



## Parent Education & Advocacy Leadership

### Sometimes Getting There is Half the Fun! By Kerri Hanlon

*Vacations for exceptional families require flexibility, persistence, a sense of humor, and a view of the world as the glass being half full.*

If "getting there is half the fun," our family has had more than our share of fun times. Over the years, I've learned the other half of the equation is flexibility, persistence, and a sense of humor.

As a family of five with kids ages 13, 11, and 9, our summer vacation is all about relaxation. We journey, with two other families, to the quietest beach spot we can find in the Outer Banks of North Carolina. With six adults and eight kids (seven boys! Yikes!), it's rarely quiet, but always peaceful.

Last year, our journey took an unusual twist. A week before we were to leave, we were at our friends' house, planning crucial last minute details (who brings vodka, who brings tequila). My youngest son, Sean, sprang a fever and took a whiter shade of pale to a whole new level. Sean has severe cerebral palsy, and since he can't talk, I get to play the guessing game of "what's wrong."

Unfortunately, I lost.

Sean wound up in the hospital with pneumonia—the first time he had experienced this, or should I say, our family experienced it. As you may know, a hospitalization is not just about the child who's checked in; it's about the whole family.

"Are we still going on vacation?" my 11 year old, Connor, asked.

"Of course!" I replied, never dreaming Sean would be hospitalized for eight days.

A typical year of hitting the beach looks something like this:

Pack clothes, groceries, beach toys, linens, umbrella, beach chairs, boogie boards, pool toys. Try to remember how to attach the rooftop carrier to the van so our possessions don't wind up scattered on I-95. Try to find the bike carrier. Take chunk out of left shin attaching bike carrier to car.

Then we pack Sean's stuff. Formula, feeding tubes, anti-seizure emergency medicine, everyday meds, meds in case he develops diarrhea, rash, allergic reaction, fever, and anything



*(Vacations Continued on page 2)*

### A Veces el Como Llegar es la Mitad de la Diversión Por Kerri Hanlon, Traducido por Astrid Arroyo

*Vacaciones para familias excepcionales requieren flexibilidad, persistencia, un sentido del humor, y una visión del mundo como un vaso medio lleno...*

Si "el como llegar es la mitad de la diversión", nuestra familia ha tenido más de nuestra ración de tiempos de diversión. Con el paso de los años, yo he aprendido que la otra mitad de la ecuación es la flexibilidad, la persistencia, y un sentido del humor.

Como una familia de cinco niños de edades 13, 11 y 9, nuestras vacaciones de verano es un tiempo de relajación. Viajamos, con otras dos familias, a la playa más tranquila que podemos encontrar en los Bancos Exteriores de Carolina del norte. Con seis adultos y ocho niños (¡siete varones! ¡Ay!), es raro que sea tranquilo, pero siempre pacífico.

El año pasado, nuestro viaje tomó un giro inusual. La semana antes de irnos, estábamos en la casa de unos amigos, planeando a último minuto los detalles cruciales (quien va a traer la vodka, quien va a traer la tequila). Mi hijo menor, Sean, le dio una fiebre y su blanca palidez tomó un nuevo nivel completo. Sean tiene parálisis cerebral severa, y como él no puede hablar, me toca a mí a jugar el juego de adivinanzas de "¿qué está mal?"

Desafortunadamente, yo perdí.

Sean terminó yendo al hospital con pulmonía – la primera vez que él ha tenido esta experiencia, o debería decir, nuestra familia ha tenido esta experiencia. Como ya debes saber, la hospitalización no sólo afecta al niño que es admitido; afecta a la familia completa.

"¿Todavía vamos nosotros de vacaciones?" preguntó Connor, mi hijo de 11 años.

"¡Por supuesto!" respondí yo, nunca pensando que Sean fuera ser hospitalizado por ocho días.

Un típico año de ir la playa se ve algo como esto:

Empacar ropa, compra, juegos de playa, ropa de cama, sombrilla, sillas de playa, tablas de

*(Diversión Continued on page 3)*

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*The Mission of the PEAL Center is to ensure that children, youth and adults with disabilities and special health care needs lead rich, active lives and participate as full members of their schools and communities by providing training, information and technical assistance based on best practices to individuals, families and all people who support them.*

**(Vacations** *Continued from page 1*)

else you can think of.

This whole process of getting it together, packed and loaded usually takes about two weeks and every suitcase, backpack, and pool bag we own. This year, it took 18 minutes and five duffel bags.

We have a few general rules in our family. One is that no one person's needs will dominate. It's always a little tense when Sean is sick, and not wanting everyone to sacrifice summer vacation because Sean was hospitalized (Hello, sibling rivalry!), we went to Vacation Plan B.

