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Lame Duck Session Helps Families of Children and Youth with Special Health Care Needs

By Janis Connallon, Family Voices staff



After mid-term elections and before the new Congress begins in January, the existing Congress usually has some last-minute work to finish before adjourning. This is referred to as a “lame duck” Congress. Often, few pieces of significant legislation pass during this time. However, this most recent lame duck was very significant for families of children and youth with special health care needs!

Congress passed two very important bills:

Lifespan Respite Care Bill: This newly-passed (assuming it is signed by the President) legislation will provide \$30 million in grants to states and local-level entities to improve respite care. Over the next five years, \$300 million will be available for this purpose. Additionally, the bill allows for a more coordinated effort at the state and federal levels to ensure access to quality respite care. Family Voices will be closely involved as this new program is implemented. Please watch Friday’s Child in the coming months for more information.

SCHIP Budget Shortfall Fix: The State Children’s Health Insurance Program (SCHIP) faced a funding problem. Due to the implementation of the SCHIP legislation more than \$900 million in unspent SCHIP dollars was scheduled to become unavailable to the program. This might have caused significant numbers of children and youth covered by SCHIP to lose access to health care services. However, during the lame duck session, Congress fixed the problem and much of the funding has been restored!

Legislation such as this does not get passed without untold hours spent by advocates and families working very hard! Thank you for sharing your gifts and using your voice throughout the year to accomplish important things for families of children and youth with special health care needs!.

New Family Voices Reports Available!

by Peggy Curran, Family Voices Staff

Family Voices is pleased to announce that two new reports are now available: Families in Program and Policy FiPPs MCH Report and Families in Program and Policy FiPPs CSHCN Report.



These reports summarize interviews conducted by parent leaders with state Title V MCH and CSHCN Directors/Staff, regarding participation of families in their program and policy activities. Such activities include advisory committees, addressing state performance measures, special initiatives, the Block Grant process, in-service trainings, and families employed as program staff. These reports provide extensive quantitative and qualitative information on the progress of family leader participation in Title V. Hardcopies of these reports (\$3.00/ea) may be ordered through the [Family Voices Online Catalog](http://www.familyvoices.org) or by calling the Family Voices National Office at (505) 872-4774. Copies may also be downloaded at <http://www.familyvoices.org/projects/fipps.php>.

Gift Giving Ideas !



Just in time for the New Year. . . . The 2007 Family Voices Calendar loaded with wonderful pictures, great quotes and more. To order your copy and extras to give as gifts, go to <http://www.familyvoices.org/catalog.php>.

Looking for a way to celebrate a special person? During this holiday season, please consider asking friends and family to make secure, online donations to Family Voices. Or make them yourself on behalf of another! Simply visit our website, 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, Inc.
2340 Alamo SE, Suite 102
Albuquerque, NM 87106



As a special thank you to a friend or caregiver, why not give them a Family Voices mug filled with homemade candy, cookies or flowers? You can find this and lots of additional Family Voices merchandise at the Family Voices Store at Cafe Press—

www.cafepress.com/shopfv



Making holiday gift purchases through Amazon.com? Just click on the Amazon link on the Family Voices home page. By linking to Amazon.com from Family Voices, a portion of the sales is given back to Family Voices.

Network News



We are delighted to welcome another Network member to the Family Voices family! **Ann Phillips**, a parent advocate since her son's motor vehicle accident in 2000, is a graduate of Partners in Policymaking. Ann works at the Center for Disabilities Studies (CDS) at the University of Delaware in Newark, DE on a Traumatic Brain Injury (TBI) grant. She is a facilitator for the Managed Care Parent Panel and serves on several boards and committees, including the

University of Delaware Advisory Council, Delaware Brain Injury Committee, Delaware Assistive Technology Initiative Advisory Board, the Governor's Commission on Community Based Alternatives Health Care Committee and the Delaware Caregivers Support Coalition. Ann collaborated with the University of Delaware CDS on Connecting the Dots—a guide for families with children with newly diagnosed disabilities that helps them understand how to access services and the questions that they need to ask. Ann joins Beth MacDonald and Bruce Orr in sharing information and resources with families of children and youth with special health care needs in Delaware.

