

Director's Update

It's hard to believe that a school semester has already gone by. We hope your child and family have experienced great success to start out the 2009-2010 school year. Please remember that our services are always available to you. Whether you are interested in attending a support group, learning new techniques at one of our workshops or need individual assistance and consultation, we are here to help. Simply give us a call to receive immediate assistance.

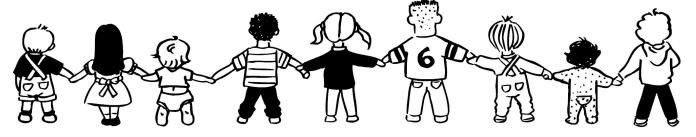
Please check out the calendar section of the newsletter as many events will be held throughout the Spring semester. The first of these events is the statewide CARD conference "Together We Can" being held in Lake Mary, Florida on January 29 - 31, 2010. Topics to be addressed during the conference include research advances, early intervention, transition, technology and best practices for adult and family issues. Please check out the "Cyberbullying" article on Page 10 for a preview from one of the presenters at this conference, FAU Associate Professor Dr. Sameer Hinduja. For reservations and conference updates please visit www.ucf-card.org.

Locally, we have scheduled Dr. Andy Bondy, co-creator of the Picture Exchange Communication System (PECS) to present, "PECS Across the Day" to families and professionals. On March 25, 2010 Dr. Bondy will present his training on our MacArthur campus in Jupiter, and on March 26, 2010 he will present on our Treasure Coast campus in Port St. Lucie. Keep in mind that these are the same presentations presented over two days and two campuses. Additionally, our 4th Annual Family Connections Conference will be held on April 24, 2010. This year we will feature a mother's perspective on raising a daughter with autism, as well as two adults with Asperger Syndrome.

Finally, and most importantly, I want to thank each of you for the many ways you support FAU CARD. Your advocacy and financial assistance helps us keep many of our support efforts and programs intact that otherwise would have to be scaled down during these tight economic times. So, thank you for helping us help others.

All the best,

Kyle Bennett, Ed.D., BCBA Director





Autism and Drowning

Some may say the holidays are the wrong time to think about something as sad as children with autism drowning. I believe it is the right time! Children with autism tend to drown at rates much higher than other children their own age. They can often be skillful in their efforts to leave safe, supervised places and many children with ASD are very interested in water. The dangers usually don't register with them, especially if they are young. These factors combine to increase the chances of drowning. In Palm Beach County, two young children with autism have died over the last two years. Just this Thanksgiving weekend a 10-year-old boy with autism drown in Ocala. He left his home and wandered to a neighbor's unattended pool. This is a real problem not just a theoretical issue.

What can parents and other caregivers do? The first thing is to become aware of the problem. We all may wish that the child was more alert to dangers in the environment, but parents and other responsible adults have to be the ones to actively monitor for safety at all times. When your child is in the water, practice what the American Academy of Pediatrics calls touch supervision. "This means that the adult is within an arm's length of the child at all times." The link for the AAP Pool Safety Tips for Children is www.aap.org/family/ tipppool.htm. Supervision within the home is just as critical. We advise many families to install latches and alarms so that they will know if a child leaves a designated area. Even with good supervision, a child can wander away. Project Lifesaver of Palm Beach County (www.pbcprojectlifesaver.org) is outfitting an increasing number of children with electronic wristbands to help the Palm Beach County Sheriff's Office quickly locate a child should they wander. Other systems are available but this one is especially good in that it has the solid support of the Sheriff's office and their search and rescue team. Barriers are the next things to emphasize. Pools need to have good fences with self-latching and self-locking gates. Doors and windows giving access to pool areas must have alarms on them. As mentioned already, front and side doors may need alarms to let you know your child is leaving the house. Good barriers are not sufficient on their own, they only help when combined with competent adult supervision. The third focus area is classes for water safety instruction, CPR and child first-aid training for adults. Additionally children should take swimming lessons and classes for water safety instruction for children. Even when children know how to swim, they are still at a high risk if they swim unsupervised.

