

**Family Resource  
Center for  
Disabilities &  
Special Needs**

# The Coalition

**Parent Training  
& Resource  
Center (PTRC)**

**September 2016**



## New Funding for PTRC

The YIPEE!! you may have heard coming from West Ashley in the middle of August was the collective sound of rejoicing made by the folks at the Family Resource Center. This happiness came with the news that the FRC had received the federal grant that funds the Parent Training and Resource Center (PTRC). If all goes well, we can count on this funding for five more years. YIPEE!!

First funded by the US Department of Education in Oct 1999, the PTRC has been providing information and training to families and professionals in Berkeley, Dorchester, and Charleston Counties ever since. During that time, the PTRC has provided direct mentoring and 1:1 training to well over 2500 families in the tri-county. This included accompanying parents to over 4,618 school based meeting such as Individual Education Program and/or manifestation/expulsion meetings, and 504 Planning (data for the current fiscal year has not yet been compiled). In addition, 1,055 parents and 599 professionals have attended training workshops conducted by PTRC staff. This doesn't include all of the folks who attended our annual/biennial conferences. We are pleased we have had the opportunity to provide information and training services to our tri-county community.

Although the Department of Education began funding Community Parent Resource Centers in 1998, they have not increased the amount of the award since then. As is so often the case with things, the Department is now expecting us to do more with no

increase in funds. Complying with new requirements has required clever thinking on our part, close examination of our services, and some hard decisions. Consequently, some parts of PTRC programming have been impacted so that we can make sure the most successful aspects can be maintained.

Beginning Oct 1, the structure of the PTRC will change slightly. Our roster of Parent Mentors will be Lisa Riddle, Ruth Burrows Harkleroad, Melinda Hawk, and Charmagne Horry. When needed, Sharla Gould and Paula Brady will provide mentoring to families also. Susan Clark will continue as Training Coordinator although with a reduction in hours. Allyson Kneib will continue mentoring families but will also provide adjunct support to the Project Director, Bev McCarty. It is important to note that all staff with the PTRC can & will provide direct mentoring to parents. One of the changes that will be put into effect is a cap on the direct 1:1 mentoring that parents currently receive. Because the purpose of the PTRC is to empower parents to be their child's best advocate, mentoring services will be faded as parents achieve this.

Even with careful planning, some aspects of PTRC programming have to be discontinued. One of the hardest parts of the project to let go was the conference that was held in collaboration with the Psychology Department at The Citadel. In fact, this conference predates our PTRC award. Over the years hundreds of parents and professionals took part in these conferences both as presenters and attendees. We can't thank Dr. Conway Saylor, as well as other Citadel faculty and staff, enough for all the support she provided over the years to make these conferences successful.

We here at the FRC/PTRC are realists and we know families in our community are busy people, especially parents of children who experience disability. We know that not everyone who receives this news-

*Continued on Page 7*

## Center for Parent Information & Resources (CPIR)

Remember NICHCY - the National Dissemination Center for Children with Disabilities? There was a time when it was the place to find quality information on the Internet. It was funded for decades by the Office of Special Education Programs (OSEP) at the U.S. Department of Education. Funding for NICHCY ended on September 30, 2014.

So, what happened to all of that quality information? Much of the rich library of materials and publications that NICHCY produced over the years has a new home with the **Center for Parent Information and Resources (CPIR)**.

### What is the CPIR?

The Center for Parent Information and Resources (CPIR) serves as a central resource of information and products to the community of Parent Training Information (PTI) Centers and the Community Parent Resource Centers (CPRCs) - like our Parent Training and Resource Center - so that they can focus their efforts on serving families of children with disabilities.

CPIR has three main objectives:

- to provide PTIs and CPRCs with products and materials to support their work with families;
- to increase Parent Centers' knowledge and capacity in specific domains; and
- to increase the coordination of parent training efforts throughout the network.

