on movement seemed to suggest this assumption was valid. Working with DJ Savarese, however, led her to question it. "An autistic child will interact with others," she explains, "but you have to follow the child's lead. You have to try whatever you can to get into the world of autistic children. Once you're there, you need to let them know their world is OK. When you've established a connection, you can try to show them that our world is pretty cool as well."

Or, take the assumption that children who have autism don't notice as much of what's going on as other children do. Jennifer no longer believes this either. She tells the story of how, after taking DJ Savarese to occupational therapy for some time, she began to wonder whether he might be persuaded to break his ritual of always leaving by the front door. So, one day she paused as they were about to leave, trying to signal as little as possible about her intentions. "DJ looked at me," she says, "and then at the back door, and then back at me. Then, he went and opened the back door all by himself." Amazed, Jennifer had to conclude that DJ, far from registering less than a developmentally typical child might, was reading minute details of her behavior and activity.

When she's asked what she likes best about working at CARD, Jennifer initially—predictably—stresses the big picture: "You get to work with individuals, as well as with large and small audiences. You get to work with parents, physicians, and children." Then, seeming uncharacteristically to narrow her focus, she confides, "Mostly, I like the kids"—but perhaps, after all, they are the big picture.

TIPS FROM THE CARD STAFF

Communicating With Your Child's Doctor

By Jennifer Nye

Your relationship with your child's doctor *can* be very rewarding. Most physicians—especially those who see patients with autism spectrum disorders (ASD)—choose their fields out of genuine concern and interest. However, busy schedules and tons of commitments limit their time and focus their attention. These tips can help you to make the most of your visits to the doctor.

Part 1: Preparing for the Appointment

When a child with ASD makes a trip *anywhere* different it can cause anxiety (in both you and your child!). To make your child feel as comfortable as possible about an upcoming doctor's visit, answer the following questions. **WHO will I see there? WHEN will we go? HOW LONG will we be there? WHAT will happen (specifically)? Will you stay with me? What's my payoff if I cooperate?**

- 1. Ask the doctor to give you a routine of what happens during a visit.** (You may need to explain why you're asking for *details*.) Of course, the routine may not be exactly as expected, but having it written down will benefit *everyone*—*your child* can know what happens next; *you* will be prepared if the routine changes and your child realizes that the script in his head does not match what's happening; and, *the doctor* will be more apt to follow a routine that is written down!
- 2. Use a calendar to show your child the day of the appointment** and what will *not* happen that day (e.g. school). Assure her that the next day will be a "regular" day.
- 3. Create a picture "schedule" of the expected routine and review this with your child the night before.** -OR- **Write a social story about visiting the doctor, using the same information.** If possible, use photographs of the following: the doctor (portrait style); front door of the office (anything your child identifies as "doctor's office"); waiting room; a secretary or nurse whom your child likes; the scale, blood pressure cuff, etc.; the office where your child will be examined.
It is important to **go over the schedule or social story sometime BEFORE the appointment.** For some children, the night before is enough time, but most kids may need a few days of "practice." The idea is to give the child ways to deal with his anxieties and fears ahead of time. Think of this process as rehearsing for a play: your child needs to know the script, experience the emotion, and rehearse how he will react. You may find that you can more readily identify the emotions your child experiences and find ways to calm and reassure him when you are in "rehearsal" and not in the midst of the real appointment.
- 4. If you know that your child can sit still for, say, 10 minutes MAXIMUM, schedule breaks** every 10 minutes during the visit. Here, again, a written or pictorial schedule helps.
- 5. Put together a "Bag of Tricks" to bring with you to the appointment.** Include favorite toys, books, puzzles, interactive games you can play together, paper and markers, snacks and drinks (be sure to ask your doctor what is appropriate, especially if blood is to be drawn).
- 6. Bring any communication tools your child uses** (pictures, communication book, sign language dictionary, computer, other). Especially bring tools your child uses to request a break, go to the bathroom, get a drink and ask for help.

7. **Schedule a preferred activity following the doctor's visit and let your child know that if she can "hold it together" during the appointment, the reward is hers!** Remember that the doctor's visit may be a stressful experience for your child, so your expectations for "good behavior" may be lower than in other situations.
8. **Use techniques you have found to be calming and reassuring for your child:** touch, pressure, talking, singing, swinging (if available), dancing. You may get some funny looks in the waiting room, but better funny looks for dancing than mean looks because your child is having a tantrum!
9. **Gather the following and bring copies to the appointment:** ANY medical records (including birth history), school records, formal evaluations and any other information that might be useful. As a rule, if in doubt, BRING IT! If possible, make copies of these to send BEFORE your appointment so the physician has time to review them prior to your visit.
10. **WRITE DOWN your concerns and questions to bring with you to the appointment.**
11. **Bring with you a spouse, friend or relative** whom your child knows and can help out in case you need to talk with the doctor alone.