In response to this issue, FAU CARD helped bring together members of a number of community agencies. I would like to thank each of the agencies that came together on this: Palm Beach County School District ESE and FDLRS, Drowning Prevention Coalition of Palm Beach County, American Red Cross of the Greater Palm Beach Area Chapter, Renaissance Learning Center, Palm Beach County School for Autism, Reaching Potentials, International Swim Instructors Association, Therapeutic Recreation a program of Palm Beach County and the Children's Services Council of Palm Beach County. Linda Olson of the Red Cross was our meeting host and safety guru and I want to offer special thanks to her and the Red Cross. We developed a brochure and with the help of the Palm Beach County School District's FLDRS (Florida Diagnostic and Learning Resources System) printed and distributed copies in schools for the families of students with ASD. If you did not receive a copy you can download the content at www.coe.fau.edu/CARD. Go to the bottom of the home page and click on "Drowning Prevention Brochure". Please take the time to become familiar with this important topic and then do what you need to do to protect your children.

Have a great holiday season and a wonderful new year.

Jack Scott, Ph.D., BCBA-D Executive Director

A Cocktail Reception Benefitting the FAU Center for Autism and Related Disabilities

Wings of Hope

Thursday, February 4, 2010 6:30 to 8:30 p.m.

At the home of Judi & Craig Donoff

Please RSVP by January 15

Contact Kyle Bennett at 561.297.3052 or kbennett@fau.edu





MEDICAL UPDATE

The New Normal: I in 90? Prevalence of Autism Spectrum Disorders - What Does This Mean for Families Judith Aronson-Ramos, M.D.

The American Academy of Pediatrics recently published a study about the prevalence of ASD based on a comprehensive interview of over 78,000 families in 2007*. The results of this study found the prevalence of autism spectrum disorders (ASDs) is about 1 percent of U.S. children.

For this study, thousands of parents of children between the ages of 3 and 17 were questioned in a telephone interview. They were asked whether they had ever been told by a health care provider that their child had autism, Aspergers Syndrome, Pervasive Developmental Disorder (PDD) or Autism Spectrum Disorder (ASD). If the parents said yes, they were then asked if their child still had the diagnostic label and if so, how severe were the symptoms.

Based on these parent interviews, the prevalence of ASD was 110 per 10,000 children (or 1 in 91), representing an estimated 637,000 children ages 3 to 17 with a diagnosis of ASD in 2007. This is higher than the previous estimate from the CDC of 1 in 150 in 2002.

Researchers have suggested the increased prevalence might be partly explained by differences in the ways the two surveys were conducted. This new survey includes Aspergers Syndrome, PDD-NOS and Autism Spectrum Disorder. In addition, previous studies have shown the average age of diagnosis is decreasing, which leads to an increase in total prevalence at any one point in time.

The odds of having autism were four times higher for boys than for girls, and Caucasian children were more likely than African American children or children from multiracial families to have autism. Children diagnosed with ASD were also significantly less likely than other children to receive care in a medical home, and they had more problems obtaining referrals and coordinating their care. Parents of half the children with ASD described the condition as mild. Another third of parents described their child's condition as moderate, and the remaining parents described it as severe.

About 38 percent of the children who were ever diagnosed with ASD were reported by their parents to no longer have the diagnosis. Researchers proposed several possible explanations, including the imprecision and difficulty of diagnosing very young children, who may no longer meet the criteria for ASD as they age. Children who had "lost" their autism diagnosis were more likely to be diagnosed with other developmental or mental health conditions, such as attention deficit/ hyperactivity disorder, anxiety problems, or behavioral problems.

No study is perfect, this one included, and there may be an "over labeling" bias in these numbers as more professionals and parents become aware of ASDs. On another note, the positive outcomes for nearly 2/3 of the children in this study whose symptoms were mild, or for those children who lost their label, points to the very positive outcomes we see in our children on the spectrum.

