

# The Post CARD

A Publication of the Center for Autism and Related Disabilities  
at the University of Florida/ Gainesville

Spring 2003

Dear Families and Friends of CARD,

## APRIL IS NATIONAL AUTISM AWARENESS MONTH!

Some of the most important and most fun things we do here at the Center for Autism and Related Disabilities are our efforts in the area of Public Education. Informing the people in our communities is one of the four missions of CARD that we are required to address by the legislation that created our Centers and our contract with the Florida Department of Education. This year, our Center staff have planned a variety of exciting programs and activities to celebrate National Autism Awareness Month and to inform the public about autism, and about CARD.

On Wednesday April 9, we will be hosting an Open House at our NW 16th Avenue office from 2:00 to 7:00 PM. We are hoping many of you will use this opportunity to meet our staff, learn more about autism and CARD, browse our lending library and meet other parents and professionals. We are looking for a great turn-out from the community. Burger King is also helping us to get the word out about autism. Autism posters will be displayed and information sheets placed in "to go" bags at four Gainesville Burger King restaurants thanks to the assistance and support of the Gatton family and Gina Britton at Burger King of Gainesville, and our handsome poster boy, Sam.

We also need your help this month. The more we can educate the public about autism the better. You are in contact with doctors, dentists, hairdressers, police officers, merchants, school principals, parents, day care providers, Sunday School teachers and many, many other community members who are not aware of autism and CARD. You can help us to inform the public by wearing an autism awareness ribbon, handing out ribbons and literature, and talking to people in your community. We have ribbons, literature, videotapes, and general information available for you to use. Just come by our office or call us and we will do our best to get you what you need to promote autism awareness in your community. The early identification of young children with autism can make a difference for them and for their families. For older children and adults with autism to participate in our communities, we need our neighbors, friends, and community members to know about autism. Thank you for your help. We hope to see you soon!

*Greg Valcanti*

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Our Lending Library is Growing!  
Thanks to a generous donation  
of \$2000 from the  
**John Maxwell Biasco Foundation**

We have added extra copies of our most requested books and videos and many new titles. If you would like to borrow any library items please stop by our offices located at  
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800/754-5891 or 352/846-3456  
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# A Week in the Life of CARD/UF Gainesville

Have you ever seen something or heard something you thought was a fascinating idea and decided to run with it? Well, several months ago, I saw a small article in the newsletter from the West Virginia Deaf-Blind Project, entitled, "A Week in the Life of the Deafblind Project" in which the editor briefly described the activities conducted by the three staff members throughout the week. I thought it was a wonderful way to give the reader an idea about what types of assistance the project staff members provide. So the staff here at the UF CARD agreed to humor me, with some apprehension about what the final product would look like. The fact that you are reading this now means that the product was worthy of print.

After much discussion, we decided that we would ask all staff members to document their activities throughout the last week in October. We included evenings and the weekend because some of our activities occur outside of typical working hours. Of course, in only documenting a one-week sample, we may have missed some additional activities that occur monthly or bimonthly, but you will get the idea!

To put the article in perspective, of the 12 staff members, only half work full-time for CARD. The staff members included the Director Greg Valcante (at 90% time); Associate Directors Donna Gilles (60% time) and Art Wallen (80% time); Support Specialists Robbin Byrd (100% time), Jennifer Nye (100% time), Cathy Zenko (100% time), Karin Marsh (100% time), and Caroline Raye (50% time); and Program Assistants and Support Staff Carole Polefko (50% time), Margie Garlin (100% time), Leannis Maxwell (100% time), and Alex Green (38% time). Also be aware that sometimes the same staff member may have been engaged in more than one activity. For example, in the last section under "Daily Operations", we really didn't have 15 staff members available. The staff member who helped put the "Emotions Binder" together may have also been the one to help with the pictures for the conference and making visual supports.

The article reflects information that never rolls off of our tongues when someone asks "Just what does CARD do? So, if you have ever wondered about the specifics of what we do, this story may satisfy your curiosity. Enjoy! And thank you, Carole.