You should know that the CPIR isn't just for the network of federally funded parent centers. A wealth of information on a variety of topics can be found with just a click of a mouse or keypad. For example, there are resources you can use to learn more about these: Behavior, Disability, Dispute Resolution, Family supports, IDEA, Mental Health, Parental Rights, Research, Section 504/ADA, and Technology. The team at CPIR have organized the resources and created links that make navigating the internet for the specific information you need a much easier endeavor. If you want to learn more about accommodations in the classroom, Assessments, effective teaching practices, school reform policies, self-advocacy or transition from school to adult life, you'll find that CPIR can handle that search. Not only do they provide all of this wonderful information but they also sponsor webinars free of charge. These webinars are archived on the website. AND—their information is available in Spanish. They will also be adding resources in other languages as well.

Be sure and take advantage of this great, no-cost resource by visiting:

**<http://www.parentcenterhub.org/>**

Spend some time browsing this website. Bookmark it - you'll be glad you did!

Some of you may know that an organization called The PACER Center used to provide technical assistance and support to the network of federally funded parent centers. During that time, they accumulated a library of resources which are still available on their website and it is well worth your time to check out: [www.pacer.org](http://www.pacer.org).

### ADHD Guidance from OCR US Department of Education

On July 26, 2016, the U.S. Department of Education's Office for Civil Rights (OCR) issued guidance clarifying the obligation of schools to provide students with attention-deficit/hyperactivity disorder (ADHD) with equal educational opportunity under Section 504 of the Rehabilitation Act of 1973.

The guidance provides a broad overview of Section 504 and school districts' obligations to provide educational services to students with disabilities, including students with ADHD. The guidance:

- Explains that schools must evaluate a student when a student needs or is believed to need special education or related services.
- Discusses the obligation to provide services based on students' specific needs and not based on generalizations about disabilities, or ADHD, in particular. For example, the guidance makes clear that schools must not rely on the generalization that students who perform well academically cannot also be substantially limited in major life activities, such as reading, learning, writing and thinking; and that such a student can, in fact, be a person with a disability.
- Clarifies that students who experience behavioral challenges, or present as unfocused or distractible, could have ADHD and may need an evaluation to determine their educational needs.
- Reminds schools that they must provide parents and guardians with due process and allow them to appeal decisions regarding the identification, evaluation, or educational placement of students with

## Save the Date 2016 SC Down Syndrome Conference

Friday, Nov. 18, 2016

**Saxe Gotha Presbyterian Church  
5503 Sunset Boulevard • Lexington, SC**

### Keynote: I'm Determined Project

The I'm Determined project, a state directed project funded by the Virginia Department of Education, focuses on providing direct instruction, models, and opportunities to practice skills associated with self-determined behavior. This project facilitates youth, especially those with disabilities, to undertake a measure of control in their lives, helping to set and steer the course rather than remaining the silent passenger. To learn more out I'm Determined:

[www.imdetermined.org](http://www.imdetermined.org)

For more information on the Conference contact  
Family Connections at: 1-800-578-8750



### Summerville Teen is SC Children's Miracle Network Hospitals Ambassador

In the fleeting moments that Zion Thomas met President Barack Obama, the teenager's sports jacket, bow tie and confident smile made an impression. "I didn't really get to say a lot to him, but he said, 'That's a well-dressed young man,'" Zion remembered.

Only 15 years old, Zion already has done some politicking. He has traveled to Capitol Hill to advocate for sickle cell anemia awareness. He helps to emcee events for the MUSC Children's Hospital that pull in thousands of people and tens of thousands of dollars. And his list of friends includes recording star Darius Rucker, U.S. Sen. Tim Scott and former Clemson University quarterback Tajh Boyd.

Zion hopes to work as a lawmaker in Washington after college but plans to return to his hometown of Summerville after a few years on the Hill. That's why, when Children's Miracle Network Hospitals selected him as this year's Champion for the state of South Carolina, the role made sense. "I'm just going to have to keep on being myself and brightening people's days," Zion explained. His tenure as Champion will take him back to Washington, to Florida and to events around the state to raise awareness about Children's Miracle Network Hospitals.

