

**Center for Autism and Related Disabilities - Jacksonville** 



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#### **Constituency Board Officers**

Rom Alderman - Chair Ron Timonere - Vice-chair

CARD serves Baker, Clay, Duval, Flagler, Nassau, & St. Johns County

We offer services to family, schools, and community organizations who's lives com in contact with the autism community. CARD also provides services to individuals with vision or hearing impairments or dual sensory impairments.

All CARD services are at no cost to the individual.

# Second Annual Deliver the Dream Event

July 2011, will mark the second annual CARD Deliver the Dream family retreat.

The retreat, held at the Cerveny **Conference** Center (<u>www.campweed.org</u>) in Live Oak Florida, provides a once in a lifetime, structured weekend of therapeutic family-centered activities that offer respite,

relaxation, and recreation.

Lodging in hotel-style rooms, daily activities, and meals are all provided at no charge to the individuals.

This retreat allows families to relax, enjoy time together, create new friendships, and build support groups with the other families

during several days filled with games, team building, outdoor play, arts and crafts, and dining.

Last year, families arrived with some excitement and some hesitation. For many, this was the first time they had experienced a real family vacation, without concern about the perceptions of others. Each family was assigned the Dream about the Deliver the at least one buddy or

volunteer for the weekend. It was great to see families

laughing and building relationships www.deliverthedream.org/

# **Coming Soon**

- In an effort to better meet community needs, CARD will soon be surveying its constituents for topics they would like for upcoming workshops.
- CARD is currently planning a series of online and publically projected webinar presentations from Rethink Autism (www.rethinkautism.com)

To be added to the CARD Mailing List email anthony.rhodes@jax.ufl.edu

with one another. It was also great to see everyone, parents and children, participating in games and activities. When the final day arrived, nearly everyone expressed



their thankfulness and gratitude, occasionally accompanied with tears of joy and happiness.

This year, of the multitude of applicants, fifteen families were selected to attend the retreat. Applications and deadline dates were announced in the Weekly Updates during May and

For more information Dream Foundation and

details of their services visit their website at:

#### CARD's Mission

To educate and empower individuals and families throughout the lifespan by providing support, assistance, and awareness within the community; with the goal of optimizing the potential of all individuals with autism and related disabilities.

Dear CARD Families,

This last budget cycle has impacted all CARD Centers around the state. Overall, the UF Jax CARD Center received a 20% funding reduction from last year's level as did every other CARD program. As a result of these cuts, services will continue, however, at a reduced level as we will not be able to sustain the previous levels of support. Over the last 4 years the UF Jax CARD's budget has been reduced almost 35%.

Effective July 1<sup>st</sup>, only one of the staff members will remain full time in CARD. Other staff who will remain with CARD part-time have been assigned to work in other areas in the Division of Developmental Pediatrics for the remainder of their time and salary.

The new CARD staffing allocations will be:

Preschool services	24 hours/week (3 days)
School-aged services	32 hours/week $(3\frac{1}{2} \text{ days})$
School-aged services	24 hours/week (3 days)
Adolescent/adult service	40 hours/week (5 days)

Recently, a staff member resigned and this position will not be replaced. This will result in a reduction in 3 clinical staff members since 2009. In 2009, UF CARD was able to provide 200 hours per week of services. Due to budget cuts, the service time will be reduced significantly.

As specified by the legislature, CARD services can be provided to families with significant autistic behaviors. When indicated, we will continue to provide screenings for families without a diagnosis to assess initial eligibility while waiting on a formal diagnosis. These screenings will not be as timely as in the past, again due to the limited availability of staff time.

Continued services:

- Provide group services, parenting support classes and family services.
- Provide trainings for the regional school district personnel.
- Provide satellite clinics to Nassau, Flagler and Baker counties.

We will continue to be available for individual family appointments. Unfortunately, in completing the above requirements which require advance scheduling, the available time for individual family supports will be limited compared to previous years.

In order to provide services to the greatest number of families, we will continue to emphasize group level service at our Center. Families entering the program will be asked to complete a CARD 101 presentation of 15 -30 minutes in conjunction with their initial visits in order to introduce them to our program and to ensure a standardized introduction to services.

While these changes will be a departure from previous levels of access, we are striving to maintain as many services as possible with diminishing resources for the families we serve, with a hope that the fiscal climate for our state will improve in the upcoming years for all CARD Centers.

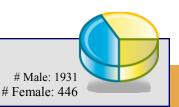
Thank you for your understanding and continued support of our efforts to provide services to you and your family.