Donna Gilles  
Associate Director

## Individualized Assistance

During the week of October 26th - November 1st.....

9 new constituent intakes were received

8 staff members went on 8 school visits and 12 home/community visits

62 constituents received services

81 people including parents, grandparents, support coordinators, staff of an adult constituent's home, an occupational therapist, a social worker, a UF Psychiatry Resident, a Positive Behavioral Support Team, teachers, teachers' aides, a speech language pathologist, an ESE administrator, and other school personnel were contacted

CARD Staff tried to help constituents with...

school, housing, health insurance, sensory diet, communication, social relationships, behavior, routines, visual supports, social stories, shopping, curriculum modification/accommodations, self-injury, peer empathy, suspension from school, PBS (Positive Behavior Support), eating, classroom environment, inclusion, sleep, English as a second language, IEPs, toileting, restaurant behavior, siblings, foster care, apartment living, support services, the need for a psychiatrist who can sign, medication outcomes, and relationship development

- 2 staff members worked on creating an "Emotions Binder" for constituents
- 2 staff members prepared visual supports for constituents

## **Training**

During the week of October 26th - November 1st.....

10 trainings were prepared - Literacy Institute, Asperger Syndrome Inservice, 2 DOE Workshops, Teacher Training Programs, PBS(Positive Behavioral Support) Training Series, Collaborative Teaming, Visual Support Training Series, Division of Early Childhood Conference Presentation, Visual Supports (1 day training)

2 trainings were held - Positive Behavioral Support Training Series & Collaborative Teaming

## **Public Education**

During the week of October 26th - November 1st.....

The following Public Education activities occurred:

- 485 training reminder emails were sent out
- 1 staff member worked on updating resource sheets that provide information on service agencies for all 14 counties in our region
- 2 staff members collected contact information about early intervention providers
- 1 staff member gave autism information to a physician from Ethiopia and provided information on communication to another physician from Bangladesh whose patient is a 5 year old child with out any support services
- 1 staff member worked on creating a CARD UF/Gainesville listserv
- 1 staff member created a bulletin board for sharing information about autism and CARD services with patients at the Shands Child and Adolescent Psychiatry outpatient clinic

## **Technical Assistance**

During the week of October 26th - November 1st.....

The following Technical Assistance activities occurred:

- 1 staff member attended a Florida Respite Care Meeting
- 2 staff members prepared for a Sibshop
- 1 staff member helped plan for housing for a potential constituent
- 2 staff members created a technical assistance packet to be used for follow up to the our teacher training workshops
- 1 staff member contacted the Florida Inclusion Network to plan for the Department of Education sponsored regional workshops
- 1 staff member prepared for providing technical assistance to a school
- 1 staff member talked with the Yale Child Study staff about sibshops
- 4 staff members prepared for Parents' Night Out
- 1 staff member created a visual supports folder to take on visits
- 1 staff member assisted a parent of a potential constituent with accessing resources and an evaluation
- 1 staff member helped other staff members with data collection strategies for a child with a sleep disorder
- 1 staff member researched the eligibility rule for Vocational Rehabilitation
- 1 staff member spoke with a physician about collaborating with Shands Child and Adolescent Psychiatry outpatient unit
- 1 staff member participated in an Autism Project meeting at the Shands Child and Adolescent Psychiatry outpatient unit
- 1 staff member talked with a Parent Partner about their duties
- 1 staff member provided consultation to School Board of Alachua County staff
- 3 staff members conducted a Sibshop

(continued on page 4)

# CONSTITUENT HIGHLIGHT: BRIANNA ROBBINS

## Living with a Sibling with Autism

By Jaclyn Robbins (age 10)

Brianna is an 8 year old girl who lives in Ocala, Florida with her mom, dad and her older sister, Jaclyn (the author of this story). Life is very different because most people have a normal sibling. Well, I don't. What I like about my sister is she looks up to me and I help her on the computer. I wish we could go to the movies together. She's the best bike rider ever. I teach her to stop, turn and pull over. I wish I could have a cure for her problem. I help her communicate by using pictures and talking.