Correction: In the December 1st edition of Friday's Child we reported, in error, that Sheila Donnelly was from Western PA. Sheila and her family live in Factoryville, PA, in Northeastern PA.

News You Can Use: Resources and More

Families USA Invites You to a Conference Call on SCHIP Reauthorization

A new installment of Families USA conference call series will be on Tuesday, December 19th, 2006 at 3:00 PM Eastern Time. This topic of this call will be: What is the State Children's Health Insurance Program (SCHIP) and What are its Prospects for Reauthorization?

One of the biggest items on Congress' agenda next year will be reauthorizing the State Children's Health Insurance Program (SCHIP). Don't know what that is? Heard of it, but don't really know the difference between SCHIP and chocolate chips? Do you work on enrolling kids in your state's Medicaid or SCHIP program, but don't understand what all the fuss is about in Washington? If so, then this call is for you! Leading the call will be Rachel Klein and Lena O'Rourke from Families USA, and Jocelyn Moore from the staff of Senator Jay Rockefeller (D-West Virginia). To RSVP for this conference call, go to http://ga3.org/familiesusa/events/schip_121906/register.tcl?trx_id

Estimating the Impact of State Implementation of the Family Opportunity Act

The Catalyst Center has just released a technical brief— [Methodology for Estimating the Impact of State Implementation of the Family Opportunity Act](#)—to be included when sharing first round estimates on FOA implementation with policy makers and key stakeholders in your state.

The [Catalyst Center](#) is a national center funded by the Maternal Child Health Bureau to help the Bureau achieve measurable progress towards the national goals related to children and youth with special health care needs (CYSHCN) by ensuring that all families of CYSHCN have access to adequate public and/or private insurance to pay for the services they need. Visit their [website](#) to learn more. Look for their FAQ on FOA to be posted there soon!

Online Survey about Health and Wellness for CSHCN



The Family Voices and Tufts University research team invite you to complete an anonymous online survey about Health and Wellness for Children with Special Health Care Needs. The team is looking for as many responses as possible from families who have children, 6 - 18 years old, with special health care needs (this includes special mental health/behavioral/emotional needs). Please go to <http://go.tufts.edu/familymatters> to access the survey.

SAVE THE DATE!



Family Voices 15th Anniversary Gala and National Conference May 23-36, 2006 Washington, D.C.

Join Family Voices in our nation's capital for a celebration of 15 years of family/professional partnerships and accomplishments! Meet with veteran and emerging family and youth leaders and national and state partners from across the country. Gain new understanding of current critical issues! Working together as families, partners, and communities, we can move forward the agenda of health care and build a better future for our children.

FEATURED EVENTS:

- May 23, 2007: Leadership Institute, a 1-day training at the Grand Hyatt (registration limited)
- May 23, 2007: 15th Anniversary Gala Celebration, an evening of celebration at Decatur House
- May 24-26, 2007: National Conference, 2 1/2 days of keynote sessions, workshops, networking opportunities, and more at the Grand Hyatt

Watch for more information and online registration at <http://www.familyvoices.org>.

News You Can Use: Resources and More, *continued*

EMSC Launches New Website

The Emergency Medical Services for Children (EMSC) Program is pleased to announce the launch of its new website located at: <http://mchb.hrsa.gov/emsc>.

Special features of the new site include: (1) a toolbox highlighting information about specific topics, such as pediatric pain management, pediatric disaster preparedness, and pre-hospital education; (2) up-to-date EMSC News items; and (3) a navigation bar providing quick links to helpful information, such as state activities, funding opportunities, and EMSC products and resources.

Take time today to visit the new website and to see all the information now available to support grantees, health professionals, and families regarding pediatric emergency care issues. Please note that the old EMSC website (www.ems-c.org) no longer exists. All individuals linking to the old address will be automatically transferred to the new site.

SAMHSA Unveils National Mental Health Anti-Stigma Campaign

The Catalyst Center has just released a technical brief— The Substance Abuse and Mental Health Services Administration (SAMHSA), in partnership with the Advertising Council, launched a national awareness public service advertising (PSA) campaign designed to decrease the negative attitudes that surround mental illness and encourage young adults to support their friends who are living with mental health problems.

