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## Supporting And Engaging Diverse Families

*Over the past year, SPAN NJ (State Parent Advocacy Network) has been working intensively with Spanish-speaking immigrant parents of children with deaf-blindness and other significant disabilities as part of the Culturally Competent Outreach Project. Read on to learn more from Mercedes Rosa about this project, a collaboration of the National Deaf-Blind TA Center, the NJ Deaf-Blind FACES project, and SPAN's Family to Family Health Information Resource Center grant, designed to meet the needs of Spanish speaking families of children with deaf-blindness.*



**Families with language barriers can fall through the cracks.** We acknowledged that, based on their registry, there was group of Spanish-only speaking parents of children with deaf-blindness that could not access the supports they needed for their children with deaf-blindness and other special health care needs. We would attempt to locate them and offer assistance. We discussed the various strategies that had failed in the past and agreed to allow the needs of the parents to dictate how we should tailor both the outreach and support plan.

How did we reach them and what was the outcome? Families were contacted by phone and mail to schedule convenient places and times to meet, and focus groups were conducted both in person and via telephone to identify what types of materials and family supports would best meet their needs. The families were eager to meet with us and help us understand their needs. While some families were suspicious of our motives, over time we became a sign of hope for many that felt isolated and forgotten by the agencies they briefly interacted with early on. "Why were we left alone to deal with so many obstacles?" many asked us through tears. We assured them we would help them and voice their concerns. We shared our findings and plan we'd developed to address the complex needs expressed by the families with team members.

### Build Bridges and Create Access

#### **We asked the families to allow us to earn their trust and allow us partner with them!**

Through the project, parents were provided parent-centered supports including monthly parent support group meetings/trainings, respite, lunch, fellowship and reimbursements for associated respite and travel expenses. We made ourselves available to assist with translation and school-related issues. Recognizing that many of the families were isolated, in-person meetings became an essential outlet for their well being. We maintained frequent contact by phone and home visits. Ongoing outreach allowed the parents to bond with us and to establish new friendships with other parents of children with deaf-blindness.

**Intensive supports** Many of the families needed help completing applications to access health coverage, housing and other services from agencies. Communication was an issue for most families, so we were available to provided translation services as needed. We helped them schedule appointments; accompanied them to doctor's visits, hospitals, government offices so that they could complete necessary forms and communicate their needs; and assisted families in finding doctors that accepted their insurance plans so that they and their children could access routine and follow-up care.

## SCHIP Update

Congress is home for the August recess. Now is the time to visit your state's congressional delegation while they are working in their home district offices. (You can visit their websites to find their district office information.) Republican members of both the House and the Senate are extremely important to visit and get to know!

**Problem:** The House and the Senate both passed versions of the SCHIP reauthorization. The House version provides for \$50 billion; the Senate version provides for \$35 billion over the next five years. The President has said that he will veto any bill that authorizes more than \$5 billion in SCHIP spending over the next five years.

**What will happen next?** Congress is out on recess now until after Labor Day. When they come back, the Conference Committee will work to resolve the differences between the two bills. They have until September 30th, when the SCHIP funding will run out. If the President has not signed a reauthorization bill into law by then, Congress will need to pass a continuation bill in order to continue the program. However this will most likely be at last years' funding levels--and not nearly enough to fund the program.

**Action Needed Now:** While Congress is at home, it is extremely important to hit Republican members with the importance of SCHIP. Republicans need to call the President/the Administration and ask him to sign at least the Senate version (\$35 billion) of SCHIP.

**Get to know these guys now!** Get them to know families in your state. And get them to get the President to sign a bill with \$35 billion over the next five years!!!! Families can do this! It is extremely unpopular for the President to veto this bill with an election coming up. If he gets pressure from his own party—maybe we can get an SCHIP bill that will work for kids and families!!! In addition, use the Family Voices Legislative Action Center - <http://www.familyvoices.org/lac> particularly with Republican Members...and ask them to put pressure on the President .

At monthly meetings we provided training on topics of interest such as parental rights and improving communication skills. Parents attended conferences and monthly workshops offered by SPAN and other agencies serving families. Most of the families, we learned, did not have an effective way to communicate with their children who were being taught sign language at school. Sign language videos we supplied helped parents build their capacity to communicate effectively with their children. We supported the parents at school visits and at their IEP meetings. Families with limited language access were hindered from getting educational supports and services for their children; most had never read their children's IEPs and assessments because they were written in English. As a result, tools were created and support given to help parents write their school districts to request that all written materials sent to them be written in Spanish.

