

St. Johns County School District—ESE Department

WINTER 2012

Parents as Partners

VOLUME 2, ISSUE 2



WHY DIDN'T ANYONE TELL ME?

If there is one question I am asked the most as the Advocacy Specialist at The Arc Jacksonville, by parents of children who have a developmental disability (DD), it's "Why didn't anyone tell me about applying for the Medicaid DD Waiver?" The answer to that is that it is no one's legal responsibility to tell you. Often, knowledge of the program happens as a child is exiting school and needing supports to continue a meaningful path in life or sometimes just to have health and safety concerns met. To find out that there is a program out there that could help with funding, but that there is a waitlist of over 20,000 people in the state of Florida, which at current funding is projected to be at least a 10+ year waitlist, and that they could have applied for their eligible child at the age of three, can be very frustrating and infuriating.

What is the Medicaid DD Waiver (now called iBudget Florida, effective July 1, 2012)? Waiver/iBudget is a program, administered by the Agency for Persons with Disabilities (APD) and AHCA, where a person with an intellectual or developmental disability, specifically Autism, Down Syndrome, Cerebral Palsy, Prader-Willi, or Spina Bifida, can enroll beginning at the age of three years old. If children are between 3 to 5 years old, and are at high risk of being diagnosed with a developmental disability, they also may be eligible. Once the individual is receiving services, the Medicaid DD Waiver/iBudget provides those services in the community as an alternate to services provided in an institution. Some of these services include Adult Day Training, Supported Employment, Residential Habilitation, Supported Living, Nursing Care, Environmental Adaptation, and Respite.

You may wonder how this applies to your child, or why you should worry about enrolling your child now. The public school system does not provide services to your child after the age of 22. So, even though it is hard to imagine now, you have to look at your child as if 10 or 15 years have passed, and think, "Will my child need these services in the future?" If you suspect that the answer will be "yes" or "possibly", and your child is eligible under the criteria of the program, contact the Agency for Persons with Disabilities (904)992-2428, located on Hodges Boulevard, and ask for an application, or go to their website www.apdcares.org for more information. If your adult child (age 18-59) does not meet this eligibility criteria, but still has a disabling condition, contact the Department of Children and Families, Adult Protective Services, (www.dcf.state.fl.us/programs/aps/) to inquire about other waivers that may be applicable, if there is a waitlist for services, and how long that waitlist is.

How can you stop information from slipping by you in the future? Become involved with your local nonprofits, which are here to serve you and your child. Ask if they have an e-mail list that you can join that will send you news and resources found in the community. Through these e-mail lists, become aware of legislative alerts that may affect funding for the waitlist in the future and other quality of life and legal rights issues. If information is not going to come to your door, go out and seek it. An informed and connected parent is a child's strongest advocate.

Ami Caswell is the Community Outreach Specialist for ASK, the Advocacy Department of The Arc Jacksonville, council member of the City of Jacksonville Mayor's Disability Council, and parent of three boys, one of whom is a nine year old student in St Johns County Schools and has cerebral palsy, a developmental disability. She can be reached at 904-358-1200 or ask@arcjacksonville.org.



ESE Parent Advisory Committee Meeting
40 Orange Street—3rd Floor Auditorium
February 28, 2013 6:00 pm—8:00 pm

The purpose of the Parent Advisory Committee is to identify barriers experienced by exceptional students and their families. This information is then shared with those who can effect changes (administration at schools and exceptional student education staff at the district level). A copy is also provided to those who attend the meeting. If you need special accommodations, please contact Nancy Morrison (547-7672) one week prior to the meeting. The District contact for the Parent Advisory Committee is George Freeman (547-7704).



Save the Date
Free Event for Parents



TOOLS FOR SUCCESS FAMILY CONFERENCE

18th Annual Conference for and about families of children with Special Needs ages birth to 22.