Here are some tips for being a good sibling:

-Never be embarrassed to have a sibling with autism. Even when they do very silly things, don't be embarrassed. Never be embarrassed because they're humans just like you.

-If somebody makes fun of your sibling, stand up for them.

-Give them space, because they can hurt you sometimes, even if you're the older sibling.

I help my mom at home and out in public. When my sister is having problems, I help my mom carry stuff and help my sister get out of the area. She's my best friend and I love her alot!!

(continued from page 3)

## Daily Operations

During the week of October 26th - November 1st.....

In addition to the regular office activities such as answering phone and email messages, entering contacts and visits into our database, picking up and returning rental cars, signing people up for trainings, preparing for meetings, recording meeting minutes, filing records, photocopying, restocking our dissemination file and handouts racks, checking library items in and out, and mailing out information, the following operational activities occurred:

- 1 staff member contacted several people about overdue library items
- 2 staff members worked on our quarterly report for the Florida Department of Education
- 2 staff members worked on the CARD UF/Gainesville budget
- 1 staff member prepared for an upcoming staff retreat
- 1 staff member gathered addresses for the Autism System of Care research project
- 1 staff member contacted the other CARDS regarding an upcoming Committee Meeting and computer support
- 2 staff members prepared pictures and other materials for the CARD conference
- 1 staff member summarized training evaluations
- 1 staff member worked on staff goals and objectives providing each staff member with a list of their responsibilities regarding CARD Goals and Objectives for 2002-2003
- 1 staff member worked on advertising upcoming trainings
- 1 staff member updated the database of community professionals who provide service to our constituents
- 1 staff member reviewed job applications for an open position at CARD

# STAFF HIGHLIGHT: KARIN MARSH

By Greg Valcante



Karin Marsh is a woman on the move. From Tallahassee to Atlanta, to Washington D.C., to Orlando, to Charleston, S.C., Connecticut, Seattle, WA, to Gainesville, FL, her path has led her to her current role as Coordinator of Education / Training Programs for the UF/ Gainesville CARD. Karin has always been interested in working with children and families and started

out in education as a substitute teacher and as a para-professional even though her parents who are both college professors warned her to "never be a teacher". After graduating from Agnes Scott College in Georgia as a Rhodes Scholar Candidate, Karin pursued graduate studies at the University of Central Florida and earned her Master's degree in Early Childhood Special Education at the University of Washington. Karin's husband and childhood sweetheart, Lee, was a Naval Officer so she was limited in where she could apply to school. "We had a good feeling because not a lot of people wanted to go to Washington" Karin says of her move to Seattle. With Lee busy with his career as a Jag submarine officer, Karin was finding her own direction. "It was kind of a good time for me to do my schooling because I could concentrate on my studies" she said. Living in Navy housing with a 2 hour commute to and from school each day that included three busses and a ferry each way did not deter her.

Karin's first job after being graduated from UW was at the Holly Ridge Early Childhood Center in Seattle. While there she began to do home visits, run parent - toddler play groups, use incidental teaching strategies, teach parents how to use sign language, teach in a pre-school programs for 2 to 3 year-olds in the morning and do home visits in the afternoon. After one year, the Holly Ridge Center opened a new site in the small finishing village of Poulsbo, Washington (nearer to home for Karin) and she was put in charge of the new center. There she began "Mommy and Me" classes for parents and kids together and worked with children who had speech and language delays, Down Syndrome, autism, Cerebral Palsy, and a variety of other disabilities. At the new center, Karin teamed with a Developmental Pediatrician and began a program that was inclusive, serving children with and without disabilities together. The parents of the typically developing children "loved it" according to Karin and she recalls it as "an absolutely wonderful experience" for all involved.

In 2001, Karin and Lee moved from Seattle Washington to Gainesville, Florida for Lee to enroll in the University of Florida Levin College of Law. Karin

had heard about the CARD program at FSU from a friend in Tallahassee who has a child with autism and went on a mission to find the CARD at UF/Gainesville as soon as she arrived in Gator Country. We are fortunate that she found us at the very time we were looking to fill an open position. Karin impressed everyone on the CARD staff so much with her interview that we could not wait for her to join our team. After a year and a half at CARD, there are now many more families, children and teachers and other professionals who are as delighted as we are that she is a full time member of the CARD staff.

