

# COMMUNITY

**CENTER FOR AUTISM & RELATED DISABILITIES** 

at The University of South Florida

Louis de la Parte Florida Mental Health Institute, Department of Child & Family Studies — Volume 11, Issue 2 • August 2008 - January 2009

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## **Message from the Director**

Our newsletter feels bittersweet this time due to the many wonderful things that CARD-USF has brought to the communities we serve this year within such a depressed economy. Our gas prices have skyrocketed which was bad enough, but then our CARD center, along with all other CARD sites had to send back 4% of our budget for the

In the new fiscal year..., we will lose over \$102,000 of our budget.

previous year. In the new fiscal year beginning July 1, 2008, we will lose over \$102,000 of our budget and likely an

additional four percent. All of the CARD centers are experiencing similar losses and as a result, will not fill vacant positions. This translates into lost services to our families, for which we apologize up front. Our reality is that delivering services to one family at a time, in their home, becomes more and more difficult as we continue in these economic times. We have been working hard to determine a more efficient course of action so that we can continue to be a proactive resource for our communities. We will be looking at projects that have a greater impact for the families and professionals we serve. This may be delivered through trainings via the web, collaborations with partners where we enhance each other's work, or an orientation process that builds social networks for families when support is most needed.

Your advocacy for CARD funding over the years has been greatly appreciated. And now, more than ever, as new legislation will be coming into play for the next session, your voices are more important than ever. CARD



Dr. Karen Berkman, CARD Director

services still represent the only free resource families have in Florida for high quality autism expertise. We need your help to continue the conversation with your legislators about what is most important to you. This is one case where one person can make a big difference. Your personal stories and pictures are what legislators remember most. So schedule a visit with your local representatives, bring your pictures and story to leave behind.

...your voices are more important than ever.

Tell them what CARD has done to support you and how important it is to fund our program at a level that can meet the

demand of the ever-increasing families who come to us for help.

Thank you for your support and we all hope for better economic times.

-Karen Berkman, Ph.D.

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#### **CENTER FOR AUTISM & RELATED DISABILITIES**

at The University of South Florida

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#### **Our Mission**

The mission of the Center for Autism & Related Disabilities (CARD) at the University of South Florida is to provide support and assistance that optimizes the potential of people with autism and related disabilities. Our effort to achieve this mission is exemplified in the four "components for caring" that are the focus of our work:

- Direct Assistance Providing individualized support for people with autism and related disabilities, and their families, in natural community settings.
- Technical Assistance & Consultation –
   Undertaking activities on behalf of programs
   (e.g., classroom, supported living residence,
   supported employment site, etc.) that serve
   people with autism and related disabilities.
- Professional Training Providing instruction on autism and related disabilities through our workshops, conferences, in-service training, and college courses.
- Public Education and Awareness Developing and disseminating information about people with autism and related disabilities.

As one of seven regional, university-based CARD sites, CARD-USF provides its services to individuals with autism and related disabilities, their families, related professionals, and the general public throughout a fourteen county catchment area in west, central, and southwest Florida.

#### **Endorsement Policy**

As a policy, CARD will not lend its name to the endorsement of any specific program, practice, or model that is offered for service to people with autism and related disabilities. However, the sharing of information and training opportunities are key functions of the CARD program.

Events, activities, programs, and facilities of the University of South Florida are available to all without regard to race, color, marital status, sex, sexual orientation, religion, national origin, disability, age, Vietnam or disabled veteran status as provided by law and in accordance with the University's respect for personal dignity.

## 3rd Annual Community Leadership Award Ceremony

On April 2, 2008, CARD was very proud to honor 4 individuals from the City of Tampa Parks and Recreational Department for their outstanding contribution to persons with autism. The four recipients of the award were Karen Palus, Sandy Fiallo, Lalita Lovett, and Charles Bradley. They all played a part in implementing and supporting an inclusive summer camp at the Loretta Ingraham Recreation Center in South Tampa. The ceremony was held at the Tampa Marriott Waterside and included friends and family of the surprised recipients.



Community Leadership Award recipients along with Mr. Santiago Corrado

They received plaques that were created by VSA which is an inclusive art program that promotes artists with special needs.