Kyra, our 13-year-old daughter, and Connor each packed their own duffel bag. It takes a great deal of trust to allow an 11-year-old boy to pack his own suitcase. I was just hopeful he packed extra underwear, a bathing suit, and toothbrush. Kyra and Connor left with our friends on Friday. You know these must be good friends. How many people voluntarily take extra kids in their car on an eight-hour trip?!

The tricky thing about pneumonia is that you just can't predict how long it will take to clear. Because Sean is prone to seizures, he had never been vaccinated for pertussis and was on "contact precautions." It's a little known fact that if the hospital labels you "contact precautions," you can't fly

on a commercial airline. When my conversations with our doctor started involving the Federal Aviation Administration (FAA) and the Centers for Disease Control and Prevention (CDC), I knew it was time to move to: Plan C.

**Plan C.** We're not made of money, but how much would it cost to charter a plane for Brian, my husband, Sean and me to fly down? Plan C was very short lived. The answer, in case you were wondering, is a lot.

**Plan D.** Brian, Sean, and I would drive straight through to the beach once Sean discharged. You'll notice that taking Sean home to recover from his hospitalization was never an option. If you have to recover somewhere, you may as well do it at the beach.

Sean's grandmother stayed with him overnight on Friday so Brian and I could actually see each other and get some much-needed sleep. (Note for file: Do not talk with the CDC and FAA while dealing with sleep deprivation.) Saturday morning, Brian and I packed a duffel bag each and threw them in the car. Driving to the hospital to pick up Sean (Of course he would be discharged today, right?!), the doctor called. Sean's fever had returned, and he wasn't going anywhere.

**Plan E.** While Brian talked with the doctor, I booked a ticket on the next flight to Norfolk, VA. It was a small plane—the kind where they ask you how much you weigh to determine your seat assignment. I was tempted to ask

my fellow passengers if anyone was going to the Outer Banks, and if I could have a lift from the airport to the beach, but given the current climate and security issues, I thought better of it.

Having landed in Norfolk, I went to the rental car counter. No cars. No problem. Taxi? Considering the fare for the two-hour taxi ride (and the trip back), the charter plane fee suddenly wasn't looking too bad.

Now it was just Brian and Sean. Sean finally discharged on Sunday. Brian ran him to the car before the doctor could change her mind and hit the road. Eight hours, several stops for chest PT (Sean) and coffee (Brian) and one speeding ticket later, they arrived at our beach house around 3 am. When everyone woke up Monday morning, our family vacation officially began.

Of all our family photos from the beach, this one is my favorite. We found these "Half Full" shirts in the Life Is Good store. Since everyone had pretty much run out of clean clothes (some earlier than others), we each got one. It's a great way to mark the spirit of our trip. While we could have wallowed in self-pity that our trip was "ruined" by Sean's illness, we found strength in each other and our great friends and had one of our best vacations ever.

You should hear about the trip home...

## Parents of Children with Special Health Care Needs

*We are looking for parent voices!*

The Pennsylvania Department of Health, in partnership with the Pennsylvania Chapter of the American Academy of Pediatrics and the Parent Education Advocacy Leadership Center, is planning a conference on June 22, 2009 (6:00 to 9:00 pm networking session) and June 23, 2009 (8:30 am to 4:00 pm) at the Harrisburg Hilton in Harrisburg, Pennsylvania and we hope many of you will be able to attend.

This Pennsylvania Consortium for Children and Youth with Special Health Care Needs will be an opportunity for families, state agency representatives, policy makers, health care providers and child serving agencies to dialogue together about these issues.

To learn more about how to apply for the conference go to: [http://www.pealcenter.org/images/Parent\\_invitation\\_in\\_English\\_to\\_June\\_conference.pdf](http://www.pealcenter.org/images/Parent_invitation_in_English_to_June_conference.pdf)  
The deadline has been extended to May 27.

## Padres de Niños con Necesidades Especiales de Cuidado de Salud

*!Buscamos voces de los padres!*

El Departamento de Salud de Pensilvania, en colaboración con el Capítulo de Pensilvania de la Academia Americana de Pediatras y el Centro de Educación de Padres y Liderazgo de Apoyo, está organizando una conferencia el 22 de Junio del 2009 (6:00 a 9:00pm sesión para establecer contactos) y el 23 de Junio del 2009 (8:30am a 4:00pm), en el Harrisburg Hilton en Harrisburg, Pensilvania. Esperamos que muchos de ustedes puedan asistir.