^{*}The study, "The Prevalence of Parent-Reported Diagnosis of Autism Spectrum Disorder Among Children in the United States, 2007," published in the Oct. 5 issue of Pediatrics, draws on data from the 2007 National Survey of Children's Health, a telephone survey of parents conducted jointly by the Health Resources and Services Administration and by the Centers for Disease Control and Prevention's National Center for Health Statistics. The study can be found online through www.aap.org.



Please visit www.ucf-card.org for details and registration.

Jupiter Event Event will be held in the Administration Building, room 119.	Date	Time
PECS Across the Day Dr. Andy Bondy, co-creator of the Picture Exchange Communication System (PECS) will present to families and professionals on how to utilize the system across environments with individuals with ASD.	3/25	8:30 AM - 4:30 PM

Boca Raton Events - Groups Unless otherwise specified, all events will be held in the College of Education, room 411.	Date	Time
Kid's Club Children with an autism spectrum disorder ages 7-11 will have the opportunity to make friends, play games and talk about issues in a safe and friendly environment. Room 447.	1/11 2/8 3/8 4/5	4:30 - 5:30 PM 4:30 - 5:30 PM 4:30 - 5:30 PM 4:30 - 5:30 PM
Parent Support Groups Parents and caregivers are invited to join us for open discussion, networking opportunities and problem solving.	1/11 2/8 3/8 4/5	4:30 - 5:30 & 6 - 7 PM 4:30 - 5:30 PM 4:30 - 5:30 & 6 - 7 PM 4:30 - 5:30 PM
Teen Group & *Community Activities* Teenagers with an autism spectrum disorder ages 12-17 will have the opportunity to meet others, make friends and problem solve issues that teenagers may experience. Teens and parents will also meet in the community for fun activities. Dates are indicated with an asterisk (*).	1/11 2/8* 3/8 4/5*	6 - 7 PM 6 - 7 PM 6 - 7 PM 6 - 7 PM
Adult Group Adults with an autism spectrum disorder ages 18 and older are welcome. The group meets to discuss issues, problem solve and form friendships. Room 457.	1/11 2/15 3/15 4/19	7 - 9 PM 7 - 9 PM 7 - 9 PM 7 - 9 PM

REGISTRATION IS REQUIRED FOR ALL EVENTS.

Boca Raton Events - Training	Date	Time	Location
Overview of Autism Spectrum Disorders			
Families and professionals are invited to attend this workshop. A thorough review of the characteristics of Autism, Asperger Syndrome, PDD-NOS, Rett Syndrome & Childhood Disintegrative Disorder will be presented.	1/21	5:30 - 7 PM	ED 120
	3/18	5:30 - 7 PM	ED 120
Toilet Training Strategies for beginning toilet training and working through accidents will be presented.	2/11	5:30 - 7 PM	ED 120
	4/1	5:30 - 7 PM	ED 120
Visual Supports for Inclusion in Regular Education Settings			
Parents and professionals will learn how to use and implement visual supports in the home or classroom with individuals with ASD. Visual supports are used to communicate choices, provide direction and aid in transitioning.	2/25	5:30 - 7 PM	ED 120
	4/22	5:30 - 7 PM	ED 120
Behavior Basics			
Parents and professionals will learn basic behavior management strategies that can be used in the home and the community to promote positive behaviors.	2/18	5:30 - 7 PM	ED 120
	4/8	5:30 - 7 PM	ED 120
Requesting and Protesting			
Many problem behaviors that children emit are attempts to communicate some want or need. This workshop will help parents and professionals teach children vital communication skills to prevent problem behaviors, or replace them once they already exist.	1/14	5:30 - 7 PM	ED 120
	3/11	5:30 - 7 PM	ED 120



REGISTRATION IS REQUIRED FOR ALL EVENTS.