## SIBSHOP UDATE

Since the last newsletter, we have had several sibshops for children of a variety of ages.

On June 29th, five siblings (ages 5-8) attended a sibshop at Faith Presbyterian Church in Gainesville. This event had a circus/carnival theme. The kids and staff enjoyed playing many games and watching a fabulous magic show by B-Magic the magician. Some other favorite activities included making gak and mud pie! Thanks to Hungry Howie's for donating free pizzas for lunch. We are also grateful to both Faith Presbyterian and B-Magic for donating the space and entertainment.

On August 24th, six siblings (ages 12-16) joined us for an exciting sibshop at the Gainesville Rock Gym. Although admittedly a little scary at times, we all had fun learning to climb and "belay." In addition to the climbing, we played a lot of really silly games and shared stories about our siblings. A big thanks to the Rock Gym for giving us a discount and opening early and to Five Star pizza for donating our lunch!

On October 26th, eight siblings (ages 8-12) met at the Reitz Union at the University of Florida. Here we played games, talked about our siblings, made crafts and went bowling. We had some requests to have bumpers in the lanes next time!

Finally, on January 25th six siblings (ages 5-8) attended a sibshop at Sun Country Gymnastics. We had fun doing gymnastics, playing silly games, doing art projects and decorating (and eating) chocolate cookies. A big thanks to Hungry Howie's Pizza in Jonesville for donating free pizzas for our lunch!

The next sibshop will be for 12-16 year olds at Skate Station on March 29th.

If you have attended a sibshop (or are a parent of a child who has) and you have any input/suggestions, don't hesitate to contact me. In addition, if you have any ideas about upcoming locations or activities, please let me know.

Thanks, Karin Marsh 352/392-4171

# Siblings: An Integral Part of the Family

By Karin Marsh

*"You are about to embark on one of the most rewarding journeys of your life."*

This message was written on the top of a Sibshop manual given to me shortly after beginning work at CARD. This manual was prepared by Danielle Liso, former CARD staff member, and her words were very true!

Over the past few decades, the medical and educational fields have made attempts to make services "family friendly." However, the majority of the efforts define family as the parents. Many schools and communities have begun parent support groups and publications. About 13 years ago, Don Meyer founded the Sibling Support Project to include siblings in the definition of family. He acknowledges that brothers and sisters "will be in the lives of family members with special health and developmental needs longer than anyone."

One of the initial goals of the Sibling Support Project was to identify siblings' unique needs. By surveying brothers and sisters of varying ages, Don Meyer and Patricia Vadasy, identified some common concerns. These include embarrassment, guilt, shame, resentment and isolation.

The Sibling Support Project advocates addressing these needs by providing siblings with information and support. Brothers and sisters can receive information by talking with parents - keep the disability an open topic and attempt to answer questions. Since 1990 many books have been written for siblings. Many of these materials are referenced on the Project's website: <http://www.thearc.org/siblingsupport/>.

Support can come from parents and peers. Setting aside a special time just for a sibling with Mom or Dad is priceless for many brothers and sisters. Additionally, it is very powerful for siblings to meet their peers and realize, as one sibshop participant said, "I am not the only person in the world with a sibling with a disability."



One opportunity for peer support is Sibshops. In Sibshops: Workshops for Siblings of Children with Special Needs, Don Meyer and Patricia Vadasy outline the 5 goals of these workshops: 1) Provide siblings an opportunity to meet other siblings in a relaxed, fun setting; 2) Provide siblings opportunities to discuss common joys and concerns; 3) Provide siblings opportunities to learn how to handle commonly experienced situations; 4) Provide siblings with opportunities to learn more about the implications of their brother's/sister's special needs and 5) Provide professionals opportunities to learn more about siblings. Sibshops are designed to be fun events. Discussion-type activities are dispersed among games, cooking and crafts. There are over 200 Sibshops in existence in this country and others.