The PSAs, which are being distributed to media outlets nationwide, include radio, television, and print. Interactive advertising directs audiences to visit a new comprehensive website, <http://www.whatadifference.samhsa.gov>, to learn more about mental health and what they can do to play a role in their friend's recovery.

To support the campaign, SAMHSA recently released "Developing a Stigma Reduction Initiative," a resource guide that provides information on how to mount a statewide anti-stigma campaign, examples of outreach materials, reports on the best practices for stigma reduction, and a resource list for technical assistance. A copy of the guide can be obtained by going to: <http://mentalhealth.samhsa.gov/publications/allpubs/sma06-4176/> and clicking on PDF version.

Improving the Health of Immigrant and Refugee Communities Grant

The Robert Wood Johnson Foundation has just posted a call for proposals related to Vulnerable Populations—Fresh Ideas: Improving the Health of Immigrant and Refugee Communities. The application deadline is January 15, 2007.

This initiative aims to give immigrants and refugees the tools and support they need to improve and maintain their own health. Today, more than 30 million immigrants and refugees live in the United States. They often have high rates of chronic health problems, due at least in part to difficulties they have getting appropriate social and health services. Language barriers, lack of education and cultural differences sometimes make it harder for immigrants and refugees to obtain culturally appropriate services, outreach or other information that could help them live healthier lives. The Vulnerable Populations Portfolio is interested in new community-based approaches to health and health care problems faced by immigrants and refugees. <http://www.rwjf.org/applications/solicited/cfp.jsp?ID=19480&c=EMC-FA144>.

Due to the holidays, the next edition of Friday's Child will be available January 5, 2007.

From us to you —
Happy Holidays!

News You Can Use: Resources and More, *continued*

☑ ADA Watch announces The Road To Freedom: Keeping the Promise of the Americans with Disabilities Act

Freedom, Inclusion and Opportunity. These are the core concepts grounding a disability coalition-led national campaign and RV road tour that have been years in the making.

Launching from Washington, DC, the Road To Freedom is an awareness campaign and yearlong, cross-country bus journey to expose mainstream audiences across the United States to the Americans with Disabilities Act (ADA) and the history of the disability rights movement — all while bringing needed attention to the ongoing struggle for equal access to healthcare, transportation, education, employment and more.

Tour riders will include Yoshiko Dart, Janine Bertram Kemp, Bobby Coward, Russ Holt, Jim Ward, Debbie Fletter Ward and Tom Olin, whose work will be the centerpiece of our traveling exhibit. Additionally, ADA Watch has partnered with Family Diversity Projects (www.familydiv.org) in the production of a joint exhibit. FDP produces award-winning traveling exhibits that tour communities nationally and internationally, and they are producing their first disability exhibit in partnership with ADA Watch/NCDR. info@adawatch.org

☑ Pharmacy Ancillary Labels

Pharmacy ancillary labels allow pharmacists to instruct patients how to use and/or provide information about the medication they are receiving. This pharmaceutical labeling tool has been developed by L.A. Care Health Plan Cultural and Linguistic Services in an attempt to reduce misuse of medications by non-English speaking patients. Visit their website - http://www.lacare.org/opencms/opencms/en/providers/document_search/index.html to find the tool, Pharmacy Ancillary Labels, translated into 10 languages.

If you find a path with no obstacles, it probably doesn't lead anywhere.

--Frank A. Clark

To subscribe to the e-newsletter version of Friday's Child, please send an e-mail to fridayschildnews-subscribe@yahoo.com. We invite you to share announcements of news, resources, upcoming events, and other information related to children with special health care needs. Please email us at kidshealth@familyvoices.org with the subject "Friday's Child", and we will try to include your listing in our next issue. This issue of Friday's Child and archived issues are available on the Family Voices website, <http://www.familyvoices.org/pub/fc/index.php>. Please forward this website to those you would like to share Friday's Child with, or they can subscribe to fridayschildnews-subscribe@yahoo.com.

Karen Anzola, Editor and Peggy Curran, Layout