



# PostCARD

## Director's Note

Dear Families and Friends of CARD,

The new school year is upon us and the CARD staff at the University of Florida are working hard to keep up with the many calls from families and schools that are coming in each day. Sadly, we are in a position of responding with fewer staff for more constituents. This summer saw the departure of two of our cherished staff members, Donna Gilles and Kirsty McIver.

In July, Kirsty left for Baltimore, Maryland since her husband graduated from the doctoral program in Psychology at UF and accepted a position at Johns Hopkins University. Kirsty was a great help to our families, schools and staff for the past two years and we miss her already. Following Kirsty North, Donna Gilles, who was an Associate Director at CARD for 13 years has accepted a position as Associate Director at the Virginia Commonwealth University Center for Excellence in Developmental Disabilities in Richmond. Donna is still serving as a consultant to the Florida Outreach Project for Students who are Deaf-Blind so we hope to see her back in Gainesville occasionally. Unfortunately, due to budget cuts already received and projected, we will not be able to hire additional staff to take their positions at this time. We hope that the budget situation improves in the future. Nevertheless, if

you or your family was helped by Kirsty or Donna in the past, don't hesitate to contact us if you need assistance and we will do our best to have another staff member available for you.

The 15th Annual CARD Conference will be held at the Lake Mary Marriott (Orlando area) this year on January 26-27, 2008. There is also a free pre-conference day for teachers and adult service providers on Friday January 25th. The pre-conference will feature Dr. Karen Erickson from the University of North Carolina who will speak on Literacy for persons with autism and related disabilities. The afternoon will highlight teachers who have partnered with CARD staff presenting on their accomplishments. Conference speakers will include Dr. Ami Klin from Yale University speaking on his eye tracking research, and Drs. Lynn and Bob Koegel from the University of California at Santa Barbara who will speak on addressing behavior problems in the home. Additionally, Dr. Pat Rogan from Indiana University (past president, National Association for Persons in Supported Employment) will speak on family issues, Dr. Peter Szatmari from Canada will present his Genetic research and Dr. Maria Bove from Vermont will present a keynote address on learning styles.

Please be sure to keep our Sibshops in mind if you are a parent or guardian and your child with autism or related

## CARD Office Hours

The CARD office located at 1405 NW 13th Street in Gainesville is "closed" until 12 PM on Mondays for staff meetings. Computers for making visual supports are available during normal business hours on Tuesday to Friday and after noon on Mondays. For an appointment please call Kathy Robinson at 352 392-4171 or 800 754-5891 ext. 9.

## CARD Website

Go to [www.card.ufl.edu](http://www.card.ufl.edu) for information about:

**current news about autism & related disabilities**

**support groups**

**professional development**

**fact sheets**

**past issues of the PostCARD**

**CARD conference information**

**and more!**

disability has brothers or sisters who could participate. There is more information in this newsletter and you can always contact Melinda Morrison, our new Sibshop Coordinator, if you have questions.

Sincerely,  
**Greg Valcante**

## Sibshop Update

**Who/What:** A program especially for children whose brother or sister has a disability

**Where:** Gainesville, Ocala, Brooksville, Palatka

**Why:** Sibshops are a series of games and fun activities that allow kids to meet others who experience some of the same family issues and to communicate about their experiences and feelings in a supportive environment

For more information and to register please call Kevi at 352 273-0581 or 800 754-5891 ext 0



## Parent Partner Program

The official diagnosis and “label” was given to my oldest son just two short days before we moved from Queens, New York to the Ocala area for the first time. It was almost ten years ago and he had just turned three years old. That evaluation team directed me to CARD and I called the moment we landed.

I was greeted by a warm, friendly voice, that of Margie Garlin, who was extremely patient with me. She had a genuine understanding and sensitivity to my stress, a wealth of knowledge much needed by the mom of a newly diagnosed three-year old (which I was), and a sense of humor. (I really needed someone who could turn my tears into laughter and get me to see the lighter side of life when things seemed so grim.) Being the parent of a child living with autism that was older than mine, she was able to help me decide what I needed to do next. I was alone and new to the area, so she directed me to where I needed to go to get those things done. I received a packet of information from her in the mail that included much needed information on autism (since I knew less than nothing) as well as a list of area resources (that included doctors, therapists, school district, etc.). Then, a short while later, an appointment was scheduled with an assistant director, to see how our family could be helped. A few visits with my family, especially my son, led to my being taught about visual strategies for the home, ways to decide what I needed and how to make the visuals myself. In addition, I was given some simple pointers on teaching appropriate behaviors, and daily living skills, and was shown ways to involve him in family activities through interactive play. Finally, realizing the need for parental support, I was put in touch with a local support group, but when they turned out to be parents of adult children, I was introduced to one of the few parents of younger children living in my area, and that mom and I took that emotional journey together one day at a time.