Este Consorcio de Pensilvania para Niños y Jóvenes con Necesidades Especiales de Cuidado de Salud será una oportunidad para familias, representantes de la agencia estatal, encargados de formular políticas, proveedores de servicios de salud y agencias que proveen servicios a los niños, a dialogar juntos acerca de estos temas.

Para obtener más información a como aplicar para la conferencia vaya a: [http://www.pealcenter.org/images/Parent\\_invitation\\_in\\_Spanish\\_to\\_June\\_2009\\_conference.pdf](http://www.pealcenter.org/images/Parent_invitation_in_Spanish_to_June_2009_conference.pdf)

La fecha tope ha sido extendido hasta el 27 de Mayo.

**(Diversión** *Continued from page 1*)

surfear, juegos para la piscina. Tratar de recordar como sujetar el portador de tejado a la camioneta para así evitar que nuestras posesiones terminen dispersadas en I-95. Tratar de encontrar el portador de bicicletas. Perder parte de mi piel en la pierna izquierda atando el portador de bicicletas al carro.

Después tenemos que empacar las cosas de Sean. Formula, tubos de alimentación, medicina anticonvulsivas de emergencia, medicinas diarias, medicinas en caso de que tenga diarreas, sarpullido, una reacción alérgica, fiebre, y cualquier otra cosa que puedas pensar.

Este proceso de estar preparado, empacado y montado usualmente toma como dos semanas y cada maleta, mochila, y bolsa de playa que tenemos. Este año tomó 18 minutos y cinco bolsas de ropa.

En nuestra familia tenemos pocas reglas generales. Una es que ninguna necesidad de una sola persona va a dominar. Es siempre tenso cuando Sean se enferma, y el no querer que todos sacrifiquen las vacaciones de verano porque Sean está enfermo (¡Hola, rivalidad entre hermanos!), fuimos a Vacaciones Plan B.

Kyra, nuestra hija de 13 años, y Connor empacaron sus propias bolsas de ropa. Se necesita una gran confianza para dejar que un niño de 11 años de edad empaque su propia maleta. Yo sólo tenía esperanza que él empacara ropa interior extra, su traje de baño, y cepillo de diente. Kyra y Connor se fueron el Viernes con nuestros amigos. Tú sabes que estos amigos son muy buenos amigos. ¿Cuánta gente voluntariamente se llevan niños extras en su propio carro en un viaje de ocho horas?!

El problema con la pulmonía es que tú no puedes predecir cuanto tiempo va a tomar para que se mejore. Porque Sean es propenso a convulsiones, él nunca ha sido vacunado contra la tos ferina y estaba en "precaución de contacto." Es un hecho poco conocido que si el hospital le marca "precauciones de contacto," usted no puede volar en una línea aérea comercial. Cuando mi conversación con nuestro médico empezó a envolver a la Administración Federal de Aviación (FAA) y el Centro de Prevención y Control de Enfermedades (CDC), yo supe que era tiempo de cambiar al: Plan C.

**Plan C.** No estamos hecho de dinero, ¿pero cuánto cuesta rentar un avión para volar a Brian, mi esposo, Sean y yo? El plan C tuvo una breve duración. La respuesta, en caso de que te preguntaras, es mucho.

**Plan D.** Brian, Sean y yo vamos a guiar directo a la playa enseguida que Sean salga del hospital. Se fijará que el llevar a Sean a nuestro hogar para recuperarse después de su hospitalización nunca fue una opción. Si tienes que recuperarte en algún lugar, es mejor hacerlo en la playa. La abuela de Sean se quedó con él de la noche a la mañana para así Brian y yo poder vernos y poder dormir. (Nota para el archivo: No hables con el CDC y FAA si sufres de falta de sueño.)

Sábado por la mañana, Brian y yo empacamos una bolsa de ropa para cada uno y la tiramos en el carro. Conduciendo al hospital para recoger a Sean (Por supuesto él va a salir hoy del hospital, ¡¿verdad?!), el médico llama. La fiebre de Sean regresó, y él no va a ir a ningún lado.

**Plan E.** Mientras Brian habla con el médico, yo reservé un boleto en el próximo vuelo a Norfolk, VA. Es un avión pequeño—el tipo donde le preguntan a

uno cuanto pesa para así determinar su asiento. Fui tentada a preguntarle a mis compañeros de vuelo, si alguien iba a los Outer Banks, y si yo podría coger pon desde el aeropuerto hasta la playa, pero dado el clima actual y los problemas de seguridad, pensé mejor.