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**Resources & Community Experiences** Families were connected, through this project, with state and national agencies that provide supports and services for children and families. They were given written materials on deaf-blindness so that they could keep learning about their child's overall development and ongoing educational needs. Many families who experienced isolation in the past were given opportunities to go on field trips to the mall, diners and to attend an annual family picnic at a state park. These outings gave both parents and their children the chance to be assimilated in the community as a family. Parents attended health fairs in other counties and participated in policy forums together. Through this amazing, shared learning experience, parents and children alike had the opportunity to get to know each other and bond.

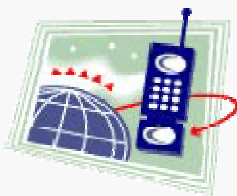
**The Outcome** We are now supporting empowered parents who have attained supports for their families and children with deaf-blindness and can navigate systems of care. The children are now more comfortable in suitable school programs and have a better quality of life now that they have proper medical care and the necessary adaptive equipment to support their needs at home. These families have learned to celebrate their children. The parents now have hope that they can help their children and use the tools they've garnered to contribute to their children's ongoing growth. Many parents are actively learning sign language to have long-awaited conversations with their children. We have budding leaders that are eager to keep learning and to provide supports to other parents. Our parents have found their voices and can effectively advocate for their children; now they seek opportunities to lend their voices to public policy forums.

*"Leadership should be born out of the understanding of the needs of those who would be affected by it."*

-- Marian Anderson

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Karen Anzola, Editor and Peggy Curran, Layout

**TOPICAL CALL:**  
**Dancing with Change,**  
 an interactive, hands on call  
 with Steve Davis,  
 Facilitator U



What do you want to leave behind when you move on from your current position? Wouldn't you like to be remembered fondly, having those you leave behind thriving as a result of your leadership? Join us in this interactive session as we explore the seven principles of sustainable leadership, design the legacy we wish to leave, and begin developing an action plan for making this legacy a reality.

**Wednesday, August 22nd, at 9 AM Hawaii/ 11 AM Alaska/ 12 PM PT/ 1 PM MT/ 2 PM CT/ 3 PM ET**

**This call is open to all, but you must register first. Please share this information with your friends and colleagues.**

To register, please complete our online registration form at [http://www.familyvoices.org/info/topical\\_calls/8-22-2007.php](http://www.familyvoices.org/info/topical_calls/8-22-2007.php).

This call is sponsored by the National Center for Family / Professional Partnerships at Family Voices, Inc. - <http://www.familyvoices.org/info/ncfpp/>

Questions? Contact Karen Anzola at [kanzola@familyvoices.org](mailto:kanzola@familyvoices.org) or Peggy Curran at [pcurran@familyvoices.org](mailto:pcurran@familyvoices.org).

Learn more about Steve Davis and Facilitator U at <http://www.facilitatoru.com>.



## Network News - Family Voices Region 10 is Growing!

Family Voices continues to grow this vibrant national Network of parent leaders, youth leaders, partners and friends. We are thrilled to welcome two new Family Voices Network members to Region 10 (AK, WA, OR, ID)—**Barbara Chambers from Alaska and Laurie Borrowman from Idaho.**

Barbara is mom to a 10-year old daughter with special health care needs who keeps her quite busy. Barbara became involved with Family Voices a year ago when she began working as a Parent Navigator with the Stone Soup Group. Barbara serves on several school committees and represents Alaska on the Western States Genetic Services Collaborative. As program coordinator for the Alaska Statewide Parent to Parent Network and a team member with the Alaska's F2FHIC, Barbara is involved in community outreach, state-wide collaboration efforts, and agency/family networking. She looks forward to sharing information she receives from Family Voices with families in AK and working for systems change.

Laurie is the mother of a child with special healthcare needs attending middle school. Having a son with special needs has brought Laurie to become involved, not only in improving the quality of life for her son, but in helping others with special needs. Laurie is a graduate of the 2003 Idaho Partners in Policymaking program, after which she worked as the chairman of the Idaho Parents Unlimited, (IPUL) legislative committee, a volunteer position. She also served on IPUL's board of directors, leaving that position in 2005. Laurie returned as a staff member of Idaho Parent's Unlimited in February 2007 working as a Parent Education Coordinator, and with the IPUL staff of the Family to Family Grant.

