

# The Coalition

Oct - Dec 09

Family Resource Center for Disabilities & Special Needs  
Parent Training & Resource Center  
Advocacy Coalition for People with Disabilities

## Preventing Harmful Restraint & Seclusion in Schools

From the Desk of Bev McCarty

On Dec. 9th, I had the honor of attending a press conference in Washington, DC, where Congressman George Miller (D-CA), along with Congresswoman Cathy McMorris Rodgers (R-WA), announced the introduction of legislation that would provide legal protections for children in public school regarding the use of restraint and seclusion. In addition to the attending press, the announcement was made to a group of invited advocates and family members. The Congressional members opened with comments attesting to need for the legislation. Following the lawmakers' comments, representatives from the National Disability Rights Network and the National School Board Association spoke in support of the bill. Standing in front of the portraits of two children who died during restraint, parents of children with disabilities spoke of their own child's restraint-induced injuries.

Advocates for children with disabilities have been anxious for this legislation for a long time. Most states, including South Carolina, have no legislation on how restraint & seclusion may be used in our public schools; there are no requirements regarding training for those who use restraint or how it is documented or reported.

The Preventing Harmful Restraint & Seclusion in Schools Act (H.R. 4247) - with companion Senate Bill (S. 2860) introduced by Chris Dodd (D-CT) - bans certain practices, addresses training components, requires documentation of events, and emphasizes the use of positive behavior support. In support of that emphasis, the bill also provides grants for training & implementing positive behavior supports. As presented, the bill is similar in scope to the Children's

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## Mark Your Calendars



**March 3, 2010  
21st Annual  
Disability  
Advocacy Day !**

Make plans to attend the 21st Annual Disability Advocacy Day on March 3rd, 2010 at the State House in Columbia. Registration begins at 9:00 AM in the Blatt Building on Pendleton Street.

This is an important event for individuals with disabilities, their families, caregivers and service providers. This year's message is "Services for Individuals with Disabilities Can Not Take Any More Cuts."

If you can not attend, call or write your state representative and explain how cutting the budget (and services) affects you and your family. If you don't know who your representative is find out at: **WWW.SCSTATEHOUSE.GOV**

Your voice might make the difference in the amount and type of services you or your family member receives next year. Don't let this opportunity to advocate for yourself or someone you care about slip by!

### South Carolina Assistive Technology Expo 2010

Thursday, March 18, 2010 - 9 AM - 4 PM  
Marriott Spartanburg at Renaissance Park  
299 North Church St. - Spartanburg, SC  
Free & Open to the Public

Advanced registration is not required  
Exhibits and workshops about the latest  
Assistive Technology for people with disabilities and age-related limitations.

For more info Call: (800) 915-4522, or visit:  
<http://www.sc.edu/scatp/expo/expo10.html>



## Workshops, Conferences, and Events

### South Carolina Council for Exceptional Children

#### Professional Development Conference

February 25th-27th 2010

Sheraton Myrtle Beach Convention Center and Hotel

A great line-up of sessions will be presented on many of the hot topics facing educators today. Preconference workshops will include "Universal Design" (sponsored by the SC Autism Society and described in adjacent column) And the following sessions from the SC Council for Children with Behavioral Disorders:

**"Seclusion and Restraint: Guidelines from the SC Department of Education to Keep Everyone Safe, Sound... and Legal"** and

**"Behavior & Progress Monitoring: Purposes, Methods and Challenges"** Other pre-conference sessions include: **Brining ABA into Your Inclusive Classroom, A workshop for meeting the needs of students with Autism Spectrum Disorder.** Transition is also addressed with a preconference workshop:

**Transition Assessment: Choosing and Using Age-Appropriate Transition Assessments for Every Student.** The full conference then gets underway with a packed agenda of professional presentations

You do not have to be a member of the Council for Exceptional Children to attend this conference. The fee scale is based on various factors including membership. You may chose to attend a single preconference session, a single day of the conference, or the complete conference. For more details and a full conference agenda please visit the SC CEC website: [www.myscced.org](http://www.myscced.org) and click on conferences.

Or Call: Susan Burkett at 802-622-5738 or go online at [www.myscceec.org](http://www.myscceec.org) and click on "conferences" To make hotel reservations call the Sheraton (1-888-627-8203) and ask for the conference rate - **deadline is Jan. 25th**

*The SC Autism Society is Sponsoring these upcoming workshops. Any questions please call the SCAS at: 800-438-4790. Be sure to visit their website ([www.scautism.org](http://www.scautism.org)) for great information, online support & discussion groups.*

#### 01/20/10 Autism 101

This is a free workshop in Columbia from 5:00 PM-7:00 PM conducted by Melissa Metts, M.Ed., NBCT. This session will be held at the SCAS office at the SCAS office at 806 12th St., Columbia.

