

SUNCOAST REGION NEWS

Mission: To support persons with developmental disabilities in living, learning & working in their communities.

Volume 1 Issue 6

December 2007

Family Café Questions & Answers Book

The Family Cafe released its latest edition of the *Questions & Answers Book*. The Family Cafe has published the *Questions & Answers Book* as a resource guide for nine years. The book includes questions, which were gathered, by the Family Café, from families from all over Florida. The Family Cafe solicits the answers to the collected questions and the *Questions & Answers Book* is the result. The complete book is available for review at the following link www.familycafe.net. Previous editions of the book from 2004-2006 are also available at the [2007 Questions & Answers Book](#). Individuals who attended the 9th Annual Family Cafe Conference will receive a copy of *The Questions & Answers Book* by mail. *Questions & Answers Books* are available by request; please contact the Family

Continued on page 2

INSIDE THIS ISSUE

- 1 Family Cafe
- 2 APD Wins Grant
- 4 Training Calendar
- 5 Announcements
- 8 Spot Light on Prader-Willi Syndrome

Community Legislative Summit

The Children's Board of Hillsborough County hosted its 2007 Community Legislative Summit last month. The inaugural legislative summit introduced policy and legislative issues submitted to the Children's Board by community stakeholders. Submitted proposals were categorized into nine topic groups. Summit participants were given the opportunity to select one of nine groups to review, discuss and prioritize identified issues for possible presentation to the Hillsborough County Legislative Delegation. The following topics were presented; Mental Health & Substance Abuse, Administration, Child Welfare, Early Childhood Education & Care, Elder Issues, Child & Family Health, Juvenile Justice and Strengthening Families. The Children's Board Advocacy Committee coordinates efforts with local, state and national advocacy groups such as CARES the Federation of Families, the Children's Campaign, and the Center for Florida's Children, the Children's Defense Fund and the Alliance for Children and Families.

"Strong and 'disabled' are by no means opposites..."

Zander

Café at Info@familycafe.net or 888-309-CAFE (2233). Along with the release of the Questions & Answers Book, The Family Cafe is preparing for the next conference. The Planning committee has begun preparation for the 10th Annual Family Cafe Conference. The venue for the 2008 conference is the Disney's Coronado Springs Resort in Orlando, Florida. The conference is scheduled for June 13-15. The planning committee is seeking those interested in presenting at the conference. If you are interested, please [click here](#) to download and print the application. The application proposals are due December 22, 2007. Persons with a disability or the parent of an individual with a disability have no registration fee all others have a \$100 registration fee. If you have any questions, please contact the Family Cafe office at (850) 224-4670.



APD Wins Three-Year Grant

The Agency for Persons with Disabilities won a three-year grant from the Centers for Medicare and Medicaid Services (CMS) within the federal Department of Health and Human Services.

The \$455,419 grant will be used for a statewide initiative called Person-Centered Planning Implementation. The first phase of the grant will be to provide training to Waiver Support Coordinators and other stakeholders on how to improve the involvement of APD customers in setting goals and planning for their future.

In the second phase, APD will schedule community meetings in the 14 regions. The goal of the workshops will be to create a community network with lasting ties for each person with a disability. All stakeholders in the community will be included, such as Florida Vocational Rehabilitation and other employment resources, Department of Health, private providers, housing agencies, and transportation providers.

"We are thrilled to have been selected to win this federal grant to focus on giving APD customers even greater voice in planning their future. APD wholeheartedly supports enhancing choice and options for people, and it is extremely important to intimately involve the local community in that planning process," said **Jane Johnson**. In accepting this Real Systems Change Grant for Person-Centered Planning Implementation, APD is agreeing to contribute about \$22,000 in employee time toward this process for a total investment of \$478,190. ❖

Florida Diagnostic & Learning Research Center

FREE*FREE*FREE

INFANT, TODDLER, PRE-SCHOOL
DEVELOPMENTAL SCREENING
AGES BIRTH TO FIVE BY APPOINTMENT
ONLY

FDLRS will conduct free vision, hearing, motor, speech, language, and cognitive, behavioral and medical screenings from 8:30a.m. until 11:30a.m. **December 7, 2007**
Evangelical Presbyterian Church ~
1107 Charlie Griffin Road, Plant City 33566
Please call (813) 837-7723 to schedule an appointment. ❖

Assessment Specialist Wanted

The SunCoast Region Agency for Persons with Disabilities is currently developing a hiring pool to fill thirteen Assessment Specialist positions. Well qualified applicants will have a bachelors degree from an accredited College, at least four years experience assisting people with disabilities and excellent computer skills.

If interested please fax Resume' to Carol Means at (727) 217-7046.

Family Care Council

Families often feel they will lose their dream of self-sufficiency and independence for their children, when they receive a diagnosis of a developmental disability (DD) for their child. However, with proper Support, both families and individuals with DD can thrive and achieve their chosen goals.