Sincerely,

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David O. Childers, Jr., M.D. Chief, Division of Developmental Pediatrics

CARD - Jacksonville Demographics (molifum, 2011)Number of Constituents:2384Those with ASD:2334Those with Related Disabilities:50



**Sibshops** By Elisha Landers

Since hosting our first official Sibshop in February, the response has been tremendous! Siblings of children with special needs join CARD staff and some special volunteers every other month for an evening of fun, games, and food! These brothers and sisters ages 6-13 get an opportunity to meet other siblings with similar experiences and relate with each other



on the ups and downs of life with their siblings. The pizza, candy and clothespin tag remain favorites and the group has great insight and advice to share with others. We will continue to host these events every other month at CARD, and would love for more to join us!

### **CARD 101**

CARD 101 is a new, introductory training for families just beginning their journey with CARD. The training informs families about the services provided at the UF-Jax CARD. It also gives parents a chance to ask questions and complete the necessary consent forms for receiving services. CARD 101 is offered several times a month in conjunction with a variety of trainings. Each training is geared for a specific age group. CARD 101 is offered in conjunction with The ABCs of Behavior and/ or *Communication and Social Skills for Emergent Language Children* for the birth to 6 age group. For the teen and Adult population, CARD 101 is offered in conjunction with Discovering Capabilities and/ or Two Feet Forward. Finally, for the 7 to 14 age group, CARD 101 is offered in conjunction with Looking at Challenging Behavior. Each of these trainings provides parents with an underlying knowledge of how to best work with their child. Once the parents have completed a CARD 101 training, they can then schedule an individual appointment with a CARD Clinician to address individual concerns. It is our hope that CARD 101 will help families better understand how CARD can assist them while providing them with important foundational skills.

## Autism Screenings and Evaluations

By Elise Bowers

Our CARD and our local UF-Jacksonville Dev. Pediatrics Center is collaborating to offer autism screenings at no cost to families. When parents call our center and are concerned that their child may be showing signs of autism, we are conducting an autism screening either on the phone or in person. Following this screening, we provide parents with specific information regarding if their child is showing signs of autism and may need further evaluation and support. We have compiled a list of providers in the area who conduct autism evaluations and an informative brochure for parents on the autism evaluation process. Here at the UF-Jacksonville Developmental Pediatric Center comprehensive autism evaluations are also available to families. Our goal is to increase the access of families to appropriate diagnostic services and necessary intervention! For more information on the UF-Jacksonville Developmental Pediatrics Autism Screening and Evaluations, please contact the center at (904) 633-0750.

# **Setting Goals and Taking Data**

By Elise Bowers

Learning doesn't stop just because school is out. Summertime is a great time to build all kinds of skills. Two key components of helping your child learn and develop new skills are: Setting Appropriate Goals and Taking Data.

How do I set appropriate goals?

- **1.** Goals MUST be child specific and reflect where your child is developmentally.
  - Remember that children with ASD don't typically have even skill development and can have some splinter skills that are not indicative of their overall development.
  - Determining your child's understanding (receptive language) is a good place to start.
- **2.** Get baseline data.
  - You must know where you are starting to get where you need to go.
  - Observation, checklist, timer, etc.
    - For example, if you want your child to be able to listen to a whole book, time how long they can sit now.

**3. Advance incrementally.** 

- Advancing little by little gives both you and your child opportunity for success.
- If, from the above example, your child can sit for 30 seconds with a book before wanting to leave, try for 35 seconds. When they can sit for 35, try 45, and so on. Remember to reinforce their efforts with praise and access to things they enjoy.

4. Make it meaningful.

- Select goals that have meaning for your child and your family, and that improve independence and quality of life.
  - For example, if your child loves water, work on asking for the hose, water balloons or learning to swim. If they love popsicles, use those to work on colors or teach them how to open their own popsicle.





The CARD Summer Academy took place June 20th to the 24th. This week long string of workshops included 33 hours worth of information and interactive learning activities. Select presentations were videotaped and will soon be available in the CARD Lending Library. Workshop Titles Included:

- Educational Programming for Students with Autism: Meeting the Needs of Students with ASDs in the Classroom
- Pivotal Response Treatment for Children with ASD
- Data Collection 101
- Preparing Students for the Transition to Adulthood
- Teaching Social Skills to Students with Emergent-Language
- Creating Behavioral Detectives: Teaching Social Skills to Students with ASD
- Best Practice Recommendations for Using Modeling and Video Modeling to Teach Students with ASD

# Parent Response to the 2011 Annual CARD Conference Scholarship:

Over the last few years, CARD-Jax has been lucky to offer a handful of scholarships to families to attend the Annual CARD conference. The scholarships cover registration and hotel expenses. Here are responses from last years recipients.