It is equally important that you, the parent or guardian, are calm and attentive during the appointment. Take care of yourself, too! Use any resources you have - babysitters, relatives, friends - to watch your children sometime before the appointment, so you can have time to gather any records you may need, write down questions or just take a break!

Part 2: During the Appointment

1. **Use the schedule or social story to remind your child (AND to remind the doctor !) what happens next.** Utilize the scheduled breaks and remind your child that "10 more minutes and then_____."
2. **The physician may need to do a medical history first. Try to answer these questions accurately but briefly.** Wait until this part of the visit is finished to bring up your questions and concerns. Use what you have written previously to guide the appointment.
3. **ASK QUESTIONS!!! ALL of your questions and concerns are valid.** If the physician does not have an answer, it is her job to refer you to someone who may.
4. **If you need a written diagnosis, evaluation report or letter, be sure that the physician is aware of this.** If you cannot get it on the spot, leave a piece of paper with the following information on it: Your child's name, your name, home address and phone number, what type of letter or evaluation you need, WHY you need it (proof of diagnosis for insurance or therapy, school, services eligibility, etc.), who and where to send it.
5. **Be aware of what you and the physician say in front of your child.** Pay attention to his behavior. Kids often understand a lot more than we think!
6. **Ask the doctor to direct some of his questions to your child.**
7. **Try to facilitate a "friendship" between your child and the doctor,** but take care not to push your child too far with this "stranger." Tell the doctor ahead of time something your child is most interested in, or take out a favorite toy, book or activity and ask the doctor to initiate play or conversation.
8. **When it's all over, be sure to hold to your promise of a reward.** Let your child know what a great kid he is! Use specific instances: "You were so good when the doctor took your blood pressure . . . I'm so proud of you." "You held it together for 20 minutes! I know that was hard!"
9. **Reward YOURSELF!!**

CONSTITUENT HIGHLIGHT

Words of Wisdom

By Kenny Anderson

Kenny Anderson, a 21 year old CARD constituent, wrote this piece before graduating from the P.K. Yonge School in Gainesville in 1998. He received an AA degree from Santa Fe Community College in December, 2001. He is currently majoring in Sociology at the University of Florida and working part-time at Publix.

This is my last article of the year, so I thought I'd do something special. I'm going to write about strange behavior. The subject has been important to me ever since I first pretended I was a rhino . . . Wait, that was in eighth grade. If we're talking about my first strange memory, it's when I was three. I went to see Snow White and the Seven Dwarfs, and I found the exit signs to be of much greater interest than the movie.

Inside every flake there's a normal person waiting to get out. Mine escaped about nine years ago and I haven't seen him since. Of course that's only one estimate. Some people set the date as late as February 12, 1998, while others set it as early as July 20, 1980, when I was born.

Let me make it perfectly clear that I don't consider "strange," "flake," or other words that mean the same thing to be insults. I'm perfectly happy with a self-image defined by being strange. I think it would be great if everyone, rich and poor, Christian and non-Christian, Kiss 105 and Rock 104, made it a rule to do one strange thing every day. (Of course, the state legislature would be exempt.)

Here's a list of strange behaviors. If you exhibit more than three of these, I'm very surprised. Also, you might want to consider the benefits of not minding being a flake, such as self-esteem and freedom.

You know you're a flake when . . .

You do something strange and everyone stares.

You do something strange and nobody stares.

Your feelings for Mr. McCall can be described as superstition.

You think Rice-a-Roni is a delicacy.

Your comeback style entails the phrase "whole body whole body whole body" and insults to yourself.

You get your spiritual inspiration from Kiss 105.

You wander aimlessly around the house long enough to get out of breath.

You burst out laughing in class about what a stupid movie Pet Shop is.

You go insane for a week and no one notices.

Upon resuming sanity, you are more, not less, likely to talk to trees.

Your list of round numbers, if taken long enough, would include 387, 420, 489.

You feel guilty for not liking Sister Hazel.

You think arms are the most important part of a girl's figure.

Wanting a social life was just a phase for you.

Sometimes you answer an insult with "Hey, that's pretty cool."

A favorite object of speculation is what would happen if you and Mrs. Isolt switched bodies.

The people at MGM tell you to put all carry-on items under your seat, and you put your shoes under.

There is zero correlation between a test's grade, how much you studied, and how much you worried.