Wednesday, February 13, 2013

Where: Schultz Center for Teaching and Leadership, 4019 Boulevard Center Drive, Jacksonville, FL 32207

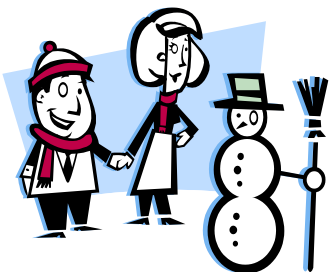
From: 8:00 am to 3:15 pm

For more information call FDLRS/Crown 904-346-4601 ext 119

Rocking the Cradle: Ensuring the Rights of Parents with Disabilities and their Children

Help the National Council on Disability (NCD) bring our new report “Rocking the Cradle: Ensuring the Rights of Parents with Disabilities and their Children” to life by submitting a photograph of your family to our new “Family Faces of Disability” photo album to be shared on NCD’s Facebook page. With the “Family Faces of Disability” photo album, we want your photos that capture your family’s day-to-day life as a way to personalize the issues faced by parents with disabilities in the United States.

All photographs submitted to NCD’s “Family Faces of Disability” photo album MUST include a visual description of the picture for accessibility reasons. NCD retains the right to remove any photo or its accompanying description without warning, if either is deemed inappropriate. By submitting your photograph, you grant permission to the National Council on Disability to display these photographs on NCD’s website, Facebook, Twitter or future print publications. Please send your photos and descriptions to familyphotoalbum@ncd.gov.



Happy Winter!

THE EXCEPTIONAL ADVOCATE

The Exceptional Advocate is a newsletter for military families with special needs.

This month, in recognition of Down Syndrome awareness, we are featuring the heart-warming story of a couple raising children with Down Syndrome. You will also hear

about a popular program getting children excited about reading. In this issue, there are plenty of resources, including information about voting and people with disabilities, emergency preparedness, adoption and more.

To view the newsletter, visit

<http://apps.militaryonesource.mil/efmp/book/2012/October>

COULD THE NEXT MISS AMERICA HAVE AUTISM?

Alexis Wineman always knew she was different.

"Socializing with my classmates, even when I wanted to, was awkward to say the least. I wouldn't get their jokes half the time. I took everything so literally," said the Cut Bank, Mont. resident.

When Wineman was diagnosed with autism at age 11, she finally had a name to put to her experience. Rather than use her diagnosis as an excuse and give up, she took the bull by the horns.

Today, Wineman, now 18, may very well be the next Miss America. She was crowned Miss Montana in June, becoming the first person on the autism spectrum to claim the sash. In January, she will travel to Las Vegas where she could become the first with the developmental disorder to capture the national title.

It's been a long road for the self-described "oddball out" whose best friend as a girl was a Winnie the Pooh doll, which she still holds onto.

"He showed me that being different was okay and there was nothing wrong with pacing or sitting in one place for hours just thinking," Wineman said. "I say why fit in when you were born to stand out."

Encouraged by her family, Wineman began to break out of her shell after she was diagnosed and engage in school activities. Performing became a way for her to face her fears and learn to cope. Wineman joined the cheerleading squad, ultimately becoming team captain and appearing in the Macy's

Thanksgiving Day Parade.

Now less than four months into her term as Miss Montana, Wineman and her mother have already put 7,000 miles on their car traversing the state to present her platform - "Normal is Just a Dryer Setting, Living with Autism" - at schools, hospitals, conferences and parades.



(Courtesy: The Wineman Family)

"It's amazing how people don't accept other people just because they're different. Being different is not something to look down on, but to be embraced," Wineman said. "People need to understand. I want to talk to kids with autism too and share with them that it's nothing to be ashamed of."

Adjusting to the unpredictability of life as Miss Montana has been a challenge, says Wineman's mother, Kimberley Butterworth.

"She has at times struggled," Butterworth said. "There isn't a set schedule, which can be very hard."

When things get tough, Wineman relies on coping skills she's developed through the years like listening to Celtic music on her iPod.

"With her iPod, she has been able to disengage for a minute, and plug herself into it and regroup," Butterworth said.

When Wineman is not on the road she's focused on preparing for the Miss America pageant by brushing up on the comedy monologue she will perform in the talent competition, exercising and eating healthy, and more often than not, walking in heels.