Treasure Coast Events -		
Groups & Trainings All groups and training locations will be held on our Port St. Lucie campus. Rooms will be announced upon registration.	Date	Time
Family Support Day		
Parent Networking Parents and caregivers are invited to join us for open discussion, networking opportunities and problem solving. Kid's Club Children with an autism spectrum disorder ages 7-11 will have the opportunity to make friends, play games and talk about issues in a safe and friendly environment.	1/21 2/18 3/18 4/22	6 - 7 PM 6 - 7 PM 6 - 7 PM 6 - 7 PM
Teen Group Community Activities		
Teenagers with an autism spectrum disorder ages 12-17 will have the opportunity to meet others, make friends and problem solve issues that teenagers may experience. Teens and parents will meet in the community for fun activities.	1/14 3/11	6 - 7:30 PM 6 - 7:30 PM
Adult Group	1/21	7 - 8:30 PM
Adults with an autism spectrum disorder ages 18 and older are welcome. The group meets to discuss issues, problem solve and form friendships.	2/18 3/18 4/22	7 - 8:30 PM 7 - 8:30 PM 7 - 8:30 PM
PECS Across the Day		
Dr. Andy Bondy, co-creator of the Picture Exchange Communication System (PECS) will present to families and professionals on how to utilize the system across environments with individuals with ASD.	3/26	8:30 AM - 4:30 PM
Enhancing Communication Skills of Students with ASD		
Participants will learn research-based interventions to promote communication and social development in young children with an ASD.	2/16	5:30 - 7 PM
Behavior Basics		
Parents and professionals will learn basic behavior management strategies that can be used in the home and the community to promote positive behaviors.	2/22	6 - 7:30 PM

Treasure Coast Events -		
Training All training locations will be held on our Port St. Lucie campus. Rooms will be announced upon registration.	Date	Time
Visual Supports for Home & Classroom		
Parents, caregivers and professionals will learn to use visual strategies to support individuals with autism spectrum disorders at home, school and in the community. Participants will learn what visuals are and when to use visual supports to increase positive behavior or to promote communication skills.	3/11	5:30 - 7 PM
Toilet Training		
Strategies for beginning toilet training and working through accidents will be presented.	3/16	5:30 - 7 PM
Asperger Syndrome 101		
Learn about the characteristics and strengths of individuals with Asperger Syndrome, as well as strategies to help them be successful.	3/22	6 - 7:30 PM
Establishing Routines in the Home		
Participants will learn creative strategies to establish structure and routines, promote positive behaviors and facilitate social interactions within the dynamics of the home.	4/13	5:30 - 7 PM
Advanced Visual Supports		
Parents, caregivers, and professionals will learn to implement visual supports at home, at school and in the community. Implementation of visual supports for use in increasing positive behavior, promoting communication, and teaching expectations will be discussed. Video will be used to demonstrate the use of visual supports.	4/15	6 - 7:30 PM
Teaching Social Skills to Students with ASD		
Parents will learn specific strategies to encourage social integration skills for their children with Asperger Syndrome.	4/29	6 - 7:30 PM

REGISTRATION IS REQUIRED FOR ALL EVENTS.



SPECIAL COLUMN

Florida Atlantic University

Cyberbullying and Asperger Syndrome, How to Help Victimized Youth with AS Sameer Hinduja, Ph.D.



I recently spoke at an autism conference and presented information on cyberbullying victimization and youth with Asperger's Syndrome (AS). I am particularly interested in this population as one of my close friends has AS, and has shared with me his experiences being harassed by peers who perceive him as "different." We all know that these youth are especially susceptible because of the difficulty they have with conversation, social convention and integration, and appropriate responses to nonverbal cues. Further complicating the matter are their struggles with motor clumsiness, articulating a need for help, and dealing with change. Finally, Internet-based communication is absolutely essential in meeting the daily relational needs of youth with AS, because online interaction eliminates many of the conversational nuances that they may not pick up on (in face-to-face conversations).

Not only do these factors (and others) cumulatively lead to youth with AS being harassed online, many are easily manipulated by mischievous bullies who goad them to mistreat others in cyberspace, download pornography or hack into other computers and they agree to do it, simply because they want to fit in and be well-liked. The bottom line is that we are dealing with very vulnerable adolescents who are in need of our help.

