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Bringing A New Dimension To Policy Advisement: Leolinda Parlin



Meet Leolinda Parlin, a woman of many “hats,” many talents, and a proven track record of getting things done. Leolinda is the State Coordinator for Family Voices of Hawaii, the Project Director of the Hilopaa F2FHIC, and is a Parent Faculty for the Department of Pediatrics at the John A. Burns School of Medicine, in Honolulu. While her titles are impressive, it is the work that she does that is really exciting. Leo is an active family representative on the Medicaid Waiver Policy Advisory Council, and the Utilization Review

Committee, charged with ensuring that individuals with developmental disorders and mental retardation have access to the resources they need. Because Medicaid Waivers are discretionary and not entitlement programs, the state has the responsibility of customizing support services on a case-by-case basis. Leo helped create new guidelines for children under the age of two.

Becoming Family-Centered in a Client-Centered System

In her work on the Utilization Review Committee, Leo brings the real-life family perspective to discussions. She looks at how the recommendations—which might look good on paper—actually fit into the life of a family needing the services. Until the change in guidelines for children under two, most of the cases were adults, not small children, so there were many resources that F2F representatives like Leo knew about that were unfamiliar to Medicaid case managers.

F2F representatives are also able to talk candidly with case managers about what it is like day in, day out, and at night with a child with complex medical needs. “That insight is so important,” says Leo. Leo and the other F2F members help the Committee see the whole picture of life in a family’s home, beyond the details of each individual child.

Who Better to Be the Ombudsman?

Another project with Medicaid that Leo is working on deals with the process of converting 40,000 remaining individuals in fee-for-service Medicaid to managed care. Thanks to the efforts of Leo and her staff, the F2FHIC will become the ombudsmen for the system, taking phone calls, advising individuals of their rights, helping people find the services they need.

When the new program was ready for roll-out, the Medicaid Agency planned to send out a letter to each family. Leo helped the professionals to see how impersonal this would be and suggested instead that they hold a family meeting so that F2F staff could “answer (questions) in a family way to explain how the new guidelines would affect them.” This helped create a partnership between the families and the professionals. Although the professionals were not used to working in this manner, they quickly realized its value and are more likely to have this kind of open meeting in the future.

To subscribe to the e-newsletter version of Friday's Child, please send an e-mail to fridayschildnews-subscribe@yahoogroups.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/fo/index.php>. Please forward this website to those you would like to share Friday's Child with, or they can subscribe to fridayschildnewssubscribe@yahoogroups.com.



Highlights from Family Voices

Family Voices GALA - February 23, 2009- Celebrates Families



The theme of the Family Voices' Gala is One Heart, Many Voices: Celebrating Families. As such, many creative ideas about celebrating our families have arisen from our Family Voices family! We wish to share these ideas with you and invite your participation.

- **FAMILY & FRIEND DEDICATIONS** (\$50 MINIMUM) - Send in a photo of a loved one and one-line message to be included in a special section of the Gala Program Book.
- **TABLE SPONSORSHIP - ADVERTISEMENT PURCHASE** (ADS FROM \$175 - \$1,000; TABLES are \$2,500 FOR 10 SEATS) - The table can be named after your family or loved one, and the ad can carry any message you'd like.
- **CREATE A "FRIENDS OF" GROUP** (ANY AMOUNT): Ask family and friends to donate to Family Voices in honor of your loved one.

Contact Rachel Rodriguez (888) 835-5669 or visit our website, <http://www.familyvoices.org/2009galasponsorship.php> to learn more.

Make your plans to attend the Gala! Tickets are available on the Family Voices website:

- \$300 per individual
- \$150 discounted price for Family Voices and AMCHP members
- \$2,500 per table (seating of 10)

Not Finger-Pointing, But Problem-Solving

Obviously, Leo's ability to have this kind of influence and impact didn't happen overnight. It took years of building a working relationship. "We offered to assist in things to help the process along. We shared the burden and the work—we weren't just criticizing, we were willing to do the heavy lifting." She adds, "We are at the table willing to work. We're not finger-pointing, we're problem-solving. We just jump in and say we will help out in the trenches. It builds camaraderie."

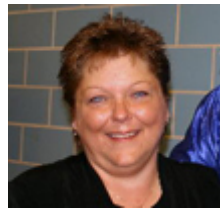
Hawaii is a little unusual in that the population is smaller than other states, but the principles of making this kind of partnership work are the same. Nurture the relationship—and don't be afraid of a little hard work!

Learn more about the Hilopa'a F2F HIC at <http://hilopaa.org/default.aspx>.



Thank you, Leolinda, for all your efforts!