Your cat's sleeping places include the litter box and a pile of Legos.

You take the financial advice of a kid who still poops his pants and who disbelieves the law of demand.

You make National Chemistry Week a religious holiday.

You have to invent new words to describe some things you do.

Here's an anecdote about strange behavior. A guy went into a place where you can have people customize your cakes. He said, "Price is no object. I want a cake shaped like an 's.' And I want it by May 9." He went away and came back on May 8. When he saw his cake, he said, "No, no, no! It was supposed to be a small 's.' You've made it a capital 'S!' You'll have to do it over and it'll still be due tomorrow." They protested, but he insisted on having it made over. The next day he came in, looked at the cake, and paid for it. They asked if he wanted it delivered or just put in a box. He said, "That's all right. I'll just eat it here."

The Florida Department of Education, CARD UF/Gainesville, the Florida Inclusion Network, and FDLRS/Springs are pleased to present an all day workshop on:

Teaching Social Skills to Children with Autism and Related Disabilities

Date: April 24, 2002
9:00 AM-3:30 PM
(Registration begins at 8:00AM)
Location: Best Western at 39th Avenue & I-75
Gainesville, FL
Presenter: Phil Strain, Ph.D.
University of Colorado at Denver
Cost: **FREE!**
Pre-registration is required.
Please contact Leannis Maxwell
by phone at 352/846-3455 or
800/754-5891 or by email at
maxwell@mbi.ufl.edu.

About the Speaker:

Philip S. Strain, Ph.D., is a Professor of Educational Psychology at the University of Colorado at Denver. Dr. Strain holds a Ph.D. in Special Education from Peabody College. He has held faculty appointments at American University, Peabody College, University of Pittsburgh, and the Medical College of Pennsylvania.

In his 32 years in the field, Dr. Strain has been a special education teacher and teacher supervisor; Supervisor of Research, Children and Youth Services, Tennessee Department of Mental Health; Principal Investigator of 20 major governmental grants, including two national research institutes that produced over 250 peer-reviewed papers and chapters. Intervention strategies that he has developed have been translated and implemented throughout South America, Europe, and Asia. He has chaired various national and state-level consensus-building committees pursuing definitions of best practice in early childhood/special education, joint policies on inclusion, and joint policies on Goals 2000.

This workshop will focus on the following teaching concerns in the social interaction domain:

1. What are the crucial skills to enhance?
2. What level of intensity should be used?
3. How to create a classroom context to support peer-related social skills?
4. How to teach typically developing children to be intervention agents?

Third Annual FIN (Florida Inclusion Network) Inclusion Conference

"All Students...All Schools: Building Inclusive Communities"

July 11 - 13, 2002

Fort Lauderdale, FL

FREE!!!

This conference promises to be an exciting and rewarding experience for all educators, parents, administrators, service providers, advocates, and others interested in improving programs and services for all students. Presentations, information, and resources to foster inclusive programs in all schools will be shared.

Highlights will include keynote speakers, workshops, concurrent sessions, technology lab, spotlights on success, vendors and displays. There is no registration cost for this fabulous conference. Funding to assist with travel expenses may be available through your local FIN office. For more information, please check it out at www.FloridaInclusionNetwork.com or call toll free (866) 801-4211.

Camp Care 2002 News

Howdy Partners! Time to start planning our summer camps. This is our 7th year the Autism Society of Florida will be working with the Diocese of St. Augustine to have a unique Summer Camp-Western Style. There are opportunities for seven (7) one-week sessions at our beautiful location of the St. John's River Campground at Switzerland, Florida. Camper and buddy applications are available now. Tuition is \$150.00. Every camper has a one-on-one buddy. Activities include swimming, fishing, boating, reptile show, petting zoo, cookout, arts & crafts. Nursing staff on site 24 hours.

Camp I Am Special (Ages 6-12)

Session I June 2-7
Session II June 9-14

Camp Promise (Ages 13-99)

Session I June 16-21
Session II July 14-19

Camp Promise Session III (Adults Only)

July 28-August 8

Camp Care (All Ages)

July 21-25

Buddy Training

May 4 and May 13

Buddy Training Camp Care

July 20

Leadership Training

May 25

Contact:

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Developmental Disabilities
Diocese of St. Augustine
134 E. Church Street
Jacksonville, FL 32202
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Need more details?

Contact:

Carol Monroe, Camp Liaison
Autism Society of Florida
358 Perthshire Drive
Orange Park, FL 32073
(904) 272-8988, Phone and Fax
Email: bandcmonroe@fcol.com

Deadlines:

Camper Application - May 1
Buddy application - April 10