When it comes to suggestions as to how we can respond, a few things stand out in my mind.

First, it is really important to try to understand exactly what is wrong, why the youth with AS is being bullied, and how it makes him or her feel. We also need to realize that what may seem normal to us, in terms of social interaction, may not be normal to youth with AS. We have to venture into their definition of "normalcy" to fully empathize with how they are struggling. The traditional ways that we help youth without AS may not bear much fruit when working with youth with AS, just like it is useless to implement multicolored lights on an instrument panel when the operator is color-blind. Youth with AS receive social signals but cannot decode their meaning with any beneficial level of reliability. They have what could be considered subjective blindness, and it is not a fault of theirs it is simply how they are.





Florida Atlantic University

SPECIAL COLUMN & COMMUNITY NEWS

continued: Cyberbullying and Asperger Syndrome, How to Help Victimized Youth with AS

Sameer Hinduja, Ph.D.

Personally speaking, I have found that youth with AS tend not to ask for help, not because they prefer isolation or independence, but because it does not naturally occur to them that another person will have a different perspective, different experience/knowledge, and thus might find a different or better solution. Encourage them to tell you how they are feeling, even though they may not respond. If they can't answer directly, perhaps they will share their thoughts on how the same instance of cyberbullying might make another person feel. That might clue you in to the emotions they are wrestling with.

When you are trying to share advice or suggestions, repeat your message often for reinforcement and heavily use logical explanations. To aid their decision-making processes, it may be wise to create and use simple flowcharts to depict human behavior. These can show actions, the way in which the actions affect others, and the way in which others' responses then affect the subject. For example, "if I do X, it will cause effect Y on other people, which will cause them to respond to me with Z".

Finally, when working with cyberbullying victims with AS, it may be useful to jointly analyze stories, characters, plots and motivation in fiction, to point out tropes and story cues, and to figure out why characters act as they do. Also, try using comic books or comic strips - which often convey some of the story through characters' emotion-laden expressions, but in simplified "cartooned" art that is easier to

comprehend. Comic strips with humor that relate to real life situations are especially good; they teach typical motivations, reading faces, understanding humor, decision-making, and coping/response mechanisms all at once.

Dr. Sameer Hinduja is an Associate Professor of
Criminology and Criminal Justice at Florida Atlantic
University, and Co-Director of the Cyberbullying
Research Center www.cyberbullying.us. His latest
book is entitled "Bullying Beyond the Schoolyard:
Identifying, Preventing, and Responding to
Cyberbullying" by Corwin Press, Sage Publications. He
will be presenting on cyberbullying at the 17th Annual
CARD conference in Orlando on January 29 - 31,
2010.



Treasure Coast News

Hope Center Relocation

The Hope Center Charter School is a public school within the Martin County School District. In January, it will move from its current location in Jensen Beach to a newly renovated building in Stuart on Indian Street. It will also have space available for private providers such as, speech and language therapists, occupational therapists and behavioral therapists. For more information please visit, www.hopecenterforautism.org.



COMMUNITY NEWS

Florida Atlantic University

Renaissance Learning Academy

New Charter High School Update

The Renaissance Learning Academy continues to expand its' services to meet community needs. The new charter high school of choice is now offering standard and special diploma options to those students and families who appreciate a strength-based program that puts emphasis on social skills development, transitional independent living and life skills acquisition. Skills are taught in a collaborative environment that promotes self-determination, individual choice and relationship building and friendships. Activities at the school have included a Halloween Dance (ballroom dancing lessons were a pre-requisite for students), a backstage tour of a local Burger King, a Thanksgiving dinner prepared by our culinary students, a tailgate party and FAU football game, and many other exciting events. Individually, RLA students have accomplished some pretty great things: One student built eight computers for the RLA computer lab and helped install software in several others. Another student has been learning to operate the RLA switchboard and can now answer and transfer calls and take messages. One is getting ready to star in our first musical show and another student, our golf star, will represent Florida in the Nationals of the Special Olympics in Nebraska.