For siblings who can't or wish not to attend Sibshops, they can receive some peer support using 2 listservs found on the Project's website. SibKids is for younger brothers and sisters and SibNet is for older siblings (usually 18 and up). Siblings can chat with brothers and sisters all over the world.

In graduate school, I was fortunate to hear Don Meyer speak on several occasions. Each time, I promised myself that some day I would get involved to help honor brothers and sisters. My employment at CARD has given me this opportunity. Being involved with Sibshops is truly an amazing and rewarding experience. I plan to continue to celebrate brothers and sisters for their vital roles and valuable contributions!

## Help Wanted!

Are you 16 or older and have a sibling with autism or a related disability? Would you be willing to share your experiences on growing up with your sibling? If so, we need your help at our Sibshops!

Please call Karin Marsh at 352/392-4171



## **Camp C.A.M.P. Children's Association for Maximum Potential**

CAMP was founded by doctors and nurses interested in providing overnight camping experiences to children with special needs who were not eligible for other camps due to the severity of the child's condition. Children with tracheostomies, ventilator support, gastrostomies, central catheters, peritoneal dialysis, overnight drip infusions, etc. can be served. Many campers have no verbal or communication or self-help skills. Others require multiple medications around the clock. Some children have milder problems but slip through the cracks and for some reason are unable to attend other camps.

CAMP's ultimate goal is consistent with the Americans with Disabilities Act of 1990 (ADA) which states that special health needs will not bar a child from any camp. However, until other camps are ready, CAMP's goal is that every child, regardless of medical or staff supervisory needs, has the opportunity to experience Camp CAMP now!

**Professionals can attend Camp C.A.M.P. too!**  
Physicians, nurses, physical therapists, occupational therapist, speech therapists, educators,

and graduate students can earn CEUs or graduate school credits. They attend classes every morning taught by experts in the field from all over the nation. By living side-by-side the campers, professionals learn first-hand what it is like to be a parent of a child with special needs. As a result, they gain new insight regarding the needs of the children and their families. This will hopefully enable them to be better service providers when they return to their communities.

Check out Camp C.A.M.P.'s website for details - [www.campcamp.org](http://www.campcamp.org) or contact them at:

**CHILDREN'S ASSOCIATION FOR  
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[www.campcamp.org](http://www.campcamp.org)**

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

- ◆ Cut down on paper clutter in your home and 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](mailto:maxwell@mbi.ufl.edu). Please be sure to give her your current delivery address.

### **CARD UF/Gainesville Library News**

Due to a large number of unreturned library items we have recently implemented a new library policy. Lenders may borrow library items for a three week period. If at 4 weeks the library item is not returned borrowers will receive a reminder call. If the item is still not returned by 7 weeks then a Suspension Letter is mailed out. The purpose of our new library policy is not to punish anyone, but to be sure that library items are available to all of our constituents.

### **Your Input is Needed!**

#### **Sleep Study at UF Department of Psychiatry**

Dr. Jodi Star is conducting a research study documenting sleep problems in children with autism spectrum disorders and exploring the effects of this on family members. She will also be looking at the effects of various medications and other supplements (especially melatonin) on children with ASD. She would like to know...

- 1) Does your child have sleep problems?
- 2) If so, do these problems in turn affect other family members' sleep?

Please email your replies to Dr. Jodi Star at [jstar@psychiatry.ufl.edu](mailto:jstar@psychiatry.ufl.edu)

# 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](mailto: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.

## In celebration of Autism Awareness Month CARD UF/GAINESVILLE is having an Open House!

- ◆ Learn more about CARD's services
- ◆ Browse our lending library
- ◆ Ask our staff questions
- ◆ Chat with other families and professionals

Date: April 9, 2003  
Time: 2PM - 7PM  
Place: 806A NW 16th Avenue  
Gainesville, FL

For more information  
contact Leannis Maxwell  
352/846-3455 or 800/754-5891  
[maxwell@mbi.ufl.edu](mailto:maxwell@mbi.ufl.edu)

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Go to  
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lated disabilities  
\*support groups  
\*trainings  
and more!