Mayor Pam Iorio was gracious enough to send a representive to speak at the ceremony. The representative was Mr. Santiago Corrado who is the neighborhood services administrator and oversees the Tampa Parks and Recreational Department. He gave CARD a proclamation from the city and CARD presented the mayor's office with a plaque in recognition of its efforts to build an inclusive community

for indiviuals with autism.

Dr. Jose Hernandez represented the Office of Diversity and Equal Opportunity at the University of South Florida and spoke to the award recipients about their impact on a diversified community.

The ceremony was followed by a buffet and an opportunity for the award recipients to meet the community members who applauded their efforts.

### Tee it up "Fore" CARD

CrossRoads Community Church once again invited us to partner with them for their 8th Annual Golf Classic on Saturday, August 23, 2008 at Plantation Palms Golf Club. The Golf Classic benefited CARD and CrossRoads. Golfers and volunteers enjoyed a sunny morning of golf, fun and friendships. The rains came in just as teams were finishing their final holes and prizes and lunch were enjoyed in the dry, cozy clubhouse. Thank you to CrossRoads and all of our sponsors, volunteers and golfing teams!

To host or sponsor an event for CARD, please call Christine at 813-974-9264 or email crover@fmhi.usf.edu for more information.



Chase poses with the CARD team.



Pastor Greg's team



Chase gives Uncle Hailie a high five.

# Governor's Task Force on Autism Spectrum Disorders

Excerpt taken from www.healthyfloridians.com

The Governor's Task Force on Autism Spectrum Disorders was established by Executive Order 08-36 on March 7, 2008. The Task Force will develop a comprehensive report of recommendations for addressing autism in the state of Florida. The Task Force was created to advance public policy for the research, screening, education, and treatment of autism, to assess the availability of insurance coverage for appropriate treatment

of autism, and to recommend a unified and coordinated agenda for addressing autism in Florida.

Please visit this website and select the tab for autism task force to view the latest information on the work of this group.

CARD-USF is very pleased that Karen Berkman, Director, was appointed to this task force and is co-chair for a committe that is tasked with "putting the pieces together."

### **Save the Date!**

ANNUAL STATEWIDE

CONFERENCE

Hosted by CARD at Florida Atlantic University

Hilton Palm Beach Airport

Friday, January 16, 2009 thru Sunday, January 18, 2009

## CARD Contribution to Awareness in April

As a part of our Autism Awareness activities in 2008, CARD created and disseminated a variety of educational materials addressing effective strategies for individuals diagnosed with Autism Spectrum Disorder (ASD). Teachers, clinicians, and pediatricians, throughout the fourteen counties in the CARD-USF catchment area received bags that were tailored to their educational needs. For example, bags included instructional CD's, interactive books, and screening tools to promote early identification of ASD.

In addition, families who attended our literacy event received a bag that had materials to promote reading for young children. CARD supports the commitment of families and communities to individuals with ASD and hopes to provide additional tools needed to enhance the successes of children and families touched by autism.

\*\*This article is an explanation of services available to Spanish speaking families\*\*

# Seguda Reunion Hispana de CARD-USF

La Segunda Reunión Hispana auspiciada por CARD-USF se llevó a cabo este pasado sábado, 7 de junio del 2008. Catorce familias hispanas se dieron cita para compartir en un ambiente alegre y cómodo para todos.

El tema inicial de nuestra reunión fue la discusión del significado de la comunicación. La comunicación es sumamente importante para todos, pero puede ser influenciada por el punto de vista de cada cual y por la manera en que la recibimos. Para ilustrar este mensaje, hicimos juegos como "pasa el secreto", juegos de "mimica" e interpretación de dibujos. ¡Muchas gracias a todos los participantes por hacernos pasar un rato tan divertido!

Al igual que el año pasado, terminamos nuestra reunión disfrutando de bocadillos deliciosos y postres que nuestras queridas familias aportaron.