It’s been more than ten years and another diagnosed son since my experience began, and the number of children living with autism in our area has grown considerably. So it goes without saying that

the need for more help has also increased, and with it, the need for more “Margies”. In an effort to meet that need as well as extend CARD’s reach directly into the community it serves while getting help to the families in the shortest amount of time, the Parent Partner Program was introduced a little over three years ago. I am privileged to have been a part of the program from the beginning, giving to others what Margie gave to me. **Sylvia Miller**

## Book Review

**Reasonable People: A Memoir of Autism & Adoption – On the Meaning of Family and the Politics of Neurological Difference**

Author: Ralph James Savarese

The story is about DJ, a child that was, as the author puts it, “written off as profoundly retarded”. A child abused, non-verbal with autism and in Foster Care in Gainesville, Florida. With the unconditional love of the author and his wife, DJ is not only saved, he is triumphant!

The author kept meticulous details about DJ’s experiences and struggles as he progressed into a functional and successful teen able to communicate. There is even a chapter in the book written by DJ!

The book covers their experience with Florida Foster Care, issues of Adoption, Special Education, Regular Education, Facilitated Communication (FC), Trauma and Autism.

In the introduction, the author expressed a thought that has lingered in my mind: “*If DJ, a “classic” case of hopelessness, can achieve, how many other kids might as well?*”

Now when I am teaching my own children with disabilities, and I get frustrated and ready to throw in the towel I try to remember that. The best lesson that I got from reading this book is Hope! **Amparo Perales**



Ralph, Emily, and DJ Savarese sign copies of *Reasonable People* in Gainesville this past spring.

## 2007 Mercedes-Benz Dealer Championship Golf Tournament

The Mercedes-Benz Dealer Championship, a nationwide amateur-only event for men and women 21 years or older was held at the Gainesville Golf and Country Club on Sunday, September 9, 2007 and this year funds raised were donated to the CARD UF/Gainesville. Thanks to the generosity of Duval Motor Cars, and the hard work of Mr. Roger Daigen and Mr. Kevin Snyder, the registration fee of \$100 per person was designated for CARD. One hundred and three golfers participated, including some parents of children with autism from our area. Thus the total amount raised for CARD was \$10,300! A fantastic time was had by all who attended. We are very grateful to Mercedes Benz, Duval Motor Cars, Mr.

Snyder, Mr. Daigen and all the golfers who participated in this event. The money raised will be used to help pay for scholarships for families to attend the CARD conference, for Sibshops for siblings of Children with autism and related disabilities and for materials to create visual supports for families to use at home.

Greg Valcante



## The ABA Corner

Many constituents of the UF/CARD ask for information about Applied Behavior Analysis (ABA) and this section of the POSTCARD has been reserved for discussion of applications to autism and related disability issues. An initial plan is to share brief information about current therapies, assessment techniques, consumer information, and current events of interest to CARD constituents in the area of ABA and Behavioral Support. In addition, we would like to encourage readers to submit requests for information that we will do our very best to answer. Topics can include the full spectrum of Applied Behavior Analysis applications to the needs of individuals with autism and related disabilities; from principles and methods that make up ABA, to discussion of issues in the area of ethics and values, interviews with clinicians and researchers about autism and related disabilities, how to access ABA services and consumer information, as well as sharing information hot off the research presses.

For our first appearance I would like to preview some of the topics that are on tap for upcoming installments of The ABA Corner. In our next issue, we will cover the area of motivation; creating learning circumstances for individuals that are fun, positive, and growth oriented. Subsequently, given the widespread interest in the Early Intensive Behavioral Intervention model of early intervention we will spend some time describing where it came from and what it is. Other topics that have been suggested include Applied Behavior Analysis approaches to language development, social skills, "autism"-specific treatments such as teaching joint attention, education, and challenging behavior supports. We look forward to your submissions and will keep you posted on upcoming developments. And remember, CATCH'EM BEING GOOD! Please address submissions to me.