Habiendo aterrizado en Norfolk, fui al mostrador de alquiler de carros. No hay carros. Ningún problema. ¿Taxi? Teniendo en cuenta la tarifa para las dos horas de viaje en taxi (y el viaje de vuelta), el rentar un avión de repente no parece demasiado.

Ahora era sólo Brian y Sean. Finalmente Sean salió del hospital el Domingo. Brian se lo llevó al carro corriendo antes de que el médico cambiara de opinión y salieron en camino. Después de ocho horas, varias paradas para terapias de pecho (Sean) y café (Brian) y una multa por exceso de velocidad, llegaron a la casa de playa alrededor de las 3 de la mañana. Cuando todo el mundo se levantó el Lunes en la mañana, nuestra vacación familiar comenzó.

De todas nuestras fotos familiares de la playa, ésta es mi favorita. En la tienda de La Vida es Buena encontramos unas camisa que leían "Medio Lleno." Dado que casi todos nosotros nos habíamos quedado sin ropa limpia (algunos antes que otros), compramos una para cada uno de nosotros. Mientras que nosotros pudimos haber revolcado en autocompasión de que nuestro viaje fue "arruinado" por la enfermedad de Sean, nosotros encontramos fuerza en cada uno de nosotros y en nuestros gran amigos y tuvimos una de nuestras mejores vacaciones.

Usted debería oír del viaje de regreso...

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## **Statewide Forum on *Education Advocacy in the Stimulus Era:* *Strengthening Resource Equity and Opportunities to Learn for all Students in Public School***

Come to Harrisburg to learn about important and timely education and budget issues, talk with community leaders and groups from around the state, meet legislators, and have a real impact at a crucial time when decisions are being made about public schools, special education, federal stimulus dollars, the state budget, and high school graduation standards.

**Date:** Tuesday, June 2, 2009

**Where:** Temple University, Harrisburg, PA in Strawberry Square on Market Street by the train station across from the Capitol Building

**Details:** This is a free event but limited to the first 75 people and will include lunch.

**Schedule:** Main Program is 11 a.m. to 2 p.m. Optional pre-and post forum policy background discussions are at 10 a.m. and 2 p.m. Time to schedule your own meetings with your state legislators is set aside before 11 a.m. and after 2 p.m.

**Featuring:** Donna Cooper, Secretary of Policy and Planning for Governor Ed Rendell; Paul Weckstein, Director, Center for Law and Education, Washington, D.C.; and other local, state, and national policy leaders.

**Sponsors:** Education Law Center and Good Schools Pennsylvania. *For information contact* Sandy Zelno, School Reform Associate, Education Law Center at [szelno@elc-pa.org](mailto:szelno@elc-pa.org) or call 412-255-6414.

## Invitation to Provide Feedback \* Invitación para Proporcionar Opinión

The Pennsylvania Department of Health will host a public meeting to discuss the Title V Maternal & Child Health Services Block Grant (MCHSBG).

The purpose of the Title V, Maternal & Child Health Services Block Grant is to improve the health, safety and well-being of **all** mothers and children, especially those with low income or limited availability of services.

In Pennsylvania, Title V supports programs such as:

- Primary and preventive care for children
- Services for children with special health care needs
- Lead Poisoning Prevention
- Newborn Screening
- Prenatal Home Visitation
- Traumatic Brain Injury School Re-entry

***Please come to hear about the State's maternal and child health priorities and programs. We want to hear your input about services and what is needed to support families in your community.***

For information contact Ken Huling via email at [khuling@state.pa.us](mailto:khuling@state.pa.us) or by calling (717) 346-3000.

El Departamento de Salud de Pensilvania celebrará una audiencia pública para discutir los Fondos Estatales para los Servicios de Salud de la Madre y el Niño (FESSMN).

El objetivo del Título V, Fondos Estatales para los Servicios de Salud para la Madre y el Niño es mejorar la salud, seguridad y bienestar de **todas** las madres y niños, especialmente de quienes cuentan con bajos ingresos o servicios disponibles limitados. En Pensilvania el Título V patrocina programas tales como:

- Cuidado primario y preventivo para niños
- Servicios para niños con necesidades especiales de cuidado de salud
- Prevención de Envenenamiento de Plomo
- Evaluación de recién nacidos
- Visita Prenatal de Casa
- Lesión Cerebral Traumática Reentrada de Escuela

***Por favor venga a escuchar acerca de las prioridades estatales de salud materna e infantil. Queremos oír sus opiniones acerca de servicios y que es necesario para apoyar las familias en su comunidad.***

Para información adicional contacte a Ken Huling via email [khuling@state.pa.us](mailto:khuling@state.pa.us) o llame al: (717) 346-3000.