## Kaleisia Family Development Project

On Sunday evening, February 10th 2008, Kaleisia Tea Lounge at Fletcher and 15th Streets in Tampa hosted the Gifts of Love Celebration to benefit CARD. Silent and live auction items were available, as well as, of course, a selection of Kaleisia's finest teas and goodies. Live entertainment and educational information about CARD rounded out a delightful evening. Kaleisia Tea Lounge has donated nearly \$7,000 to support the Autism Services Fund at CARD. A huge thank you to all of the staff and customers of Kaleisia for your "gifts of love" to the community!

In honor of the giving community spirit of Kim Pham and Lan Ha, the owners of Kaleisia, CARD has created the *Kaleisia Family Development Project*. The Kaleisia Project was established to provide funding for services related to autism in the areas of training and development for families and individuals with autism spectrum disorders. Families and individuals can request stipends to help pay for registration fees for trainings, educational programs, conferences or workshops. Please check out our website for additional information and an application.

## Lieutenant Governor Jeff Kottkamp Celebrates Autism Bill Passage at Florida Gulf Coast University

At a press conference at Florida Gulf Coast University's College of Education, Kottkamp, of Cape Coral, said the bill's passage was long overdue.

"It was just all the stars coming together," he said. "I can tell you this: We're not done."

Governor Charlie Crist signed the bill into law Tuesday May 20, 2008 in Tallahassee, calling it "a bold step in the right direction." The proposal passed through the Legislature May 2 after heavy debate between the Senate and House of Representatives.

The bill, which will go into effect July 1, states that private insurance companies must cover \$36,000 a year in autism treatment. It also requires that the Office of Insurance Regulation establish a group that will work with insurance companies to cover children with other developmental disabilities.

With a 3-year-old of his own, Kottkamp said he could understand why parents would want to give their children the best life possible. He promised parents that the passage of the bill is just the start in helping kids with developmental disabilities and their families. The bill is summarized below:

# FINAL HOUSE SUMMARY OF SB2654 THAT PASSED

Source: Florida House of Representatives, 2008 Session Summary

#### **M**EDICAID

The bill authorizes the Agency for Health Care Administration (AHCA) to seek federal approval for a Medicaid waiver or state plan amendment to provide home and community-based therapies and behavioral interventions to children under age 6 diagnosed with a developmental disability, autism spectrum disorder, or Down syndrome. The bill limits such Medicaid benefits to \$36,000 annually not to exceed \$108,000 in total lifetime benefits. AHCA is required to

report progress and recommendations to the Legislature annually starting January 1, 2009, and is prohibited from implementing the new program without prior legislative approval.

# ts. Fort Myers s. Anne. To recommendations to the



Fort Myers satellite office staff Leigh Anna Nowak and Anne Allen, pose with Lt. Gov. Kottkamp

#### **Insurance Compact**

The bill requires the Office of Insurance Regulation (OIR) to convene a working group of representatives of all licensed insurers and health maintenance organizations (HMOs) to negotiate an industry compact that includes a binding agreement regarding coverage and access to services for persons with developmental disabilities or autism spectrum disorder. The working group also includes representatives of employers with self-insured plans, two designees of the Governor and one designee each of the Senate President and Speaker of the House. The compact must include: Requirement that each signatory increase coverage for behavioral interventions and therapies when medically necessary due to the presence of a developmental disability.

Procedures for clear and specific notice to policyholders identifying the amount, scope, and conditions under which coverage is provided. Penalties for documented cases of denied claims for medically necessary services due to the presence of a developmental disorder or autism spectrum disorder. Proposals for new product lines that may be offered in conjunction with traditional health insurance and provide a more appropriate means of spreading risk, financing costs, and accessing favorable prices. Upon completion of compact negotiations, OIR must report the results, and beginning Feb. 15, 2009, OIR annually report specified information regarding the compact.