Art Wallen

## Research Opportunities

### Family Training Research Project

Volunteers are needed for an intervention study for children with autism and their parents. The purpose of the study is to help fathers of children with autism learn to interact with their children during play sessions. Fathers will also learn how to train mothers to use the same interventions. The study is done in your home. This study is funded by the National Institutes of Health and approved by the Institutional Review Board of the University of Florida Health Sciences Center. For more information you can contact the Principal Investigator, Jennifer Elder, R.N., Ph.D, Associate Professor, College of Nursing 352 273-6359.

### Study of Autism and Severe Behavioral Problems

As many as 1.5 million Americans today are believed to have some form of autism, and this number is on the rise. Dr. Tanya Murphy and the University of Florida are conducting an investigational research study in children and adolescents 6-17 years of age with Autism and severe behavioral problems, such as tantrums, aggression and self-injurious behavior. All study related procedures are provided at no cost to you. Please contact Dr. Jane Mutch at 352 392-7855 for more information.

### Study to Identify Contributing Genetic Factors for ASD

Are you a parent of the child who has Autism Spectrum Disorder (ASD)? Are both biological parents available to participate in the study? If so, please help us to identify contributing genetic factors for ASD. During the study, the child will receive a comprehensive evaluation for the developmental, adaptive and cognitive function and behavioral characteristics. We will collect blood samples from each member of the family (biological mother, biological father, and the child) for genetic study. Feedback will be provided to the family summarizing the results of evaluation at the end of study participation. For more information please contact Soo-Jeong Kim, MD-Principal Investigator, Department of Psychiatry, University of Florida at 352 392-7322 or soojkim@ufl.edu.

## Save the Date! 15th Annual CARD Conference - January 26 & 27, 2008

The 15th Annual CARD Conference will be held at the Lake Mary Marriott (Orlando area).  
 Conference speakers will include:  
 Dr. Ami Klin - Yale University  
 Drs. Lynn & Bob Koegel - University of CA at Santa Barbara  
 Dr. Pat Rogan - Indiana University  
 Dr. Peter Szatmari  
 Dr. Maria Bove

Free Pre-Conference Day for teachers and adult service providers on Friday January 25th:  
 Dr. Karen Erickson - University of North Carolina  
 Presentation on teacher/CARD collaborations

Brochures will be available soon. You may also visit this website for updates - <http://doepartnership.usf.edu/>

### Support Groups

#### Autism Spectrum Disorder Focus Group

Palatka, FL

Contact: Cheryl Brenner 386 467-3820

A support group for parents to network with one another, share stories and give each other ideas on helping their children succeed. Occasional trainings are provided to help parents learn how to help their children. This month parents will be able to observe parent/child games developed to improve communication and sensory issues. Childcare is provided. Meetings begin at 6PM.

Location:

William D. Mosely Elementary School Media Center

1001 Husson Avenue

Palatka, FL

(Park in rear of school)

Scheduled Meeting Dates: Please contact Cheryl

#### Helping Hands Parent Support Group

For parents with autistic/special needs children

Ocala, FL

Contact: Sylvia Miller 352 624-1360

A support group for parents of children with Autism Spectrum Disorders that welcomes parents of all special needs children. Meets last Wednesday of each month from 6PM-8PM.

Location:

Ocala Public Library - Conference room A

2720 East Silver Springs Boulevard

Ocala, FL

<http://phpf-fountain.org>

Scheduled Meeting Date: 11/28

#### Special Parents of Exceptional Children Support Group (SPEC)

Gainesville, FL

Contact: Pam Kissoondyal 352 318-3155

A local parent-formed support group SPEC (Special Parents of Exceptional Children) meets at the CARD office each month. The informal meetings are from 7PM-9PM, but newcomers are welcome to show up at 6PM to meet and discuss their concerns.

Parents of children with any disability are welcome.