### Date/Fecha & Location/Dirección

#### PITTSBURGH

**Date/Fecha:** May 26, 2009 /26 de Mayo del 2009

**Time/Hora:** 10 a.m. - 12 p.m.

**Location/ Dirección:** 400 North Lexington Ave.

University of Pittsburgh

Office of Child Development

Pittsburgh, PA 15298

(enter through security entrance and go to lower level)

(ingrese por la entrada de seguridad y vaya al nivel bajo)

#### PHILADELPHIA/FILADELFIA

**Date/Fecha:** May 28, 2009 /28 de Mayo del 2009

**Time/Hora:** 10 a.m. - 12 p.m.

**Location/ Dirección:** St. Christopher's Hospital

Angelo DiGeorge Conference Center

3601 A. Street

Philadelphia/ Filadelfia, PA 19134

#### ERIE

**Date/Fecha:** June 9, 2009 /9 de Junio del 2009

**Time/Hora:** 10 a.m. - 12 p.m.

**Location/ Dirección:** John F Kennedy Center

Gymnasium

2021 East 20th Street

Erie, PA 16510

#### WILKES-BARRE

**Date/Fecha:** June 11, 2009/11 de Junio 11 del 2009

**Time/Hora:** 2:30 p.m. – 4:30 p.m.

**Location/ Dirección:** Maternal and Family Health Services

6th Floor Conference Room

15 Public Square

Wilkes-Barre, PA 18701

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### \* ALERT\* People Currently Receiving Services From the Mental Retardation System Are At Risk of Losing Their Services

This is an urgent message from *The Disability Rights Network of Pennsylvania* for all persons and their families who are currently receiving services from the Mental Retardation System. The proposed budget passed by the Pennsylvania Senate last week (SB 850) not only eliminates all money for the waiting list but **terminates services for up to 3,550 people currently receiving services**. This includes up to 550 people in the Consolidated Waiver and 3000 people receiving family support.

Senate Bill 850 reduces support for Mental Retardation Consolidated Waiver services by \$32,720,000 (state & federal).

This cut will cause up to 550 people currently in the Consolidated Waiver to lose their services. This cut totally eliminates the emergency waiting list initiative, which was to serve 793 new people next year.

This includes the termination of services for over 180 children who are currently in residential facilities but whose funding will end because they are turning 21 and are no longer eligible for the services they were receiving.

This includes termination of residential services for over 100 adults who are in emergency situations. There is no doubt that because of these massive cuts some of the people who lose their services will end up in institutions (ICF/MRs) at a greater cost to the tax payer.

## New Concepts in Employment for Disabled Adults

by Allen Heverly, Via

Via is an organization located in Bethlehem, Pennsylvania that traditionally provided employment for citizens with disabilities in Via provided workshops and day employment. However, new initiatives began a few years ago and Via created a program that found work in the community based on Person Centered Discovery, a method being advanced by Griffin-Hammis (see *Resources Section on Page 7*). Through the use of the Discovery method, the consumer is given greater powers in the job search process. Past procedures involved first finding an open job, then finding a consumer who has the skills to match. Person Centered Planning involves discovering what the person is really about then creating, through job carving, the "perfect job" for the person. This approach opened the eyes of many experts in the field. Before long successes were appearing and people with disabilities and their families were more satisfied with the outcomes.

Self-employment emanated from Person Centered Planning. If we could create customized jobs, why couldn't people with disabilities create their own businesses based on their individual skills?

In 2007, Via partnered with the City of Bethlehem to initiate a groundbreaking program that would allow disabled citizens to finance their own businesses. Both organizations funded a full-time self-employment specialist to do the Person Centered Planning, market research and business startup for people with disabilities. The City provided loans to applicants from Via and to date two business have begun to operate under this program.

Mike Menio who lives with disabilities and whose family enjoyed Polka music was in need of employment. His memory of the songs and singers goes back into the 1960's. Mike can remember all the members of specific Polka bands and the songs they played. For a period of time he had his own show on a local radio station, but the lack of advertising funds left him with no air time. Mike desperately wanted to continue to pursue his love for the music, but employment in that area is difficult to

find. Through Person Centered Planning, Via created an opportunity for Mike. Mike would play his music for the people who would appreciate it the most – senior citizens in homes and senior centers around the Lehigh Valley.

Mike's equipment was purchased through the loan program from the City of Bethlehem. Mike trained on the equipment and polished his act with the support of a grant from the Office of Vocational Rehabilitation (OVR). With all the assistance from these organizations, Mike's business is starting off with a bang. He has already booked several engagements and is now appearing for donations in Senior Centers that have been hurt by the poor economy and lack of government funding. Both Mike and his audience enjoy the music that brings back memories for our most treasured resource: our senior citizens.