♥ Donene Feist: A Hand to Hang On To



The Congratulations to Donene Feist, Family Voices of North Dakota (the F2F HIC in ND- <http://www.fvnd.org/>), for being one of 10 recipients of this year's Robert Wood Johnson Foundation Community Health Leader Award. Chosen from more than 800 nominations, Donene's work with families with special needs in North Dakota has been honored—and rewarded with \$125,000! Donene works tirelessly to ensure access to services for more than 20,000 North Dakotan children with special needs, many of whom are in

families living below the federal poverty level. In a large state with a relatively sparse population, access to services often means traveling long distances—and extra costs. Donene is delighted to have won the award and will put the money to good use, saying that the families are "not looking for a hand out, they are looking for a hand to hold on to, to keep from drowning in this complex system." Read the RWJ press release at http://www.communityhealthleaders.org/news_features/pr/43938 or view the video at <http://www.rwjf.org/newsroom/product.jsp?id=36028>.

Way to go, Donene!

♥ Just Released! Family-Centered Care Self-Assessment Tools

The newly-published Family-Centered Care Self-Assessment Tools from Family Voices are designed as an opportunity for health care practices and families to assess current areas of strength and identify areas for growth, plan future efforts, and track progress toward family-centered care. These tools include a Family Tool, a Provider Tool, and a User's Guide. The User's Guide provides a detailed set of steps to use the Family and Provider Tools. The Family Tool is designed for families, both individually and within family support and advocacy organizations, to increase awareness and knowledge of the specifics of family-centered care. The Provider Tool was created for health care settings to use in quality improvement activities and to support development of the first key component of a medical home as defined by the American Academy of Pediatrics — "provision of family-centered care through developing a trusting partnership with families, respecting their diversity, and recognizing that they are the constant in a child's life" (AAP, 2002). This tool can be used to increase family satisfaction with the care setting and to increase its standing in the community. An online feedback survey will soon be available to give input to help us to continue to improve these tools. These tools may be downloaded from the Family Voices website — <http://www.familyvoices.org>.



Family Voices 2009 Calendar



This delightful 12-month calendar features heartwarming photographs of members and friends of the Family Voices family, inspirational quotes, and space to keep track of your important dates. Please visit our online catalog -

<http://www.familyvoices.org/catalog.php> to order your copies today!

Save The Date: Family Voices National Conference

The Family Voices National Conference is slated for May 3-5, 2009 at the Marriott Wardman Park Hotel in a Washington, DC. The National Conference will open with a reception on Sunday evening, followed by a full day of activities on Monday. The conference will end on Tuesday at noon. KASA, Family Voices Board, Regional Coordinators and Regions, etc. are discussing pre-conference meetings and F2FHICs and D-70 Integrated Services grantees will add meeting time following the conference. For volunteer opportunities and more information regarding the conference, please contact Family Voices' Executive Director, Sophie Arao-Nguyen, (888) 835-5669.

Upcoming Topical Calls on Risky Business

12/1/08: RISKY BUSINESS II will examine the symptoms of risk and vulnerability within an organization and its leaders.

12/8/08: RISKY BUSINESS III will examine organizational and leader vulnerabilities and how to prevent them from interfering with the growth and sustainability of an organization.

http://www.familyvoices.org/info/ncfpp/topical_calls.php



Public Health Policy Progress

Election year often brings with it legislative action, and this year is no exception. Several recent bills have passed that are good news for Family Voices families:

Mental Health Parity Bill: What do wind and solar power as alternative fuels and more generous health insurance coverage for mental health have in common? They are both part of new legislation passed by Congress. While the link between those items might seem curious, the news is good for individuals who have experienced higher co-pays and stricter limits on mental health coverage than is common for physical health coverage. According to Conni Wells, Chief Officer of National Programs, United Advocates for Families and Children,

"Families within the mental health movement across the nation celebrate as the historical mental health parity legislation becomes a reality. In the past, countless families have given up custody of their child, had them arrested, or lost their life savings as they struggled to access services and meet the high costs of their child's mental health services. This legislation will present a balance to the affordability of the services their child, youth or family might need. In addition, because it offers new payment and service opportunities, we anticipate an increase in the number of providers and promoting research on better ways to treat the mental health needs of children and youth. Good news for all of us!"

Federal Foster Care Assistance: In what the Child Welfare League of America calls "major steps forward," a new bill signed by President Bush has made federal foster care assistance available to kinship and relative caregivers. Eligibility for the federal adoption assistance over time will no longer be tied to the old Aid to Families with Dependent Children (AFDC) program. Kinship care for foster children can mean stability in a challenging situation, and the break with AFDC makes all special needs adoptions eligible for federal assistance. The net effect will be more adoptions and greater support for the children and families.

Americans with Disabilities Amendments Restoration Act of 2008: In the midst of the financial crises that have gripped the country this fall, President Bush signed the ADA Act into law. Over the last two decades, narrow court decisions have restricted the original intent of the 1990's Americans with Disabilities Act to protect people with disabilities in the workplace. This new Act is intended to "restore the intent and protections" of the original act. Kids as Self Advocates (KASA) Board members commented:

"I thought it was cool cause there were still some serious issues even after all these years (of it being in effect)..."