Location:

CARD Offices

1405 NW 13th Street

Gainesville, FL 32601-4058

Scheduled Meeting Dates: 11/9, 12/14, 1/11, 2/8, 3/14, 4/11, 5/9  
 (2nd Friday of the month from September – May)

#### Support Group for Adults on the Spectrum

Gainesville, FL

Contact: Robin Byrd 352 846-3700 or [byrd@mbi.ufl.edu](mailto:byrd@mbi.ufl.edu)

This is a discussion group for adults with ASD. Meetings are the last Thursday of every month at 12:00 noon. Please feel free to bring your lunch!

Location:

CARD Offices

1405 NW 13th Street

Gainesville, FL 32601-4058

### Event Highlight

#### Communication Development for Persons Who are Nonverbal and/or Challenged Communicators

Presenter: Dr. June Downing

November 15 - 17, 2007

Orlando, FL

Dr. June Downing is a national leader in the field of education for students with severe and multiple disabilities, including deaf-blindness. As a professor of Special Education, at California State University, Northridge, and prior to that, at the University of Arizona in Tucson, Dr. Downing prepared teachers to work with students who have moderate to profound disabilities. She currently continues her training efforts as an independent educational consultant. She has published numerous articles, chapters, and books on communication, literacy, assessment, vision use, and tactile strategies. Her work and writings emphasize the benefits of inclusive education for students with disabilities. Contact: Pam Kissoondyal 800 667-4052, 352 846-2757, or [pam.kissoondyal@mbi.ufl.edu](mailto:pam.kissoondyal@mbi.ufl.edu)

## Tech Tip How to Override Internet Browser Settings

Our last Tech Tip was about accessibility features in Windows and Mac OS. Sometimes you may want to change only the fonts in your Internet browser (make them larger, for example). Using Internet Explorer on a PC you would click on 'Tools' then 'Internet Options'. Look for buttons that say 'Fonts' and 'Accessibility'. You can change font options there. In Firefox (my browser of choice for both Mac and PC) you click 'Firefox - Preferences' (Mac) or 'Tools -- Options' (PC). The 'Fonts and Colors' section is where you can select font sizes, styles, and colors of your choice. For Safari users, click 'Safari - Preferences' and use the 'Appearance' and 'Advanced' tabs to change font settings. There are many Internet browsers, so consult the Help file of your browser for more information.

John Polefko

Next Tech Tip - Screen Captures

## Websites in the Spotlight

This month our "Websites in the Spotlight" will focus on fun and safety, especially in regard to the upcoming holidays which can sometimes be unpredictable and stressful for families dealing with ASD. Also, while we are in the height of hurricane season, I thought it would be good to tell you about some websites pertaining to handling emergencies.

### Holidays

About.com has several pages about the holidays and autism. There are also links to information about parenting typical children as well as parenting children with special needs.

How To Enjoy Halloween with Your Autistic Child

<http://autism.about.com/od/autismhowtos/ht/halloween.htm>

Before You Celebrate Thanksgiving with Your Autistic Loved One

<http://autism.about.com/od/copingwithautism/bb/beforeturkey>

Handling the Holidays with a Child on the Autism Spectrum

<http://autism.about.com/od/copingwithautism/f/holidayfaq.htm>

This link will take you to a letter written to family and friends by the mother of a child with ASD, explaining why her child may act or react to the situations that children are often introduced to during family gatherings.

<http://www.danasview.net/holiday1.htm>

### Safety

Having critical information available in an easily accessible form, prepared ahead of time could save worry and perhaps a life. You may want to consider downloading the form from this website, filling out the information, and putting it in a safe location. You may even want to keep a copy in the glove-box of your car. It includes a place for you to answer questions about your special needs child that you would not find on a typical health needs form.

Family Network on Disabilities (FND) of Florida's Take and Go Emergency Form

<http://www.fndfl.org/takeandgo.pdf>

The National Autism Association's website has an article on emergency preparedness, some tips, and links to more helpful websites.

[www.nationalautismassociation.org/safetytoolkit.php](http://www.nationalautismassociation.org/safetytoolkit.php)

The Indiana Resource Center for Autism also has a good article about emergency preparedness.

<http://www.iidc.indiana.edu/irca/communication/Emergencies.html>

This site sells car or window stickers & magnets that can alert emergency personnel that an individual with autism may be inside a vehicle or home during an emergency.