**Welcome, Barbara and Laurie!**



## SPAN Selected to Participate in Innovative Program

The Statewide Parent Advocacy Network of NJ, NJ's Family to Family Health Information Resource Center and Family Voices Chapter, has been selected by IBM to participate in its ¡TradúceloAhora! translation program! This grant program uses a special, enhanced version of IBM WebSphere Translation

Server software with added functionality and refined translation capacity to translate web sites and email from English to Spanish for schools and community organizations. As part of this initiative, the organizations selected will receive access to this software via [www.traduceloahora.org](http://www.traduceloahora.org). SPAN will be able to use the software to translate web sites that provide the most benefits to the Latino families that they serve.

Aimed at addressing the digital divide affecting Latino/Hispanic communities across the United States, this grant program continues on the success of the first phase of this initiative which involved thousands of individuals at nonprofit organizations and schools that used the ¡TradúceloAhora!

## Many Young Adults Are Still Uninsured

The Commonwealth Fund has released, "Rite of Passage? Why Young Adults Become Uninsured and How New Policies Can Help," a report that examines health care coverage trends for young adults. The report documents that young adults continue to represent the largest uninsured age group in the U.S. The report also discusses state laws to improve health coverage of young adults by allowing them to remain on their parents' health plans, as well as federal efforts that would allow states to increase access to SCHIP and Medicaid up to age 25. For the press release summarizing this article go to [http://www.commonwealthfund.org/newsroom/newsroom\\_show.htm?doc\\_id=514401](http://www.commonwealthfund.org/newsroom/newsroom_show.htm?doc_id=514401)

To download the issue brief, go to <http://www.commonwealthfund.org/publications/>

## The Family Voices Store at Family Café—One Stop Shopping for Family and Friends



Looking for a way to honor a family member or special caregiver, or seeking just the right thank you gift? Consider making contributions to Family Voices through secure, on line donations, purchases of Family Voices Merchandise at [www.cafepress.com/shopfv](http://www.cafepress.com/shopfv) or purchases from Amazon.com through the link on our web home page. Simply visit our website, <http://www.familyvoices.org>, to make a donation or to learn more about how financial gifts are used. Donations may be sent directly to:  
**Family Voices**  
2340 Alamo SE, Suite 102  
Albuquerque, NM 87106.

translation software to find information on the web on jobs, health care, immigration, legal aid and education. The Tomás Rivera Policy Institute ([www.trpi.org](http://www.trpi.org)), recognized as the nation's premier Latino think tank, conducted an independent evaluation of the first phase of the grant program which showed that the ¡TradúceloAhora! automatic translation software benefited the organizations and their constituents in significant ways.

The next phase of this grant program began October 2006, focusing on K-12 students, their parents, teachers and administrators to enhance communication by translating web content and email bidirectionally (English<=>Spanish). So, an English-speaking teacher can send an email in English to a Spanish-speaking parent; the parent receives the email in English, and then, within minutes, the translated email into Spanish; the parent responds in Spanish and it is similarly translated into English for the teacher. SPAN will be participating in this project through December 2008 but will be allowed to continue to use the program even after the project ends.

**Congratulations, SPAN!**



## News You Can Use: Resources and More

### Spanish Language Wraparound Process User's Guide

The "Manual de Usuario del Proceso del Wraparound (Asistencia Integral)" is a professionally translated version of the "Wraparound Process User's Guide," originally published in English. This guide from the National Wraparound Initiative (NWI) provides a comprehensive description of what a family can expect from the wraparound process. The guide can also serve as an introduction to wraparound for service providers, policy makers, and other stakeholders. The guide draws on previous work of the NWI, particularly the description of the phases and activities of the wraparound process. As a result, the guide is intended for use in any community that uses a wraparound process consistent with the NWI guidelines. Order printed copies of the Spanish (or English) Wraparound Guides for \$1.25 each (includes shipping and shipping insurance) via the NWI Publications page at <http://www.rtc.pdx.edu/pgPublications.php> (type "Wraparound Process User's Guide" in the Title Phrase field, click "get," select the issue(s) you'd like to order, and follow the instructions for ordering) , or download the PDF at <http://www.rtc.pdx.edu/PDF/pbSpanishWraparoundGuide.pdf>



### Report Released on Children's Mental Health

The National Center for Children in Poverty recently released the report "Child and Youth Emergency Mental Health Care: A National Problem." The report contains a summary of data and references, including substance abuse, characteristics of those who use ERs for mental health services, care and resources, and recommendations. To read the full report, go to [http://www.nccp.org/publications/pdf/text\\_750.pdf](http://www.nccp.org/publications/pdf/text_750.pdf).