"I think it's great, I mean the fact that things like this are being passed and talked about! It's indicative of the work in creating awareness and change"

Healthy Start Reauthorization: As infant mortality rates have climbed in 32 states, and serious disparities exist in prenatal and infant child care, President Bush's recent signing of the Healthy Start Reauthorization Act of 2007 provides hope of turning these situations around. Healthy Start has an impressive track record of providing care and support for low-income families that works to reduce infant mortality rates, decrease the number of low birthweight babies, and increase access to care. Healthy Start is money well spent!

And in an effort to keep us better informed about health care policy news, starting early in 2009 the Henry J. Kaiser Family Foundation will launch its Kaiser Health News available at

<http://www.kff.org/newsroom/khn102908nr.cfm>

From Our National Partners:



www.aap.org

News From AAP

➤ Last month's Friday's Child had a link to the AAP's funding information page. As a followup, here's the link to the November Funding Announcement—

http://www.aap.org/commpeds/Monthly_Funding_Announcement.pdf

f - see if it will help you find funding for your health project! If you would like to receive these monthly announcements, email docbi@aap.org.

➤ Pediatric Heroes:

Is your pediatrician your hero? Did he or she make a difference in your life, in your community? [Tell the AAP your story.](#)



www.mchb.org

MCH: On the Path to Knowledge—Domestic Violence

➤ Have you checked out the Maternal and Child Health Library Knowledge Paths at <http://www.mchlibrary.info/KnowledgePaths/index.html>? These topic-specific resource lists are treasure troves full of helpful websites, organizations, and general information. MCH recently released the new edition of the Domestic Violence website at http://mchlibrary.info/KnowledgePaths/kp_domviolence.html

"To put the world right in order, we must first put the nation in order; to put the nation in order, we must first put the family in order; to put the family in order, we must first cultivate our personal life; we must first set our hearts right."

- Confucius



News You Can Use: Resources and More

☑ **Compassionate Allowances Initiative from the Social Security Administration**

Some people have medical conditions so severe that they obviously qualify for Social Security benefits—and the Social Security Administration has decided to make it easier for these applicants. The initial rollout of this program includes 25 rare diseases and 25 cancers, with plans to add more over time. According to SSA Commissioner Michael J. Astrue, this initiative will likely shorten the decision process from months or years to a “matter of days.” Visit the SSA website— <http://www.socialsecurity.gov/compassionateallowance> to see the list of 50 conditions.

☑ **Insuring Our Kids' Future: The Importance of Health Insurance to Utilization of Pediatric Health Services**

Not surprisingly, when children are uninsured, they are less likely to receive primary care services, including well-child visits, immunizations, and acute care encounters. This report from the Child Health and Development Institute in Connecticut examines this relationship in depth, recommending insurance for all children, as well as well-child visits free of co-pays. To read the full report, go to <http://www.chdi.org>.

☑ **HealthFinder.gov**

The US Department of Health and Human Services has released a more user-friendly version of [healthfinder.gov](http://www.healthfinder.gov). The site offers quick and easy information and tools to help people stay healthy and prevent disease. This new web site is particularly valuable for those of us working in the health promotion arena. Check out especially the Quick Guide to Healthy Living and “myhealthfinder” tools on the website at <http://www.healthfinder.gov>.

☑ **Patient-Centered Medical Home: Building Evidence and Momentum**

This new report by the Patient-Centered Primary Care Collaborative's Center for Multi-Stakeholder Demonstrations looks at pilot programs across the country—their demographics, payment models, and project evaluation. Not surprisingly, the patient-centered medical home concept leads to cost-savings and increased satisfaction—a win-win situation for everybody. Read the report at <http://www.pcpcc.net/content/pcpcc-pilot-projects>. (Note: registration is required to read the report.)

☑ **Pediatric Perspectives and Practices on Transitioning Adolescents with Special Needs to Adult Health Care**

When should health care providers begin planning the transitioning of adolescents with special health care needs to adult health care? What kind of services should be offered? Check out the new fact sheet published by the National Alliance to Advance Adolescent Health (formerly Incenter Strategies) at <http://www.incenterstrategies.org/jan07/factsheet6.pdf>.

☑ **The American Public on Health Care: The Missing Perspective**

Would it surprise you to know that the top three health care issues that matter most to the American public are cost, quality, and access? A close collaboration between Accenture, The Council for Excellence in Government, and the Institute of Medicine of the National Academies has produced the results of eight months of research in a report entitled “The American Public on Health Care: The Missing Perspective.” now available at:

<http://digital.virtualmarketingpartners.com/vmp/accenture/townhall/index.php>