#### 02/25/10 Universal Design, Accommodations and Differentiation: an South Carolina Council for Exceptional Children Preconference Event.

This workshop is conducted by Dr. Patrick Schwarz of Creative Culture Consulting LLC Hours are from 9:00AM-4:00PM. The fee is \$50.00 and the workshop, held in conjunction with the Council for Exceptional Children conference, will take place at the Myrtle Beach Convention Center. Interested participants should contact the South Carolina CEC (for registration information.

#### 06/10/10 Home-School Collaboration in Positive Behavior Support for Students with Autism: Challenges and Opportunities.

This workshop is designed for parents and professionals who would like more information about functional assessments and designing positive behavior supports. Dr. Joseph M. Lucyshyn of the University of British Columbia will present at the Columbia Conference Center. Hours are 9:00AM-4:00 PM and fee is \$75.00.

### March 19 & 20 - SAVE THAT DATE !!

For the Annual

#### Family Connections Conference

This year's conference, "Celebrating Achievements", will be held March 19 & 20 at Gateway Baptist Church, Irmo, SC. As details are finalized, more information will be available on their website ([www.familyconnections.org](http://www.familyconnections.org)).

## Workshops, Conferences, and Events

### Autism Training

The SC Department of Disabilities and Special Needs/Autism Division sponsors training throughout the year on a variety of topics. Training topics for January-June 2009 are noted below. A new training calendar will be developed that begins in July 2010. The Autism Division training is generally open to anyone and may be helpful for family members, classroom teachers and other people providing direct services. Although it is not the case for the classes listed below, some trainings have prerequisites in order to attend. Advance registration is required for all sessions. All Charleston based training is held at the Coastal Autism office at 1064 Gardner Road, Suite 302, in West Ashley. Call 843-852-4120 to register. For classes outside the tricounty area visit the SCDDSN website (<http://www.ddsn.sc.gov/consumersandfamilies/divisions/autism/>) or call Toll Free: 1-888-DSN-INFO (376-4636).

#### January 20-22 and April 21-23

##### Basic Treatment Strategies

This three-day training session presents basic information about autism, and about treatment strategies, which have proven to be effective with people who have autism. Training sessions will be a combination of lecture and small group activities. *CEU's available in Social Work & SLPA. DSS Training Credit available for Child C are Workers.*

#### February 11

##### Supporting Adults with Autism

This three-day workshop presents several practical strategies for supporting adults with autism. Participants will learn techniques for relating and interacting positively with adults affected by autism. The simple "how to's" of developing and implementing basic instructional plans to teach self help and vocational skills will be addressed through lecture and role-play. *CEU's available in Social Work & SLPA.*

#### February 22 and May 3

##### Parent Training

This training provides information about autism, teaching strategies to use in the home and techniques for addressing behavioral issues.

#### March 9 and May 19

##### Introduction to Autism

A one-day workshop that presents introductory information about autism. This includes characteristics, causes, and a general overview of current treatment options. *CEU's available in Social Work & SLPA. DSS Training Credit available for Child C are Workers.*

### ASD PREVALANCE

Over the past several years, the Center for Disease Control (CDC) has been sponsoring studies to determine the prevalence of Autism Spectrum Disorder (ASD) in children. Among those conducting this research is a team at Medical University of South Carolina. One member of the team, Walt Jenner, is also a member of the FRC Board of Directors. Last week Walt sent this update on the latest findings to our board.

"The CDC today released updated prevalence findings on Autism Spectrum Disorders (ASD) with the average of 9.0 per 1000, or 1 in 110 children have an ASD. This information comes from the public health surveillance network, Autism and Developmental Disabilities Monitoring Program (ADDM), the largest multisite collaboration to monitor ASD in the United States. This number of 1:110 is a 57% increase in ASD from the prevalence number published two years ago of 1:150.

There is a range in the prevalence number across the 11 ADDM sites. In South Carolina, the updated prevalence was 8.6 per 1000 or 1 in 116 children having an ASD. This represents a significant 43% increase in ASD prevalence in SC since the first ADDM report in 2007 of 6.2 per 1000. ASD prevalence was 4.5 times higher in males than in females."