Due to increased demand, RLA will be opening a new classroom in January. To attend this tuition-free school, students must have an ASD diagnosis, be between the ages of 14-21 and be a Palm Beach County resident. For more information please call us at (561) 296-1776 or find us on the web at www.RLAcademy.com.



Therapeutic Recreation

Sports and Leisure Programs for Adults and Teens

The Therapeutic Recreation Complex in Lake Worth is offering several different community programs for teens and adults with developmental disabilities. Activities include camp outs, kick ball, cooking and dance classes. Most programs start in January and will run for two to three months. Please visit www.pbcparks.com/therapeutic_recreation or call 561.966.7015 for more information.

Autism Insurance Bill

Latest News

The benefits of the Autism Insurance Bill will start to become available to many families. The law really takes effect as your insurance company renews its policy with your employer, for most plans that is January 1, 2010. We have information on this important bill on our CARD web site, click here to view. We are happy to note that some employers who are not required to provide this special autism coverage under the Geller Bill have voluntarily decided to do so. If you know of such a plan please send an email to card@fau.edu with any details and we will post a list of these progressive employers.



ASK EPPY



Ask Eppy

A colomn provided by Eppy Financial Group, Inc.

When do I need to establish a special needs trust?

The answer is it depends on your situation. If your loved one with special needs currently has assets due to a monetary (legal) settlement or an inheritance then a first party special needs trust should be established. Be aware that it will act as a Medicaid reimbursement trust. If there are no assets it may be wise to wait and have a third-party special needs trust established via your will (i.e. testamentary special needs trust).

What is guardian advocacy?

Guardian advocacy is a type of guardianship created for persons with developmental disabilities. The Florida statute is 393.12. This tends to be a much simpler process than full (plenary) guardianship and may not require an incapacitation hearing. If a person lacks the "decision making" ability to meet at least some of the essential requirements for his/her health or safety the courts may appoint a guardian advocate. Often the decision-making powers conferred are only over financial, health, and living arrangements. As always, you should consult an attorney in your area with experience in special needs and guardian advocacy. Procedures vary by court.

What kind of services does Med-Waiver provide?

The list is long and includes: physical and speech therapy, respite care, transportation, consumable medical supplies, and job training/coaching. Please contact us for more detailed information on how and who to contact to apply for services.

What should I include in my "Letter of Intent"?

Anything and everything about you and your loved one with special needs, including but not limited to: general information, names of guardians and successor guardians-advocates-trustees, representative payee and power of attorneys (this does not replace or act as a legal will), medical history, and what works well for housing, living skills, education, work, leisure, religion, services and benefits. Email us and we will send you a formatted Word document and you will have the most detailed and complete Letter of Intent possible.

Eppy Financial Group, Inc. 1000 Corporate Drive 7th Floor Fort Lauderdale, FL 33334

Eppy Financial is a unique team of financial planners dedicated to helping families with special needs. Questions can be submitted to feppy@finsvcs.com or by calling 954.689.9482. We will answer all questions submitted either in the quarterly newsletter or with a personal response from one of our team members.



CONTACT US

Statewide CARD Toll Free Number: 1-800-9-AUTISM (288476)

FAU CARD Toll Free Number: 1-888-632-6395

Website: www.coe.fau.edu/card

e-mail: card@fau.edu

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Thank you! Thank you! Thank you!

We would like to express our most sincere gratitude to the following families and professionals for their contributions to FAU CARD:

Joe & Fran Eppy & Eppy Financial Group, Inc.

United Way

Janet Elinoff

Montgomery Foundation

Kristy DeMeo

Martha Fittro

If you or your organization would like to contribute to FAU CARD, donations can be made out to:

FAU Foundation CARD

and mailed to our office at:

FAU CARD
Department of ESE
777 Glades Road
Boca Raton, FL 33431