Caring people, that is what it takes! The Agency for Persons with Disabilities (APD) and our State and Federal government support the principles of inclusion, self-determination, community living, successful transition to adult life and integrated employment. Families, individuals with developmental disabilities and their support workers must keep the dream of a full and rich life the goal at all times.

Collaboration is a powerful tool. If this philosophy is to succeed, families must be the driving force. Barriers need to continually be identified and broken down and necessary programs and policies put into place. We must all work together for the benefit of all persons with developmental disabilities. Together - we can make this happen.

Families are the Driving Force

**SunCoast Region Training*

Calendar

December 6

Phase II

1:00pm - 4:00pm

St. Pete. Office

December 13

Phase III

9:00am -12:00pm

St. Pete. Office

December 13

Phase IV

1:30pm -4:00pm

St. Pete. Office

December 3, 4, 5

Supported Living Pre-Service

9:00am -4:00pm

St. Pete. Office

December 7

Boundaries- Where You End & I Begin

1:30pm - 4:30pm

St. Pete. Office

December 10

Providing Effective In-Home Supports

9:00am -4:00pm

St. Pete. Office

December 11

Chronic Medical Conditions

9:00am – 2:00pm

St. Pete. Office

December 13

Residential Licensure Orientation

9:00am -12:00pm

Tampa Office

December 17

AID/HIV

9:00am -12:00pm

St. Pete. Office

December 18

Medication Administration Policy (Mgrs)

9:00am -12:00pm

St. Pete. Office

***Pre-Registration is Required for All Classes**

Announcements

SunCoast Region Paraphernalia

Purchase your SunCoast Region Polos, hats, computer bags, aprons, t-shirts, computer bags, etc. Contact Glorie Singleton at (813) 233-4318 for additional information and [order forms](#).

SunCoast Region Staff Meeting & Holiday Celebration Luncheon

Our Staff Meeting & Holiday Luncheon will be held on December 14, 2007 11:00-1:30pm. Please make plans to attend and join in on the celebration. Please contact Glorie Singleton at (813) 233-4318 for questions/comments.

Name the Database Contest

SunCoast Region employees are invited to participate in the Name the Database Contest for our database system, which is currently under construction. Employees are asked to submit their recommendation for the name of the database by January 31, 2008. The winner will receive a prize and bragging rights. Following is a brief description of the database and its functions. Please submit your entry to Glorie Singleton (813) 233-4318.

Database Information

At this time, the database is referred to as ACCESS. ACCESS is a desktop database software program designed by Microsoft as a management tool. The software's design allows information to be stored in tables, which have the ability to "talk" to each other. As a result, any information stored in one of the tables can be selected and used with information stored in another table. This functionality allows the generation of reports on a monthly or one time basis with preferred information. This database can be used simultaneously for a multitude of purposes and departments.

Security Awareness Training

Security Awareness Training is required of all staff that utilizes DCF computer systems or access DCF computer related media. This applies to all APD employees, contractors and vendors. The training is available now and is accessible by clicking on the following link:

http://eww.dcf.state.fl.us/aspe/training_core.shtml

Deadline Date for Completion is December 28, 2007.

Happy Holidays



SunCoast Region

Prader-Willi Syndrome

Prader-Willi syndrome is a genetic disorder that is characterized by low muscle tone, small stature, incomplete sexual development, cognitive disabilities, behavioral problems, and a chronic feeling of hunger. PWS is the result of the lack of several paternal genes on one of an individual's two chromosome 15s. In most cases, the genes are deleted. Deletion on the same region of the maternal chromosomes results in a diagnosis of Angelman syndrome (AS). One in 12,000 to 15,000 people are diagnosed with PWS.

PWS is diagnosed through specialized genetic testing. Most PWS cases are related to genetic error. Less than two percent of the PWS cases occur due to a transformation of genes which does not affect the parent, however, it is passed on to the infant. The possibility of the sibling of a child diagnosed with PWS having PWS will depend upon the genetic make up of the sibling. A PWS-like disorder can also occur as the result of damage to the hypothalamic portion of the brain.

PWS is associated with an extreme and avid appetite that often results in obesity. Individuals diagnosed with PWS have a failing in the hypothalamus element of their brain that registers feelings of hunger and fullness. This symptom creates a very serious problem for those diagnosed with PWS. Individuals diagnosed with PWS require less food due to their bodies having less muscle and burning fewer calories. Currently, no consensus has been established as to the cause of the excessive eating symptom experienced by those diagnosed with PWS.

Prader-Willi syndrome has no cure. However, several treatments available can assist individuals with the symptoms of PWS. Such treatments consist of growth hormone replacement therapy, therapy to improve muscle tone and speech therapy. There are also new medications that have improved the quality of life for a number of individuals diagnosed with PWS. Continued research offers optimism for new discoveries.

Article provided for informational purposes only.

References:

http://en.wikipedia.org/wiki/Prader-Willi_syndrome

<http://www.pwsausa.org/faq.htm>