<http://www.buttonsandmore.com/decal/ulthm.htm>

Customized honk or whistle for locating lost children, etc.

I'll close with a tip from another mom...

*Yesterday I was downtown enjoying lunch with a friend and my daughter and several of her friends. After lunch, the girls started walking towards what they thought was the direction of their parked car. They got lost downtown. I jumped in my car and drove around looking for them, but couldn't locate them. Then I began honking our special customized honk. While Mary and her friends were trying to find me, she said "I hear my Mom". Her friends couldn't understand, but Mary knew exactly where to go to find me. Our customized honk saved the day. You can make up your own customized honk. Mine was simply left over from my high school years. The honk went to the rhythm of a cheer: "Rangers, Rangers, we are the Rangers." I use it for school pick ups, football game pick ups, etc. I practice it on the kids if I'm waiting in the driveway just so they know the honk and will respond to it when necessary.*

This same method could be used with a whistle or other noise-maker when not in the car. Great way to find kids in an amusement park I would think. **Kathy Robinson**

## CARD UF/Gainesville Staff

Robbin Byrd, B.S. **CARD Consultant**  
 Meghan Fabrizi **Student Assistant**  
 Margie Garlin **Program Assistant**  
 Jordan Ginsburg **Student Assistant**  
 Brittany Gudaitis **Student Assistant**  
 Susan Hill, A.R.N.P. **CARD Consultant**  
 Mark Lewis, Ph.D. **Executive Director**  
 Margaret Maddox **Student Assistant**  
 Leannis Maxwell **Program Assistant**  
 Melinda Morrison, RN, BSN  
**Sibshop Coordinator**  
 Tanya Murphy, M.D. **Clinical Director**

Ann-Marie Orlando, M.S. CCC-SP/A ATT  
**CARD Consultant**  
 Carole Polefko **Public Education Coordinator**  
 John Polefko, M.Ed. **CARD Consultant**  
 Kathy Robinson **Visual Supports Specialist**  
 Mallerie Sherr **Student Assistant**  
 Kevi Sirgo **Receptionist/Intake Coordinator**  
 Greg Valcante, Ph.D. **Director**  
 Art Wallen, M.S. **Associate Director**  
 Cathy Zenko, M.S., CCC-SLP  
**CARD Consultant**

## Parent Partners

Cheryl Brenner **Putnam County**  
 Heidi Jennison **Hernando County**  
 Pam Kissoondyal **Alachua County**  
 Sylvia Miller **Marion County**  
 Amparo Perales **Marion County**  
 Trish Thoburn **Alachua County**

Cover Artwork **Lauren Wooley**

## Training News

We are off to a fantastic and busy start in many of our school districts! After a productive meeting with several of our Exceptional Student Education (ESE) directors and other agency representatives in May, we are expanding our professional development for educators in Alachua, Citrus, Hamilton, Levy, Gilchrist, and Union counties.

We are also offering training for parents or any other interested parties in Putnam, Marion and Citrus counties. Topics include: Potty Training, Individual Education Programs (IEPs), Visual Supports/Communication and Behavior. Please see our website calendar ([www.card.ufl.edu](http://www.card.ufl.edu)) for more details.

Susan Hill, our resident psychiatric nurse

practitioner, conducted a great training on medications that children and adults with ASD may encounter. The workshop helps caregivers understand the implications of the medications and possible side effects. Susan expressed an interest in having this be a recurring training for caregivers. Please call 352 273-0581 if you are interested in having this training in your area.

We are in the process of scheduling our Regional Department of Education (DOE) workshops for this 2007-2008 school year. We plan to bring back Marilyn Volker in November to present her workshop on Sexuality: "Honoring All People: Addressing Sexuality, Body, and Relationships Issues."

The workshop will be in Gainesville on

November 15th. We plan to have another all day workshop on Transition issues on December 3rd in Ocala. Please check our website for updates and registration forms when they become available.

We have a training request form on our website under the "Forms/Contact Us" section. If you have training needs in your area, we are always willing to fill your requests to the best of our ability. We do ask that a minimum of five people register for any training that requires us to travel out of town. We ask that you RSVP so we can contact you in case of any time, date, or location change.

**Leannis Maxwell**

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center for autism &  
 related disabilities



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