#### **INSURANCE MANDATE**

The bill imposes a coverage mandate on all large group health insurance policies, benefit plans and HMO contracts issued or renewed on or after April 1, 2009. Plans are required to cover well-baby and wellchild screening for diagnosing autism spectrum disorder, and treatment of autism spectrum disorder through therapies and applied behavior analysis, including services habilitative in nature. Coverage is limited to \$36,000 annually not to exceed \$200,000 in total lifetime benefits, which shall be adjusted annually based on the medical price component of the Consumer Price Index. The bill prohibits an insurer from various contractual actions because an individual is diagnosed as having a developmental disability. OIR is prohibited from enforcing the coverage mandate in the bill against insurers and HMOs which are compact signatories by April 1, 2009, but must enforce the mandate against signatories which have not complied with the terms of the compact by April 1, 2010. Subject to the Governor's veto powers, the effective date of this bill is July 1, 2008.

# Literacy for ALL: Autism, Literacy and Learning Workshop



A collaborative project between the Junior League of Tampa and the USF Department of Communication Disorders presented evidence-based practices that have been shown to be effective with individuals with autism spectrum disorders and demonstrated ideas and strategies that families took home and put into practice. Fifty families joined CARD in building reading skills and a lifetime love of reading.

# **CARD Constituent Achieves Highest Honor of Scouting, Valuable Life Lessons**

"It's more than a badge. It's a state of being. You are an Eagle Scout," touts the National Eagle Scout Association.

CARD Constituent Ian Belanger received the highest honor bestowed by the Boy Scouts of America, on April 5th, 2008; he became an Eagle Scout.

A boy scout must receive all requisite merit badges previous to pursuing the Eagle Scout award. Ian Belanger successfully completed all of his merit badges, including a "Disability Awareness" merit badge by educating the members of his troop on autism

#### **Eagle Scout Pledge:**

I reaffirm my allegiance
To the three promises of the Scout Oath.
I thoughtfully recognize
And take upon myself
The obligations and responsibilities
Of an Eagle Scout.
On my honor I will do my best
To make my training and example,
My rank and my influence
Count strongly for better Scouting
And for better citizenship
In my troop,
In my community,
And in my contacts with other people.

spectrum disorders and related disabilities.

In pursuing his Eagle Scout award, Ian wanted to develop a project which could improve his community. Ian studied his community and discovered that Brookwood Florida, a therapeutic home for teen girls, could benefit from aesthetic renovations. Brookwood Florida therapeutic home provides troubled adolescent girls with an alternative living environment and therapeutic program to prepare them for self-sufficiency or successful family reunification. Ian expressed an aspiration to make Brookwood a more desirable place to live.

Ian described his Brookwood beautification project as a 5 month process which required a variety of tasks, including, but not limited to, the following: community research, project planning, cold calling, fundraising, renovation planning, material gathering, advertising for volunteers, managing volunteers, and implementing renovations.

"He met with the Executive Director of Brookwood, he made several phone calls, and he solicited for donations to raise funds for the project, none of which come easily to Ian," reported Karen Belanger, Ian's mother.

Ian's fundraising efforts led to donations of 90% of the work materials, including tools from the Home Depot, flowers from Carol's Nurseries, and materials from Carol's

Building
Supplies. He
then used the
materials to
build a new
patio, refurbish
a sidewalk, and
plant a garden for
the young women at
Brookwood.

"I learned to complete a largescale project and I managed to help someone who needed it," said Ian.

Ian further
reported that he is still
contemplating how he
might apply the skills he
gained to his future, but
his mother indicated that his persistence,
improved communication skills, and
commitment to community will serve him in
any endeavor he chooses.

NESA proudly and profoundly states, "You may have received the badge as a boy, but you earn it every day as a man."

Congratulations, Ian!

# **2008 Winners of the Hillsborough School District ESE Excellence in Action Awards**

If you care for a child with special needs who attends school in Hillsborough County and receives services through the ESE Department, you have an opportunity each year, right after the holidays, to acknowledge people who have reached out in a special and meaningful way.

These awards are unique because individuals are nominated by families. It's like the People's Choice Awards, but for schools.

Anyone who positively impacts your child can be nominated – teachers, administrators, aides, bus drivers, therapists, janitors, lunch ladies – anyone who makes a special effort to connect with your child, and makes a difference in his or her life.

Notice of the competition and nomination forms usually goes out through the FDLRS Parent Press. If you do not already receive this email newsletter, you can subscribe by contacting Phyllis Guthman at Phyllis.Guthman@sdhc.k12.fl.us.