Walt acknowledged that there was a great deal of information in the new report and did not attempt to try to summarize



**It's A Relaxing Way to Learn....**

**Announcing the first of a webinar series.**

## **Life Planning**

presented by

Mary Ann Perry, Coordinator of Consumer & Family Empowerment, SC Department of Developmental Disabilities and Special Needs.

**January 12, 2010 - 10:00-11:30 AM**

You will Learn:

- What is Life Planning?
- What five significant life areas are critical to a person's happiness?
- How life planning can benefit a person with special needs?

To register call 1-800-759-4776. **Internet access and a telephone will be needed to participate via the internet.** (You may also access the audio portion only via telephone)

To learn more about the SC Adult Sibling Leadership Network or to receive a membership application, please call the numbers listed above or visit our website [www.scadultsiblingnetwork.org](http://www.scadultsiblingnetwork.org)

*The SC Adult Sibling Leadership Network is a project of Parents Reaching Out to Parents, Inc. (PRO-Parents) and funded through a South Carolina Developmental Disabilities Council grant.*

## **ASD PREVALANCE**

*Continued from Page 3*

however he did go on to say: "There is not a single explanation for the observed increases in ASD. We know that some of the increases are due to improved identification, increased awareness, and increased availability of services, but it is also possible that there is an increase in cause of ASD. It is clear, however that more children now receive services for ASD and have symptoms of ASD documented in their health and education records than ever before.

Along with Dr. Jane Charles and our ADDM team I do want to recognize all our partners here in

South Carolina who have helped us with our SC ADDM program and ask for your continued help with our Autism and Developmental Disabilities Monitoring Program. The program moves science in a direction to better understand autism as a serious public health concern and points to the need of greater commitment for research and intervention to help service providers and families in SC."

Walter Jenner M.S., Autism and Developmental Disabilities Monitoring Network

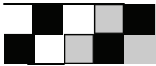
Editor's Note: It is important to remember when considering these statistics that ASD refers to the full range of the autism spectrum which includes, Autism, Asperger's syndrome, Rett's syndrome, Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS) and Childhood Disintegrative Disorder.

### **WHAT YOU MAY HAVE MISSED**

The FRC/PTRC held its 12th Annual Conference on Disabilities & Special Needs on Sept 19th, 2009 at Mark Clark Hall on The Citadel campus. The theme of the conference was **"Assistive Technology-Why Aren't You Using It?"** Attendees were introduced to different types of assistive technology (AT) and were offered the chance to see and try out different types of low tech and high tech AT. Stacy Springer and Dr. Carol Paige From the SC Assistive Technology Project (SCATP) discussed what constitutes assistive technology and explored uses of the types of assistive technology that benefits individuals with different disabilities.

The SCAPT is a federally funded program concerned with getting technology into the hands of people with disabilities so that they might live, work, learn and be a more independent part of the community. The SCAPT is located in Columbia and has dozens of samples of different types of assistive technology for anyone in SC to try out. Those interested in visiting SCATP should call first (800-915-4522) to be sure someone will be

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## Restraint & Seclusion

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Health Act of 2000 which addresses the use of seclusion & restraint in hospitals and residential facilities. As with most initial introductions, some believe the bill can be improved upon because it is considered to be too restrictive or too broad. The bill will be considered by the House Education & Labor Committee early next year.

While this is an exciting beginning, the progress has been slow and trickle down to the states is some ways off. Within six months of the Bill's passage, the Department of Education will issue regulations and the states must provide assurances of compliance within two years. States will be required to provide data to the Department which would include demographic characteristics, the specifics surrounding an event of restraint/seclusion, any injuries (or death) that resulted, and the status of staff training. This legislation applies to all children - not just children with disabilities.

Personally, I've been waiting for this for a long time. In 2003, the Developmental Disabilities Council, Office of the Governor, awarded the Family Resource Center funds for my Project REST (Restraint: Efficacy, Safety, & Training). Over the next 3 years a representational variety of stakeholders worked to develop guidelines for the use of restraint & seclusion in schools. Like the proposed bill submitted by Representatives Miller & Rodgers, our team recommended an approach that emphasized positive behavior support, appropriately trained staff, and specific reporting requirements. Further, Project REST outlined the conditions under which restraint/seclusion is never appropriate. Districts never adopted our guidelines despite close collaboration from the SC Department of Education.

Earlier this year, Secretary of Education Arne Duncan sent a letter to Chief State School Officers urging the development of guidelines that would "ensure that every student in every school...is safe and protected from being unnecessarily or inappropriately restrained or secluded." In Nov, a special work

group consisting of members of the South Carolina Advisory Council on the Education of Students with Disabilities and representatives of other interested agencies, submitted Guidelines on the Use of Restraint & Seclusion to the State Department of Education.