"I was never a girl to walk in heels, and I did not prepare. That was the hardest part," she said.

Jan Holden, executive director of the Miss Montana Scholarship Program, thinks Wineman will have no problem at the national level.

"She's a pretty special girl. She's very intelligent. That girl's got grace and poise, and she did phenomenal in her interview," said Holden. "She's come a long way, and it's her doing."

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FIELD OF DREAMS BASEBALL—SPRING REGISTRATION



Field of Dreams is a specially designed turf ball field that will allow children with mental or physical disabilities living in or near St. Johns County the opportunity to play baseball, wear a uniform and be a member of a team of their own.

Field of Dreams is a place where our area's exceptional kids' dreams of playing baseball come true.

COST: \$40 (includes full uniform)

REGISTRATION: Online at FODBASEBALL.COM

ELIGIBILITY: Any child with special needs grade K-12.

OPENING DAY: Saturday, February 2nd

SEASON: Games will be held each Saturday until April 23.

NOTE: Spring registration will be open the entire season.

WHERE: Field of Dreams/Aberdeen Park, 1401 Shetland Drive, St. Johns, FL 32259

MARK YOUR CALENDAR!

- EVERY Tuesday at 7:00pm—BASCA Activity Night at Island View Baptist Church, 900 Park Avenue, Orange Park. Computers, games, crafts, music and special guests. Call (904) 568-6023 for more information. BASCA was started in 1994 by parents in the Jacksonville area who were concerned about a quality life in their community for their children with developmental and intellectual disabilities.
- EVERY Saturday at 1:00pm—BASCA High Rollers Bowling at Bowl America (Orange Park), 361 Blanding Blvd. Sign up at 12:30. Cost is \$5.00 (includes 2 games, ball, shoes). Call (904) 568-6023 for more information.
- 12/7/12—8:30am –9:30am—FIMC-VI/Hillsborough County Public Schools cordially invites you to our 40th Anniversary Celebration (continental breakfast). Location: Manhattan Center Cafeteria, 4210 West Bay Villa Avenue, Tampa, FL 33611. RSVP by 12/4/12 (813) 837-7826.
- 5/15/13-5/17/13—Visions Conference: Transitioning Students to Life in the 21st Century. Sponsored by the Florida Division on Career Development and Transition (FDCDT). Location: Renaissance Tampa International Plaza Hotel, Tampa, FL. More information will be forthcoming.
- 6/2/13-6/29/13 (Session 1) and 7/7/13-8/3/13—The ARC Life Experience. Participants obtain a sneak preview and crash course on living independently by receiving individualized support, customized training, developing friendships and enhancing decision-making skills. Ages 18-26. \$3,900 per each session, all inclusive. Application deadline: 4/10/13. Contact (904) 620-3890 for more information.



Franklin Delano Roosevelt (January 30, 1882 - April 12, 1945). He was the 32nd President of the United States. Elected to four terms in office, he served from 1933 to 1945, and is the only U.S. president to have served more than two terms of office. In August 1921, while the Roosevelts were vacationing at Campobello Island, New Brunswick, Roosevelt contracted an illness, at the time believed to be polio, which resulted in Roosevelt's total and permanent paralysis from the waist down. Roosevelt refused to accept that he was permanently paralyzed. He tried a wide range of therapies, including hydrotherapy. Fitting his hips and legs with iron braces, he laboriously taught himself to walk a short distance by swiveling his torso while supporting himself with a cane. In private, he used a wheelchair, but he was careful never to be seen in it in public. In 2003, a peer-reviewed study found that it was more likely that Roosevelt's paralytic illness was actually Guillain-Barre syndrome, not poliomyelitis.

DARRELL GWYNN FOUNDATION DONATES WHEELCHAIRS

The Darrell Gwynn Foundation's Wheelchair Donation Program is actively seeking people who need a wheelchair. The foundation donates new, highly-customized manual and power wheelchairs to children and adults who have been denied by Medicaid, Medicare, private insurance companies, or those lacking insurance coverage.