# Congratulations to all of the 2008 Excellence in Action Awards Winners!

- Administration: Karen Stevens, ESE Specialist Sickles High School
- EELP: Jean Smith, Limona Elementary
- ESE K-5: Kelly Capote, Heritage Elementary
- ESE Secondary: Sandra Marra, Hillsborough High School
- General Education: Courtney Haase, Lockhart Elementary
- Therapist: Christa Leonard, ABA Therapist
- Support Staff: Celine Strong, Limona Elementary
- Transportation: Betty Simpson, Retired, Area VI
- Volunteers/Community: Mary Ann Massolio, The Cancer Center



#### Autism Society of America (National Organization)

Website: http://www.autism-society.org/

#### Autism Society of Florida, Inc. • Chapter #131

Mail: PO Box 970646 • Coconut Creek, FL 33097

Phone: 954-349-2820 Fax: 954-571-2136

E-mail: webmaster@autismfl.com Website: http://www.autismfl.com

#### CHARLOTTE COUNTY

#### Autism Speaks • Southwest Florida Branch

Location: Port Charlotte, FL Contact: Sharon Boyd or Krista Rosado for meeting dates and times or to be added to their mailing list for upcoming events.

Phone: 941-697-9772

E-mail: swflorida@autismspeaks.org

#### **COLLIER COUNTY**

Naples Spectrum Support Group

Meetings: 3rd Wednesday of the month, at 7:00p.m. Location: Therapeutic Integration Services offices 2960 Immokalee Rd #3 • Naples, FL 34110

Contact: Angie Rue Phone: 239-514-5010 E-mail: ruesugar@aol.com

#### HILLSBOROUGH COUNTY

#### Concerned Parents of Autistic Children

Meetings: Last Sunday of the month, 3:00 p.m. to 5:00 p.m. Location: 9631 Raiden Lane • Riverview FL 33569

Contact: Dr. Moursi Phone: 813-643-9393

#### STAND (Statewide Advocacy Network on Disabilities)

Hillsborough Monthly Chapter Meetings (All disabilities) Meetings: 3rd Thursday of the month, 6:30 to 8:30 p.m. Location: Children's Board of Hillsborough County 1002 E. Palm Avenue • Tampa, FL E-mail: advocate@standonline.info

Asperger's Support for Men

Meetings: Every other Thursday, 7:00 p.m. to 8:00 p.m. Location: 2901 Swann Avenue • Tampa, FL

Cost: \$20-\$29 per session Contact: Jason Tompkins, LCSW

Phone: 813-784-0153

Jason Tompkins facilitates a support group for men with Asperger's Syndrome. The group focuses on building new relationships as well as enhancing current relationships, job issues, and family struggles. Ideal group members are at least 18 years old, male and have a confirmed diagnosis of Asperger's Syndrome. Group costs \$25 per session and is partially subsidized by Dr. Steven Kreitzer.

#### The Parents of Autism and Asperger's Syndrome Support Group (PASS)

Meetings: First Friday of the month September through May Time: 9:30 am - 11:30 am Location: Campo Family YMCA 3414 Culbreath Road • Valrico, FL Cost: Meetings are free and open to the public. Website: http://geocities.com/thepassgroup/ PASS also hosts an online group for families at http://health.groups.yahoo.com/group/pass\_tampa/

#### LEE COUNTY

#### Adonis Autism Center of Southwest Florida

Meetings: 2nd Tuesday of the month, at 7:00 p.m. Location: Covenant Presbyterian Church Room 206 • Ft. Myers, FL

Contact: Beth Bashaw Cameron Phone: 239-995-1794

Website: http://www.adonisautismflorida.com

#### PASCO (NORTH)/HERNANDO COUNTY

#### Hernando Autism Parenting & Personal Experience Network (HAPPEN)

Meetings: 3rd Wednesday of the month, 7:00 - 8:30 p.m.

Location: Pediatric Therapy Works Contact: Leslie Bolen for directions

Phone: 352-683-0209

#### Pasco County

#### AWARE 4 Autism - West Pasco

(Are We Awake Ready & Educated for Autism?) Meetings: 3rd Tuesday of the month, at 7:00 p.m.