We are making progress, long overdue but progress just the same. However, during this long period of slow progress, children continue to be inappropriately restrained and are at risk of injury.

So what can be done in the meantime? Educate yourself about the issue. If your child has significant behavior difficulties make sure you ask questions of school administrators about the use of restraint and seclusion. Ask about their guidelines and reporting policies. Ask about Positive Behavior Support and how it is being used to address your child's behavior. Visit the Family Resource Center's website ([www.frccsn.org](http://www.frccsn.org)) and download the Project REST Manual of Recommended Practice. Learn more about the proposed legislation by reading the Bills and comments from parents and advocates on these websites:

[http://edlabor.house.gov/documents/111/pdf/legislation/HR4247Seclusion\\_Restraint.pdf](http://edlabor.house.gov/documents/111/pdf/legislation/HR4247Seclusion_Restraint.pdf)

<http://www.wrightslaw.com/nltr/09/nl.1216.htm>

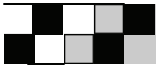
<http://edlabor.house.gov/blog/2009/12/preventing-harmful-restraint-a.shtml>

To learn more about the use of restraint and seclusion in South Carolina read the report compiled by the Center for Disability Resources (USC), Protection & Advocacy for People with Disabilities, and the SC Developmental Disabilities Council that was released on Dec 3rd. This report can be found at: <http://pandasc.org/> You may also want to contact your Congressional Representatives to let them know your thoughts.

### MAY HAVE MISSED

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on duty when you visit. An appointment is encouraged to be sure someone familiar with the technology will be available to demonstrate the items. For more info visit the SCATP website: <http://www.sc.edu/scatp/> To find out who to contact in your school district for an evaluation call Stacy Springer at 843-766-2048.



## A GOOD SUPPORT SYSTEM CAN MAKE THINGS BRIGHTER - CHECK OUT THESE GROUPS:

**Trident Head Injury Support Group:** meets the 1st Tuesday of each month at 7:00, at Westwood Plaza next to Hancock Fabrics suite 6. contact Colin Flynn-Director at 852-5550 ext 226 for more information.

**HIPS (Head Injury Support Group for Survivors):** meets every other Thursday from 1:00-2:30 PM at Westwood Plaza suite 6 next to Hancock Fabrics. For more information contact Colin Flynn, Director at 852-5550 ext 226.

**Down Syndrome Association of the Low Country:** sponsors four Information Programs and four Social Events each year - in addition to Mothers Night Out. For more information call 553-3725, check their website at [www.dsalowcountry.org](http://www.dsalowcountry.org) for a complete calendar of events or email Glenda Crain at [crainclan@comcast.net](mailto:crainclan@comcast.net)

**Parent & Guardian Association of the Coastal Center:** holds general meetings four times a year. The meetings are held on the 3rd Sunday in January, April, July, & October, for more info call Barbara West at 821-5809.

**Rett's Syndrome Support:** for families needing a contact person to access support services for girls with Rett's Syndrome contact Nancy Banov at 556-4632

**Autism Support Groups:** 1st Monday of each month at Vickery's in Mt. Pleasant at 6:30 PM. Contact Laurie Priester at 884-3062 for information. In the Summerville area a group meets from 6:30-8 PM at the Summerville YMCA (900 Cross Creek Drive off Trolley Rd.) Childcare is **NOT** provided. For more information on dates please contact Kima at 821-9337.

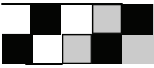
**The Palmetto Autism Spectrum Support Group** no longer meets.

**The Tri County Support Group for Children & Teens ( and their parents) with Diabetes** no longer meets.

**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 problems and receive immediate feedback. Some members use the meetings to brainstorm with peers possible solutions to ongoing problems. In addition, the group provides members with social opportunities to develop a social network. Meetings are held on the second Tuesday evening of every other month (6:00-7:30 PM). Next meeting dates are: Sept. 9; Nov. 11; & Dec 9 (Holiday party). All meetings are held at the HealthSouth Rehabilitation Hospital – 9181 Medcom Street, North Charleston, SC 29406 (Located off Hwy. 78, across from Charleston Southern University).