To apply for a wheelchair, please visit: <http://darrellgwynnfoundation.org/pre-application-checklist.php> or contact Micah Moreno at (954) 792-7223 ext.101 or micah@darrellgwynnfoundation.org for more information.

The Darrell Gwynn Foundation specializes in high-tech, custom-

ized wheelchairs. While standard manual wheelchairs are valued at approximately \$350, the wheelchairs they provide are valued anywhere from \$6,000 to \$40,000, depending on the medical needs of the recipient. There is no other wheelchair donation program in the country that provides these highly customized wheelchairs at no cost to individuals. The wheelchairs are equipped with tilt and recline systems, seat elevators, drive trains, high-tech seating systems, rugged tires, and suspension systems, all designed to dramatically improve the recipient's quality of life.

FLORIDA PARENTAL INVOLVEMENT IN EDUCATION MONTH

The Florida Department of Education understands that there is a direct connection between parent involvement and high student achievement and supports Governor Rick Scott’s recognition of November as “Florida Parental Involvement in Education Month.”

Research shows that regardless of family income or background, students with involved parents are more likely to have higher grades, test scores and graduation rates, better school attendance, increased motivation and self esteem, lower rates of suspension, decreased use of drugs and alcohol and fewer instances of violent behavior.

The Bureau of Family and Community Outreach works with school districts and community-based organizations to increase parent involvement by identifying and sharing information and resources that will lead to student success.

The Bureau developed the following resources to use during the month of November:

Join the Online Parent Community: <http://parents.fldoe.org/home>

Family Calendar for activities for the month of November: <http://www.fldoe.org/family/title1/>

Parent Involvement Pledge: <https://app1.fldoe.org/communications/forms/parentalinvolvement.aspx>

For more information regarding Florida Parental Involvement in Education Month, please contact Joyce Hobson in the Bureau of Family and Community Outreach at (850) 245-0842 or joyce.hobson@fldoe.org



Gifted Parent
Advisory Dates:

1/8—Durbin Creek Elementary School

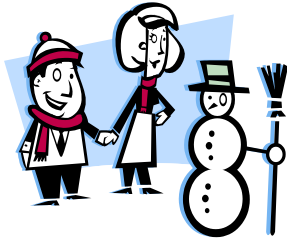
3/19—Ocean Palms Elementary School

5/13—Julington Creek Elementary School

All meetings are from
3:30-4:30



CONGRATULATIONS to Theresa Crowe! Theresa is the parent of an ESE student in our district. She has just been named the Northeast Florida IEP Coach for Central Florida Parent Center. Way to go, Theresa!!!



St. John's County School District

Exceptional Student Education Department

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Mission Statement: To identify and meet the unique educational needs of exceptional students and to provide support and resources to enhance educational opportunities so they may become productive citizens.

ESE programs and services address the unique needs of students who are gifted in kindergarten through 12th grade and those with mild, moderate and severe disabilities from age three until they graduate with a regular diploma or until their 22nd birthday. ESE programs and services are designed to assist students in reaching their educational goals through the use of instructional and behavioral approaches which are research-based and exemplify best practices. Technology is used in many creative ways to meet student needs as well.

ESE services are available at all district schools for students who have mild to moderate disabilities. Gifted students and students with more significant disabilities are served in cluster programs at selected sites. Program support is provided to students, parents and school personnel by program specialists based at the district office. Students with disabilities who are not eligible for services through the ESE program, may be eligible for an accommodation plan under Section 504 of the Rehabilitation Act of 1973.

WOULD YOU LIKE TO RECEIVE THIS NEWSLETTER ELECTRONICALLY?

We hope that you find this newsletter informative and useful. The next issue of the Parents as Partners Newsletter will be posted to the St. Johns County School District web site at www.stjohns.k12.fl.us.

Follow the link under Departments/Academic Services/Exceptional Student Education; you will find the newsletter. If you would like to receive a copy via email, please email your email address to bullarj@stjohns.k12.fl.us and we will gladly add you to our Parent Newsletter Email List.