Location: Holiday Recreation Complex 2830 Gulf Trace Blvd. • Holiday FL 34691

Contact: Monica Bice Phone: 727-945-0947

E-mail: AWARE4Autism@msn.com

#### AWARE 4 Autism – East Pasco

Support group for caregivers of individuals with an autism

spectrum disorder

 $\hat{M}$  eetings: 1st Saturday of the month, 2:00 – 4:00 p.m.

Location: First Congregational Church 7900 Fort King Road • Zephyrhills, FL

Contact: Johanna Phone: 813-782-9431

E-mail: AWARE4Autism@gmail.com

#### Koolkidz Social Skills Group for Children with ASD

Social Skills Group for Children with Asperger's Syndrome and high functioning autism.

Meetings: Activities each Wednesday to facilitate relationship

building and friendships. Cost: Free!

Contact: Suzette

E-mail: suzette@koolkidz.mysite.com

Website: http://www.koolkidz.mysite.com for current events.

#### NAMI Adult Mental Health Peer-Support Group

Meetings: 1st & 3rd Wednesday of the month, 7:00 – 9:00 p.m. Location: Community Hospital of New Port Richey Conference Room

#### POLK COUNTY

Circle of Friends Support Group
Meetings: Every other Thursday of the month.
Location: Alternate between the Winter-Haven Hospital and the Circle Building on Stuart Avenue in Winter Haven Contact: Mertice Fehringer for dates and location. Phone: 863-679-2507

#### Parental Education for Autism in Children Everywhere (PEACE)

Meetings: 1st Tuesday of the month, 6:00 - 8:00 p.m.

Location: Family Fundamentals Bldg. 1021 Lakeland Blvd. • Lakeland, FL Contact: Nicole

Phone: 863-686-1221 ext 228 E-mail: Nikki73170@aol.com

Website: http://www.peacelakeland.com/

#### A Differently Abled Parent Support Group (ADAPS)

ADAPS is a support network for families and caregivers of children with disabilities, ages birth to 21 years. Meetings: 3rd Tuesday of the month, 10:00 - 11:30 a.m. Location: Family Fundamentals Bldg. 1021 Lakeland Blvd. • Lakeland, FL Contact: Kim Ellis at 863-701-1151 ext 152 or Nicole at

863-686-1221 ext 228

Please contact CARD-USF with changes or additions. Support Group listings are provided as a service and are not an endorsement by CARD-USF.

# Understanding Autism and Co-Existing Mental Health Disorders

Autism does not grant immunity to having other medical and mental health issues. Individuals with autism and Asperger's Disorder may also have co-existing mental health disorders, according to Mohammad Ghaziuddin, M.D., University of Michigan, one of four nationally-respected clinicians and researchers presenting at the "Autism and Co-Existing Mental Health Disorders" conference held May 9, 2008 in Southwest Florida. Dr. Ghaziuddin explains:

Although autism and Asperger's Disorder were first described over 60 years ago, relatively little is known about their co-existing mental health problems. However, there is increasing recognition that several types of emotional and behavioral symptoms are common, such as, depression anxiety, and hyperactivity.

#### **CONFERENCE HIGHLIGHTS**

Increased awareness was the catalyst that motivated the Center for Autism and Related Disabilities at the University of South Florida (CARD-USF) and the Florida Center for Inclusive Communities (FCIC) at USF to host a conference, first in Tampa (2007) and recently in Fort Myers (2008). The latest conference was sponsored and funded by The Personnel Development Partnership (PDP) at Florida Gulf Coast University, the National Alliance on Mental Illness (NAMI), the Multi-agency Network for Students with Severe Emotional and Behavioral Disturbance (SEDNET), the Florida Inclusion Network (FIN), and the David Lawrence Center in collaboration with CARD-USF and FCIC-USF.