Each year all Children's Miracle Network Hospi-

tals are invited to submit nominations, and a team at the national office in Utah selects one Champion for each state. That child then helps to share the story and mission with media, corporations, lawmakers and celebrities.

Zion brings experience to the job. Diagnosed at birth with sickle cell anemia, he has been staying at the hospital for a week or two at a time since he was just six months old. Patients with sickle cell anemia, a genetic blood disorder, deal with chronic, crippling pain. "Every time I get sick, I get an IV in my arm, and it feeds fluid and morphine for a week or two," Zion said. He has no working spleen, no gall bladder. Every year, it seems, he needs testing to check on something else.

But Zion models, acts, dances and advocates. He educates lawmakers about his disease, and he accepts every chance to take the microphone at MUSC fundraising events.

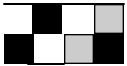
His mother, Towanda Ross, explained that physicians can do little to help her son beyond pain management. She recently earned her master's degree in health care administration, in part because of Zion. During her son's first inpatient stay, she heard a little boy in the next room -- also a sickle cell patient -- screaming that he didn't want to die over and over. "I asked the nurse, 'Is he going to die?'" Ross remembered. "She said, no, but he's in so much pain that he thinks he's going to die." Ross looked down at Zion, just months old, and made a promise. "I said to myself, with tears in my eyes, that I'm going to learn everything there is to learn about sickle cell," she said. "I want to give you the quality of life that you deserve."

For Zion, that means that each hospital visit is merely a pause in an otherwise normal life. He has a pet bearded dragon and a part-time job at a water park. His family will vacation in Mexico this summer, and he plays soccer every chance he gets.

Adults who meet Zion often marvel at his poise and wit. They tell him he'll be president one day. But for now he takes responsibility for his role and message as a hospital ambassador. "All I want is to talk to everybody I possibly can," he said, "and for everybody to get to know my story and me, Zion Thomas."

*This story, written by Allyson Crowell, Office of Development and Alumni Affairs, first appeared in a MUSC publication: <http://academicdepartments.musc.edu/development/news-events/thank-you-notes/zion.html>*

***The Family Resource Center for Disabilities & Special Needs is lucky to have Zion's mother, Towanda Ross, as a member of our Board of Directors.***



## Looking for a Support Group?

**Trident Head Injury Support Group:** meets the 1st Tuesday of each month from 700-8:30 PM at the HASCI Drop In Center, Westwood Plaza (intersection of Hwys 7 & 61), Suite 6, next to Hancock Fabrics. For more info: Marsha Mikell at 843-881-1214 or Colin DeResta at 843-852-5550. Follow on Facebook.

**Down Syndrome Association of the Low Country:** sponsors four Information Programs and four Social Events each year - in addition to Mothers Night Out. For a complete calendar of events, check their website at: [www.dsalowcountry.org](http://www.dsalowcountry.org) or follow them on Facebook. You may also call: 654-1552.

**Parent & Guardian Association of the Coastal Center:** This group supports those with a family member residing at the Coastal Center. General meetings are held four times a year. For more information contact Linda Bodiford at 821-5809 or Suzanne at 276-1001.

**Rett's Syndrome Support:** Families in need of a contact person to access support services for girls with Rett's Syndrome may call Nancy Banov at 556-4632 after 3 PM.

**Trident Spinal Cord Injury Peer Support Group:** This group is open to any person with a spinal cord injury or other mobility difficulties. The meetings provide a forum for the members to discuss issues and concerns and receive immediate feedback. Some members use the meetings to brainstorm possible solutions to ongoing problems. In addition, the group provides members with opportunities to develop a social network. Meetings are held on the second Tuesday evening of every month (6:00-8:00 PM) at AccessAbility, 7944 Dorchester Rd, #5, North Charleston. There are also special events throughout the year. For more information & to keep current with group activities contact Barb Delia at 843-557-4827.