I am very glad that I took the time to attend the CARD conference this year! There are always very well qualified people who speak very eloquently and give so much good information. There were a lot of points I took away from the conference. One thing that is very important to me is the idea of inclusion and how important it is to ensure that our kids have opportunities to really experience life and have friends. It is encouraging to hear about schools that are really pushing those opportunities for interaction even though there are challenges in class sizes and time constraints. Along the same lines, there was a lot of good information about helping and teaching children to engage and play with other kids in natural environments. It's a lot of hard work, with a lot of big payoffs in their quality of life. As a parent, I am so encouraged for the outcomes of my own child just by seeing it's all possible. I am very grateful to CARD for providing scholarships once again!

Pam Lively

As a mother of a 5 year-old boy in the spectrum, I always wanted to hear opinions and experiences from grown-ups in the spectrum. The 2011 CARD Conference gave that opportunity, and I am thankful for it. I heard them and I learned many things from their experiences. I've read many books by adults within the spectrum, but the speeches I got to listen adds a new dimension to the knowledge I can get from any book. I got the opportunity to learn more about safety at home, even how to better manage the IEP meetings and get better results expressed on the IEP.

Vanessa Vega

As the single parent of a 14 year old young man on the spectrum, I have been struggling with how to deal with his sexuality. Dealing with puberty is by no means easy with a typical child, but it is very challenging with someone who has the body of a man but the emotional capacity of a young boy. My strategy for dealing with my son's puberty was basically ignoring it, because I just didn't know how to handle it! At the CARD conference, one of the breakout sessions was Lets Talk Sex! Instructional Strategies for Parents and Educators Supporting Individuals with ASD presented by Dr. Kim Spence Cochran. I was surprised and relieved by her very frank, upfront discussion on sexuality, appropriate boundaries, and even masturbation. There was also a list of resources (books) to help sexually educate the individual with ASD. This presentation has helped me greatly by giving me the necessary information (and the courage) to use specific strategies to help my son understand his sexuality. Thanks, Dr. Kim, for such an informative discussion on such a delicate subject!

Next year the 19th Annual CARD Conference will be held, Saturday and Sunday, January 13 - 16, 2012, at the Florida Mall Hotel in Orlando Florida.



Demina Martinez

# Now Available in the CARD Lending Library



## With The Light: Raising An Autistic Child— Graphic Novel by Keiki Tobe

A Manga (Japanese style) graphic novel for adults. The Story begins with Hikaru's birth and how his mother, Sachiko, gradually comes to realize that her son is 'different.' Hikaru's condition is initially faced with denial and lack of understanding within the family and extended family, and later with the prejudice, ignorance, and indifference of many in society. The initial volumes focus on Hikaru's situation at school – where the faculty is ill-equipped to deal with autistic children.

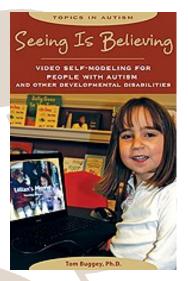
## Seeing is Believing: Video Self-Modeling for People with Autism and Other Developmental Disabilities by Tom Buggey, Ph.D.

This book describes video self-modeling, a promising technique that anyone with basic video equipment can use to help children and adults with autism and other developmental delays improve skills and behavior. Details the process related to filming and editing footage to create a video that depicts the person's best, ideal performance of a skill, and then having them view it.

Step-by-step guidance is offered on how to obtain equipment, plan filming, and edit videos. Full of case studeis, and user-friendly examples and tips, the book helps parents, teachers, and other professionals a new and rewarding series of tools to teach individuals on the spectrum.

## The Child with Autism Goes to Florida by Kathy Labosh.

A narrow, half-book reference guide for family's of children with autism looking for hundreds of tips and reviews of Florida theme parks, individual rides, and resorts. The book includes information on Islands of Adventure, Universal Studios, Magic Kingdom, EPCOT, Sea World, and many more.



Kathy Labosh

The Child with Autism

Goes to

Coming Soon! CARD will be updating the Lending Library inventory list. A copy of this list will be available in a searchable format from the CARD website.

<u>www.hscj.ufl.edu/pediatrics/autism</u>

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(904) 633-0760