Sometimes many different ideas are required to create extraordinary outcomes. Person Centered Planning, funding and creativity are all necessary. Instead of spending most of his days in a workshop, Mike will be living a life he loves and other people will benefit directly from his skills and knowledge. The lesson to be learned is that with enough creative thinking and viewing our disabled citizens in a new light, we can all benefit from each other in many ways we have yet to dare dream of!

### AHEDD's Work Benefits Counseling Program

While Social Security Administration (SSA) cash benefits and health care are critical for many persons with disabilities, there is a great deal of misunderstanding about work and receiving SSI/SSDI.

AHEDD's Work Benefits Counseling Program has been designed to provide you and your community with the very best in customer service and expertise in helping beneficiaries make informed choices and to be encouraged to pursue employment.

To find a SSA Benefits Counselor/Work Incentive Coordinator near you visit [www.ahedd.org/ssaoftices.html](http://www.ahedd.org/ssaoftices.html)

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**(ALERT** Continued from page 4)

Senate Bill 850 reduces the base mental retardation community program by \$12,117,000 (state funds).

This cut will result in a loss of services for up to 3,000 families with sons and daughters with mental retardation who live at home. This money has historically been used to provide a small amount of support to families who get no other services to help them keep their sons and daughters living at home.

Senate Bill 850 reduces Autism services by \$15,286,000 (state and federal).

Almost 50% of the individuals who were to begin receiving services under the Commonwealth's newly approved autism programs will not receive these services.

Senate Bill 850 reduces the SSI supplement by \$27,732,000 (state).

Every SSI recipient will lose approximately \$77 per year or approximately 17% of their state supplement.

#### **What can you do?**

Visit your Senator and tell him or her how your family will be affected if your son or daughter loses services. Send e-mails and letters to your Senator or Representative. Let them know what these cuts mean to you. Use the link below to find your state Senator or Representative -- <http://www.legis.state.pa.us/cfdocs/legis/home/find.cfm> Simply enter your zip code to find who represents you. Click on your Senator or Representative's name to get his or her e-mail and street address. Watch for more updates and alerts from **The Disability Rights Network of Pennsylvania** and visit their web page at <http://drnpa.org/>



## Feedback from the PEAL Conference 2009: Enriching Our Inclusive Communities

Based on feedback from presenters, parents and participants, the 2009 PEAL Conference met its goal to "create a sense of community" during the 3 days in March at the Four Points Sheraton North. The energy created by collectively "dwelling in possibilities" was captured by a radio interview on NPR/WDUQ News and in an article in the Butler Eagle. We are happy to share some of the emails and notes we received.

"The conference not only changed my life, it has changed my son's life in just a few short days. Because of the speakers (Jamie Burke) I am taking more time to listen to him and talk with him to say that I have great expectations for him. He has reacted with improved communication and his behavior issues have decreased greatly. We went to the dentist yesterday for a check-up. Last time it took three of us to hold him down for an exam. This year, I explained to him what was going to happen and what to expect and he went through the visit without any issues. The staff couldn't even believe it was the same kid. As soon as I assumed competence for my child, he showed me he could communicate and that I just needed to pay more attention to what he was

trying to say. The theme throughout the conference was inspiring. It could not have been presented any better."

*Andrea, Parent*

"I wanted to tell you how much I enjoyed the PEAL Conference last week. I thought it was informative. I also thought it had a nice relaxed atmosphere, one where parents would not feel intimidated attending. I am going to recommend it to the parents I talk to in the future."

*Sent to Gay Vroble, PEAL Board President*

"Thanks so much to the PEAL Center for the unbelievable opportunity you created for me. The right people were there for me to speak to and I was able to make a connection that is going to help my situation. I am so thankful for the PEAL Conference."

*David, Parent & Professional*

"You and your team should feel so proud of your work. The speakers you had were brilliant, inspiring and highly motivational. Congratulations!"

*Judy Heumann, Presenter  
Director, Department of Disability Services, Washington, DC*

## Project for PEACE: Parents Engaged in Advocating for Change in Education

The PEAL Center's *Project for Parents Engaged in Advocating for Change in Education* class of 2009 started this spring in northwest Pennsylvania. The current class of 25 parents is learning about Pennsylvania's initiative "Improving Student Results: A Focus on Highly Qualified School Personnel."