**Grief Support Group for Children** - Bereavement group for children ages 8-12 (1 group) and 13-15 (2nd group) sponsored by Heartland Hospice, 1064 Gardner Rd, Suite 204, Charleston. For more information contact Kimberly at Heartland Hospice, 766-7646. **PLEASE NOTE: This group is on temporary break**

**Sickle Cell Sisters** (for teenage girls with sickle cell disease) is a therapeutic support group for teenage girls between the ages of 13 and 18. The group meets every other month at MUSC Children's Hospital and focuses on psychosocial aspects of living with sickle cell disease. For more information call Christine at 843-792-4152.

**The National Alliance for the Mentally Ill (NAMI)** of the Charleston area offers support group meetings for individuals who suffer from a brain disorder and for family members and caregivers of those who have severe and persistent mental illness. Meetings are held at various locations and times. 1<sup>st</sup> Tues of the Month: *Moncks Corner Baptist Church, 500 East Main Street, Moncks Corner, SC 29461, 6-7:15 PM, in the Fellowship Hall beside the church.* 1st Thurs. of the Month: *Seacoast Church, Mount Pleasant, 750 Long Point Road, Mt. Pleasant. Enter from Egypt Road. Meetings are held at 6 PM. Family Support Group in Trailer #21 & Connection Support Group in Trailer #22.* 2<sup>nd</sup> Mon of the Month: *Seacoast Church, West Ashley, 2049 Savannah Hwy., Charleston, Use the Main Entrance. Support: 6:00-7:15 PM, Education: 7:30-8:30 PM. Education meetings for consumers and family members are held together. The speakers discuss various issues related to mental health.* 3<sup>rd</sup> Mon of the Month: *Bethany United Methodist Church, 118 West Third South Street, Summerville, 6:00-7:30 PM* Every Wednesday: Support for those in recovery: 1:30-3:00 PM at Charleston Mental Health Clinic (West Ashley), 2100 Charlie Hall Blvd. (north wing), Charleston. For more information, call 843-871-1009 or visit <http://namisc.org/>

**Summerville Autism Support** - Join the Summerville ASD Mom's Facebook page to keep up with activities. The group meets frequently, but irregularly, for a night out. Please call Jodi Hortman (870-3485) for info.

**Epilepsy Support Group** for families of children with epilepsy meets on the 2nd Saturday of each month at Cathedral of Praise, Bldg. A, Room 103, 3790 Ashley Phosphate Rd., N. Charleston. Look for SAFE sign outside building. The Group meets from 11am-1pm (First hour is education/business meeting, second hour is support group) For more information contact Karen St. Marie at 843-991-7144 or at [Karen@scepilepsy.org](mailto:Karen@scepilepsy.org). Also check out their Facebook page under "South Carolina Advocates for Epilepsy".

**Low Country Autism Support Group** sponsored by the Early Autism Project meets the 2nd Tuesday of the month at the Early Autism Project Clinic, 1123 Queensborough Dr., Mt. Pleasant, from 6:30-7:30. Speakers



*We try our best to keep this information current. If your group is listed here and no longer meets or if you have a group that should be listed but isn't, please call us: 843-266-1318*



## OSEP ADHD Guidance Continued

disabilities, including students with ADHD.

The Department also released ***Know Your Rights: Students with ADHD*** which provides a brief overview of schools' obligations to students with ADHD.