The one-day event, held on the campus of Florida Gulf Coast University in southwest Florida, was offered to help behavioral health professionals, social workers, educators, nurses and family members understand the nature of co-existing conditions and how these present in an individual with an autism spectrum disorder. Presentations included a discussion of the "red flag symptoms" for early identification of autism, vulnerability to mental health conditions, treatment issues, importance of monitoring stress and preparing for life changes, the need for individual and family-focused interventions, and school-based strategies to reduce stress



Martin J. Lubetsky, M.D., University of Pittsburgh Medical Center opened the conference with the presentation, "Autism and Mental Health in the 21st Century."

and anxiety. Continuing education credits were offered to selected professional groups.

#### LOOKING AHEAD

When asked, several professionals shared their interest in forming regional workgroups to collaborate on defining next steps on the topic of autism and mental health issues. One participant offered, "I would like to see a statewide resource network of parents and professionals, (collaborating) as a team." Current initiatives already underway include:

- CARD-USF and NAMI have joined discussions with school districts to address educational needs and to develop a professional development plan for staff.
- CARD-USF has been invited by NAMI
   Florida to be part of the Florida Family
   and Youth Search Conference to support
   consistent authentic family partnerships in
   the mental health systems serving children,
   youth and adults. Sponsoring organizations
   include Federation of Families, NAMI
   Florida and the Department of Children
   and Families (DCF).

#### **FUTURE DIRECTIONS**

"We hope this conference will be the first step toward moving beyond current access barriers to creating an integrated system of care that considers the needs of the individual," said Karen Berkman, Ph.D., Assistant Professor/Director, Center for Autism and Related Disabilities, CARD-USF.

"It's about teamwork," emphasized Martin Lubetsky, M.D. when highlighting the systems of care and networking resources to support individuals and families.

#### **PRESENTERS**

- Martin J. Lubetsky, M.D.
   University of Pittsburgh Medical
  Center
- Mohammad Ghaziuddin, M.D.
   University of Michigan, Ann Arbor
- Susan Hepburn, Ph.D.
   University of Colorado, Denver
- Jennifer Durocher, Ph.D. University of Miami/Nova Southeastern University CARD

#### RECOMMENDED READING

- Ghaziuddin, Mohammad (2005).
   Mental health aspects of autism and Asperger Syndrome.
- London: Jessica Kingsley Publishers

2008 conference materials are posted at the Personnel Development Partnership website. Go to http://coe.fgcu.edu/PDP/events.html

## **Family Unification Through Empowerment** and Learning (F.U.E.L)

CARD staff has often wondered, what keeps families together in the stressful situation of having a child diagnosed with autism? To answer that question, several members of our team gathered to create a project to determine the resiliency factors that impact families staying together or breaking apart. After a 2 year process of developing this project, writing a curriculum for an eight week training series, and a corresponding navigation guide for a one night curriculum overview, we were very excited to implement this project. We had 18 caregivers participate in the project. They selected one of three groups within which to participate (training series, 1 night event, or support services). Our goals were to 1) Define common features of participants (adult caregivers of children with autism) across groups in the areas of: quality of life; general health; locus of control and self esteem; and stress. 2) Teach 10 elements of family strengths to improve resiliency. 3) Determine the impact of the three types of support (training series, 1 night event, or support services) through postassessment measures.



Family Unification through **Empowerment and Learning** 

The study was launched in summer 2007, consents obtained, pre-assessments completed, and the curriculum was developed by CARD staff involved in this project as well as our collegues from our division. In the fall 2007, we held a training series (8 weeks) to teach participants the content of the curriculum. In addition, we held a one night event providing an overview of the curriculum and asked

participants to use the materials provided on their own over the next 8 week period. The control group received regular CARD services but was not given access to curriculum materials. Post assessments were completed as well as the follow up survey. All data was coded and entered into a password protected data base that only study administrators had access to. Data has been analyzed and results demonstrated positive trends for the training series having an impact on building resiliency skills, lowering stress, increasing a sense of control over one's life and increasing quality of life. The results from the one night group were not as significant as the training series group. As anticipated, little change occurred in our control group since they had not received any training materials.

We were very pleased to not only learn about the factors that impact building resiliency skills in families, but also that our training group yielded positive outcomes and developed strong relationships within the group. We would like to thank our FUEL participants for their time and commitment to this project!



at The University of South Florida

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