This yearly parent leadership project, currently meeting in Meadville, PA, is focused on preparing parents to partner as informed participants and decision makers in these reform strategies at the school district, IU and state level. The curriculum covers the six State Personnel Development Grant (SPDG) areas, focusing on highly qualified educational interpreters, school psychologists, paraeducators, special education leaders and revised special education certification

standards including secondary special education teachers with core content knowledge.

During the course, participants are also working on individual projects within their districts to improve the educational system for all children.

The final session of this year's class will meet on June 20<sup>th</sup> in Meadville featuring two keynote speakers. Michael Giangreco, a nationally known and respected speaker from the University of Vermont will address the group on paraeducator supports. Michael Remus, a parent, a former state Director of Special Education and currently Director of Special Education Services for an Arizona school district will talk about the role of special education leaders. *If you are interested in attending this final*

*session as a guest, contact Melissa Allen, SPDG Coordinator, PEAL Center at 412-281-4404 ext. 13.*

The Project for PEACE is meant to be a five year rolling institute across PA. Last year's graduates from southwest PA are reaching out in many organizations to advocate for education reform. In 2010, PEACE will be held in the central part of Pennsylvania.



## RESOURCES

### EMPLOYMENT

#### **The Job Developer's Handbook: Practical Tactics for Customized Employment**

Cary Griffin, David Hammis and Tammara Geary, 2007  
One of the most practical employment books available, this forward-thinking guide walks employment specialists step by step through customized job development for people with disabilities, revealing the best ways to build a satisfying, meaningful job around a person's preferences, skills, and goals. Internationally known for their innovative, proactive job development strategies, the authors motivate readers to expand the way they think about employment opportunities and develop creative solutions.

*This book is available through PEAL's Lending Library.*

#### **NEW Teleconference Training Series on Employment from Griffin-Hammis Associates**

Bring expertise on Customized Employment, Self Employment, Supported Employment, and Leadership refinement into your staff meetings without the cost and hassle of travel. Dave Hammis and Cary Griffin, along with a few of their experienced associates, including Katherine Carol, Tammara Geary, and Bob Niemiec, have designed a series of in-service training topics that will enliven staff meetings, expand the scope of your internal training program, and augment the knowledge-base of direct service, consumers, families, Board members, and management staff!  
Contact Cary Griffin at [cgriffin@griffinhammis.com](mailto:cgriffin@griffinhammis.com) or Dave Hammis at [dhammis@griffinhammis.com](mailto:dhammis@griffinhammis.com) for more information.

#### **The Healthy and Ready to Work (HRTW) Center** [www.hrtw.org](http://www.hrtw.org)

The mission of HRTW is "to create changes that will help youth with special healthcare needs transition to adult health care with funding, to work and to greater independence." This site has checklists as well as informational sheets about topics that relate to the transitioning youth.

**The Pennsylvania Occupational and Vocational Rehabilitation Office (OVR)** has the goal "to assist Pennsylvanians with disabilities to secure and maintain employment and independence." Although not a direct service provider, the agency funds the following services: vocational evaluation, vocational counseling, and training to prepare you for a job, restoration services, placement assessment, assistive technology and support services. For more information about these services go to [www.nepacil.org/OVR.htm](http://www.nepacil.org/OVR.htm).  
A list of OVR district offices can be found at: [www.equalemployment.org/cap/offices.html](http://www.equalemployment.org/cap/offices.html)

#### **Job Accommodation Network (JAN)**

The Job Accommodations Network is a service provided by the U.S. Department of Labor's Office of Disability Employment Policy (ODEP). JAN represents the most

comprehensive resource for job accommodations available. JAN consultants provide individualized worksite accommodation consultation and training through its toll free number and electronic services. (V) 1-800-526-7234 or (TTY) 1-877-781-9403

#### **National Center on Secondary Education & Transition**

[www.ncset@umn.edu](mailto:www.ncset@umn.edu)

A federal organization that provides guidance nationwide on transition issues. The state contact through NCSET is Ellen Romett with PA Training and Technical Assistance Network located in Pittsburgh. PATTAN's number is 412-826-2336.

### SUMMER CAMP

**New Horizons Creative Discovery Camp for Children in the Autism Spectrum** by the Pittsburgh Civic Light Opera, July 20 -24. Ages 5 to 8 from 5 to 6 p.m. and ages 9 to 13 from 6 to 7 p.m. Children must be verbal and high functioning.  
Drama is a powerful tool for teaching social skills, body language and social interactions. Children will explore music, movement and drama with compassionate and creative instructors in a safe, comfortable setting. The week concludes with a performance for parents. For information go to [www.pittsburghCLO.org](http://www.pittsburghCLO.org) or call 412-281-2234.