Read the complete letter and guidance at: <http://www2.ed.gov/about/offices/list/ocr/letters/colleague-201607-504-adhd.pdf>

### Discipline Guidance from OSEP US Department of Education

On August 1st, the Department's Office of Special Education Programs (OSEP) released a Dear Colleague Letter to provide significant guidance for schools and other agencies to clarify their responsibility under the *Individuals with Disabilities Education Act (IDEA)* to provide children with disabilities appropriate behavioral interventions and supports that are necessary to ensure they have meaningful access to their education. Doing so ensures that eligible children with disabilities who have behavioral needs receive a free appropriate public education (FAPE) and placement in the least restrictive environment (LRE). This guidance is not intended to limit schools' and agencies' appropriate use of disciplinary removals that are necessary to protect children; instead, it is intended to provide alternatives, which schools can use to effectively support and respond to problem behaviors so that disciplinary removals are infrequent or unnecessary. By following this guidance, schools and agencies can increase the opportunity for children with disabilities with behavioral needs to participate in instruction, avoid the negative impacts of inappropriate disciplinary removals, and maintain access to their LRE. The main points of the guidance are summarized below.

□ *IDEA* requires individualized education program (IEP) Teams to consider the use of positive behavioral interventions and supports for children with disabilities whose behavior interferes with their learning or the learning of others.

□ When a child displays inappropriate behavior, such as violating a code of student conduct or disrupting the classroom, this may indicate that behavioral supports should be included in the child's IEP; this is especially true when the child displays inappropriate behavior on a regular basis or when the behavioral incidents result in suspensions or other disciplinary

measures that exclude the child from instruction.

□ If a child displays inappropriate behavior despite having an IEP that includes behavioral supports, this may indicate that the behavioral supports in the IEP are not being appropriately implemented, or the behavioral supports in the IEP are not appropriate for the child. In these situations, the IEP Team would need to meet to discuss amending the current IEP to ensure that the interventions and supports in the IEP can be implemented, or to revise the behavioral interventions and supports that are currently in place.

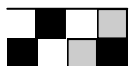
□ *IDEA* requires that needed behavioral supports in the IEP, whether provided as special education, related services, or supplementary aids and services, be based on peer-reviewed research to the extent practicable. The supports chosen should be individualized to the child's needs. Some examples of supports that schools may use include instruction on, and reinforcement of, school expectations for behavior, violence prevention programs, anger management groups, counseling for mental health issues, life skills training, social skills instruction, meetings with a behavioral coach, or other approaches.

□ In addition to behavioral supports for children with disabilities, it may also be necessary, and consistent with *IDEA* requirements, to provide supports for school personnel and training on the use of positive behavioral interventions and supports in order to appropriately address the behavioral needs of a particular child.

□ While providing individualized behavioral supports to students with disabilities who need them through the IEP process is required as part of *IDEA*, research has shown that these supports are typically most effective when they are delivered within a school-wide evidence-based multi-tiered behavioral framework that provides all children with clear expectations, targeted intervention for small groups who do not respond to the school-wide supports, and individualized supports for those children who need the most intensive behavioral services.

□ It is important for schools and agencies to keep in mind that, in general, placement teams may not place a child with a disability in special classes, separate schooling, or other restrictive settings outside of the regular educational environment solely due to the child's behavior if the child's behavior can be effectively addressed in the regular education setting with the provision of behavioral supports. The failure to make behavioral supports available throughout a





## Celebration News Continued

letter will read it. Over the years the cost to print & mail *The Coalition* has increased and the mailing list has grown. As a result, it was decided that the number of newsletters produced each year will be reduced from 3 to 2. Recipients can elect to receive their copy of *The Coalition* in print or electronically. Over the year, the PTRC may send out additional information to those who have provided us with their email address. In addition, we will utilize our website & facebook page to let folks know about events in the community, including our training workshops. Bookmark our website ([www.frcdsn.org](http://www.frcdsn.org)) & check it regularly to keep up with events.

As noted, the Department of Ed has required additional outreach from their federally funded parent centers (but with no additional funding for community based centers like ours). There is a recognized need to promote self-advocacy skills in students and to prepare them for their post-secondary life. The Department addressed this need in their priorities for funding. For the PTRC, this will take the form of "In It For Me" Clubs which will be organized annually on the campus of a high school in one of the Districts within our target community (Berkeley, Dorchester, & Charleston Counties). This initiative will begin later this fall with the first Club located at Woodlands High School in St. George. Those involved in the Clubs will hear speakers, learn self-advocacy skills, and receive incentives for participation.