**Turner Syndrome Society Support Group:** The Palmetto Chapter of the Turner Syndrome Society of the United States is back! To learn more, please contact Robin Butler at (843) 252-9622 or e-mail [auntrobin74@yahoo.com](mailto:auntrobin74@yahoo.com). You may also contact Cheryl Dashnaw at (843) 327-6769 or e-mail at [minibotl@sc.rr.com](mailto:minibotl@sc.rr.com) for more information.

**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, West Ashley, Charleston. For more information contact Heartland Hospice at 766-7646.



## Support Groups Continued

### **Sickle Cell Sisters** (for teenage girls with sickle cell disease)

Sickle Cell Sisters 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 about this group contact Jessica Hoffman or Megan Kalscheur at 843-792-1968

**Can-Teen** (for teenagers with cancer) Can-Teen is a support group for adolescents with cancer. Can-teen provides opportunities for teens to meet their peers, have fun, offer resources and promote well-being and leadership. Can-Teen was created to bring teenagers with cancer together so they can share experiences, help those that are newly diagnosed and to build friendships. This group meets the 3rd Wed of each month. Please call for meeting time and/or more information, call Michelle Vandermaas at (843)792-1380 or Christine Campbell at (843) 792-4152 or visit the Can-Teen Web site at [www.can-teen.net](http://www.can-teen.net).

**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. The meetings are 6-7:15 p.m. the second Monday of every month at First Christian Church, 1293 Orange Grove Road, West Ashley and at Sunrise Christian Church 102 Myers Road, Summerville. Another location meets on the fourth Monday of each month at Seacoast Church, 717 Longpoint Road Mt. Pleasant, nursery room 7. The support group sessions often are followed by an educational program. For more information Call Ron Rzepkowski 571-1832 or visit [www.namicharlestonarea.org](http://www.namicharlestonarea.org).

**Faith and Light Community** is a spiritual organization for persons with mental disabilities, their families and caregivers. Faith and Light is centered in the Catholic tradition but is open to people of all faiths. Its purpose is to recognize the unique gifts of the mentally disabled and to provide them a place of prayer, sharing, support and celebration. The group meets at St. Theresa's Catholic Church, 11001 Dorchester Road., Summerville, SC 29485. For more information, please contact Msgr. Edward Lofton at 875-5002

**The South Carolina School for the Deaf and Blind** has an outreach center in the Lowcountry . It is the Colson Center at 1064 Gardner Road Suite 216 in Fairfield Office Park off of Sam Rittenburg Highway in West Ashley. Contact the Colson Center at 852-4160 for more information about services and programs held here for families with children who are deaf and/or blind.

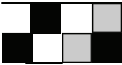
**Morning Coffee for parents of children with special needs** Meets 1st and 3rd Tuesday of each month at Atlanta Bread Company, North Main Street, Summerville from 9:30 -10:30 AM. Call 556-5010 or email [nicolebougie@familyconnections.org](mailto:nicolebougie@familyconnections.org) for more details.



**THE FOLLOWING GROUPS NO LONGER MEET:** The Coastal Autism Division Support Group; Heart to Heart; The Circle of Friends Community Choir; Tourette's Syndrome Support Group; Low Country Polio Survivors Network; The Parent/Family Support Group led by Dr. Jennifer Gans; Disability Resource Center adult support group; the support group for adults age 18 and up at Trident Health Finders; Palmetto Autism Spectrum Support Group; The Tri County Support Group for children and Teens (and their parents .)

**Please call 266-1318 to report changes to this list**

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**un grupo de soporte para padres con niños con discapacidades**

Te gustaria participar en un grupo de soporte para padres con niños con discapacidades? Te gustaria compartir ideas y experiencias con otros padres en tu misma situacion?.Ven, comparte y ayuda a tu comunidad participando en un grupo de soporte y descubre una fantastica forma de ayudar y compartir. Por favor comuniquese con Saritta al telefono 534-7471. Gracias y te esperamos.

Would you like to participate in a support group for parents of children with disabilities? Would you like to share ideas and experiences with other parents in a similar situation? Join us to share and help your community. Come participate in this support group and discover a fantastic way to be involved. Please contact Saritta at 534-7471. Thank you and we'll be waiting on you.

**OOPS!!**

We're sorry, but we received some bad information & passed it on to you. In the last issue of The Coalition we reported that there would be a local chapter of CHADD (Children & Adults with Attention Deficit/Hyperactivity Disorder) coming to the Charleston area. When attempts were made to call the designated contact person it turned out not to be "Joseph." Do not use the information in the last newsletter to contact a CHADD representative. Instead, visit their very good website: [www.chadd.org](http://www.chadd.org) to learn about the resources available there.