## Promising Practice Reports on Services for Individuals with Autism Spectrum Disorders (ASDs)

The Centers for Medicare and Medicaid Services (CMS) is pleased to announce the availability of three new promising practices reports that focus on Services for Individuals with Autism Spectrum Disorders (ASDs). Since 1999, CMS has developed an online repository of more than 75 Promising Practices in Home and Community-Based Services (HCBS) to highlight State efforts to enable persons of any age who have a disability or long-term illness to live in the most integrated community setting appropriate to their individual support requirements and preferences, exercise meaningful choices, and obtain quality services. The new reports focusing on ASDs are at:

<http://www.cms.hhs.gov/promisingpractices/>

The online Promising Practices Reports disseminate timely information on program and policy innovation. These reports on ASDs are part of the CMS' participation in the Interagency Autism Coordinating Committee (IACC), created through the Combating Autism Act of 2006. The Centers for Disease Control and Prevention estimates that about one in 150 children have an ASD, with males predominantly affected. ASDs are developmental disabilities that create impairments in social interaction and communication and include unusual behaviors and interests. Individuals with ASDs have unusual ways of learning, paying attention, and reacting to different sensations. The abilities of children and adults with ASDs can vary, from gifted to challenged. An ASD typically begins before age three and lasts throughout an individual's lifetime.

Visit the Promising Practices Website to view all of the resources posted, including three new reports:

- CA– Single Process for Diagnosis and Service Delivery
- CT– Pilot Program for Young Adults with Autism Spectrum Disorders
- DE– Supported Employment for Adults with Autism Spectrum Disorders

CMS thanks the staff from the States of California, Connecticut and Delaware, and their State Medicaid Directors, for their assistance in helping share their efforts to assist individuals with ASDs.

## ☑ Report Released on Children's Mental Health



In January 2007, the National Technical Assistance Center for Children's Mental Health at Georgetown University Center for Child and Human Development launched DATA MATTERS CORNER, an interactive online newsletter designed to enhance the center's connection and keep readers up to date on the latest in the field of children's mental health. Tied to the National Technical Assistance Center's teleconference call series, Data Matters highlights a different topic each month by profiling articles, asking probing questions and drawing attention to helpful resources.

This month the featured articles were written expressly for Data Matters by the Washington State Mental Health Transformation Evaluation Team. Featured articles highlight Washington's innovative efforts to partner with consumers, family members and youth in the evaluation process, to cultivate family leaders, to improve the lives of children and families, and to promote mental health transformation; they are excellent resources for other states who wish to engage in true consumer-led evaluations and partnerships. Go to <http://gucchd.georgetown.net/data/> to check out this wonderful new online resource.

## ☑ The 2007 KIDS COUNT Data Book is Now Available

The Annie E. Casey Foundation has announced the release of the 18th annual KIDS COUNT Data Book. Readers can peruse state-by-state rankings, supplemental data, and an essay, Lifelong Family Connections: Supporting Permanence for Children in Foster Care.

KIDS COUNT is updated every year using ten benchmark indicators that help illustrate how states have advanced or regressed over time. Nationally, the data present a complex picture of American children. In this year's KIDS COUNT, six of the ten indicators of child well-being show conditions have improved since 2000, while child well-being has worsened on four indicators.

The change in child well-being is particularly clear when comparing changes in the rate of child poverty since the mid-1990s. Between 1994 and 2000, the child poverty rate fell by 30%-the largest decrease in child poverty since the 1960s. Since 2000, the child poverty rate has increased by two percentage points, meaning almost 1.2 million more children lived in poverty in 2005 than in 2000.

The entire KIDS COUNT Data Book is available online, along with a national fact sheet and press materials, at <http://www.kidscount.org/sld/databook.jsp>. For state-specific fact sheets, some with accompanying press releases, go to <http://www.kidscount.org/sld/2007press.jsp>