The FRC Board of Directors and the staff and mentors associated with the PTRC are grateful for the opportunity to continue our work, increase our collaborations, and to help parents acquire the skills to be their child's best advocate. We're Thrilled!!

## OSEP Discipline Guidance Continued

continuum of placements, including in a regular education setting, could result in an inappropriately restrictive placement and may violate *IDEA*'s LRE requirements. Doing so may constitute failure to provide the child with access to the LRE.

☐ Schools should exercise caution in using disciplinary measures that remove a child from his or her current placement, such as suspension. Research has shown that exclusionary measures, in general, are not only ineffective at reducing or eliminating the reoccurrence of the misbehavior but may even be harmful to the child, possibly leading to lower academic performance, disengagement from school, and the decision to drop out.

☐ Parents have the right to request an IEP Team meeting at any time, and public agencies generally must grant a reasonable request from a parent for an IEP Team meeting.

☐ Parents may want to request an IEP Team meeting following disciplinary removal or changes in the child's behavior that impede the child's learning or that of others, as these likely indicate that the IEP may not be properly addressing the child's behavioral needs or is not being properly implemented. and supports that are currently in place.

A full copy of the Dear Colleague Letter, which includes helpful resources, can be found here: [www2.ed.gov/policy/gen/guid/school-discipline/files/dcl-on-pbis-in-ieps--08-01-2016.pdf](http://www2.ed.gov/policy/gen/guid/school-discipline/files/dcl-on-pbis-in-ieps--08-01-2016.pdf)



## Voting Resources for People with Disabilities

New resources are available to prepare voters with disabilities for the General Election. Protection and Advocacy for People with Disabilities, Inc. (P&A) and other members of the SC DisAbility Voting Coalition have developed a new online voting resource manual to accompany the set of videos the coalition produced last spring. This coalition of over forty non-profit and state agencies is a non-partisan group dedicated to increasing the numbers of people with disabilities who vote through voter education and improved access to the voting process.

Please visit these helpful sites:

Online voting resource manual:

<http://bit.ly/votingrightsSC>

Video on how to register to vote:

<http://bit.ly/28Sbgv9>

Video on the four ways a person with a disability can vote: <http://bit.ly/28Q89SB>

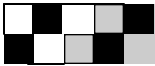
Video on the accessibility challenges a voter may encounter: <http://bit.ly/28PVCgv>

**NOTICE:** The 5th Annual Lowcountry Autism Forum originally scheduled for Oct. 15, 2016 has been postponed until Spring of 2017. For updates visit: [lowcountryautismconcordium.org](http://lowcountryautismconcordium.org)



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## Hippie Dash



Palmetto Goodwill will host it's first-ever Hippie Dash on Saturday, Oct. 8 in North Charleston at 8 AM. Far out dudes, hip chicks, flower children and funky fidos are invited to don their best 70s attire as they move and groove their way through a psychedelic 3.1 mile course around Park Circle.

The 5K fun run and walk will celebrate National Disabilities Employment Awareness Month. Proceeds will benefit Special Olympics South Carolina in the Lowcountry and help send Goodwill's Self-Advocacy Group to Washington D.C to meet with Congress about issues that people with disabilities face on a daily basis including transportation, housing and employment.

Runners, walkers, children and pups of all ages are encouraged to participate. The Hippie Dash is all about fun, friendship and supporting a good cause. Register at: [palmettogoodwill.org/hippiedash](http://palmettogoodwill.org/hippiedash).



## 3<sup>rd</sup> Annual Therapeutic Fishing Rodeo

November 12, 2016 - 10:00 AM – 2:00 PM

The Lake behind Goose Creek Municipal - Accessible locations

The event is free, food will be provided, and it's for all ages with special needs and/or disabilities

Bring Your Own Rod and Reel - Limited Bait Provided - No Coolers, No Pets, and Alcohol

**For Additional Information Contact 843.569.4242**