#### **Summer Camps for Children with Special Health Care Needs and/or Chronic Health Conditions**

<http://www.hugsandbears.com/camp08.pdf>

Compiled By: Susan Franke, RN, BSN, M.Ed,  
*Keep In Touch: A Model of Caring*

The summer camp guide was created at the request of parents and providers of services who were seeking a convenient way to locate camp information. There are 130 camps listed in the directory for people of all ages. The guide is very appropriate for all organizations that serve children with special needs and/or chronic health conditions.

### ASSISTIVE TECHNOLOGY

#### **Prentke Romich Company**

PRC offers FREE on-line trainings for anyone supporting an AAC device user! PRC e-Trainings include . . .  
-- General device operation and instructional strategies for all PRC devices.  
-- Implementation Strategies  
-- Getting to Know Your PRC Funding Submission Assistant  
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e-Training classes and other learning opportunities are being created and updated on an ongoing basis. Full details and requirements are available at [www.prentrom.com](http://www.prentrom.com)



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**PEAL has joined *Exceptional Parent Magazine's* subscription donation program**

Parents that have a complete home mailing address on file with PEAL should receive a complimentary copy of the June issue directly from the publisher.

If you wish to subscribe to this magazine and you do so under the PEAL code, \$10 of the discounted subscription rate will be donated to the PEAL Center.

You can subscribe to the magazine at <https://www.kable.com/pub/epar/spdonations.asp>.

**PEAL's code is SDP018**

**UPCOMING EVENTS IN PA**

**2nd Annual Pennsylvania Autism Training Conference (PATC)**

Hosted by Bureau of Autism Services, PA Department of Services  
May 27-29, 2009

Eden Resort Inn & Suites, 222 Eden Road, Lancaster, PA 17601  
Continuing Education available: Certified Behavior Analysts, Social Workers, Educators, Psychologists, Counselors. Visit [www.autisminpa.org](http://www.autisminpa.org) or email: [ra-bastrainings@state.pa.us](mailto:ra-bastrainings@state.pa.us)  
Call toll free: 1-866-539-7689

**Planning an Inclusive and Collaborative Transition**

Saturday, June 6, 11:30 AM – 1:30 PM  
Upper Dublin School District, Maple Glen, PA  
Presenter: Domenico Cavaiuolo, Ph.D., East Stroudsburg University.  
Sponsored by Pennsylvania's Education for All Coalition (PEAC)  
Transition Planning and Vision Building begin in kindergarten!  
Whether you are starting early or late, come and learn how to plan for an inclusive and collaborative transition to adult life for students with disabilities. *Free training open to all.*  
To register contact Lindsey Walker at [lwalker@paedforall.org](mailto:lwalker@paedforall.org) or (267) 232-0570

**Speaking For Ourselves Annual Conference  
Power Through Unity**

Friday, June 19, 2009  
Sheraton Harrisburg Hotel, Harrisburg, PA 19111  
For more information call 215-923-8600  
*Speaking for Ourselves* is an independent, grassroots organization run by, and for people with developmental disabilities.

**The Pennsylvania Community on Transition Conference:  
Success by Design**

July 22 - 24, 2009  
Penn Stater Conference Center and Hotel, 215 Innovation Boulevard, State College, PA 16803  
The primary purpose of this conference is to promote the successful transition of youth/young adults with disabilities to post-school outcomes of employment, post-secondary education and training, community participation and healthy lifestyles. Effective practices to assist youth/young adults with disabilities in achieving successful post-school outcomes will be highlighted. For more information visit the PaTTAN website:  
<http://www.pattan.net/profdev/trainingcalendar>

**Amendment to Fully Fund IDEA Introduced in Congress**

By Michelle Diament May 6, 2009

Reprinted with Permission from Disability Scoop, The Premier Source for Developmental Disability News, on the web at [www.disabilityscoop.com](http://www.disabilityscoop.com)

An Amendment introduced in the U.S. House of Representatives on May 6 seeks to fully fund the Individuals with Disabilities Education Act.

The act ensures the right to a free and appropriate education for children with disabilities. When Congress initially passed legislation mandating such educational services for students with disabilities in 1975, the federal government committed to provide 40 percent of its cost, with states and school districts covering the rest. That has never come to fruition, however, with federal funding for IDEA traditionally accounting for less than 20 percent.

"For far too long, our nation's schools have been waiting patiently for Congress to fulfill its promise to fully fund special education," Rep. John Kline, R-Minn., said in introducing the amendment. "By fully funding special education, we would free up desperately needed funds schools across America could use to address their specific needs – whether it is state of the art classrooms, additional teachers or new textbooks."