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MCHB Announces Newly Funded Family-To-Family Health Information Centers

In keeping with the goal of funding Family-to-Family Health Information Centers (F2F HIC) in all 50 states by 2009, MCHB has awarded grants to 11 new states, bringing the total to 41 and counting. These newly funded F2F HICs, developed in strong partnership with Family Voices in their respective states, will begin their 3 year grants on June 1, 2008. Congratulations to the newly funded centers at:

- University of Missouri, Kansas City, MO
- Southeastern Michigan Health Association, Family Center for CYSHCN, Detroit, MI
- Parents Let's Unite for Kids, Billings, MT
- Cerebral Palsy of Colorado, Denver, CO
- The Oklahoma Family Network, Inc., Oklahoma City, OK
- University of Delaware, Newark, DE
- Virginia Commonwealth University, Richmond, VA
- University of Connecticut Health Center, Farmington, CT
- Parent Information Center (NH Coalition for Citizens with Disabilities), Concord, NH
- Washington PAVE, Tacoma, WA
- Families Together, Inc., Wichita, KS



Full funding for F2F HICs officially began with the authorization by the Family Opportunity Act (FOA) signed into law in 2006, (as a part of the Deficit Reduction Act), and is provided through HRSA Maternal and Child Health Bureau. The FOA provided an official recognition—backed by funding—that often the best resources for families of children with special health care needs come from other families who have “been there, done that.”

The path to finding quality health care and related services and supports for CYSHCN is rarely clear and well defined for a family, and often characterized by mountains of red tape. Knowing where to start is frequently a challenge. F2F HICs, staffed by knowledgeable parents, provide invaluable help to families through information, education, training, support and referral services. The Family Voices National Center for Family/Professional Partnerships (NCFPP) provides technical assistance, training, and connections among F2F HICs and with other partnering organizations. Some F2F HICs are independent family run organizations while others are part of broad based non-profit agencies or organizations with a strong commitment to children and youth with special health care needs.

For more information about NCFPP and F2F HICs, check out the Family Voices website at:

<http://www.familyvoices.org/info/ncfpp/>.

Highlighting:



Ernst & Young Parent Network

Ernst & Young, an international accounting and professional services company, is the recent recipient of an award for their parent network program, which provides outreach and support to their employees who have children with special health care needs. Family Voices worked closely with Ernst & Young to design the Parent Network. These efforts to raise awareness and address issues among employers of the needs of families of CYSHCN were undertaken as part of the *Employee Benefits Project*, initiated by Dr. Jim Perrin of Mass General Hospital for Children. Ernst & Young is very excited about their Parent Network initiative and gives a lot of credit to Family Voices. Many Family Voices Network Members participated in the early phases of this Ernst & Young initiative. It's great to see this prominent business leader recognized for their best practices for our families!

Also as part of the *Employee Benefits Project*, Family Voices worked to include questions on supports to employees (i.e., families!) of children with special health care needs in an annual survey conducted by *Working Mother Magazine*. This survey is used to rate the work environment of the Top 100 Companies. Last year one such question was included; this year, four. We hope this will encourage discussion of issues for CYSHCN to become a regular part of the conversation in workplace settings.

Learn more about the Employee Benefits Project at <http://www.familyvoices.org/projects/ebenefits.php>.



Family Leadership in the States:

♥ Family Leader Meetings . . . Making a Difference

Family leaders from around the country are “making a difference” as evidenced by the wealth of information and resources shared at 8 face-to-face Family Leader meetings bringing together family leaders from 41 states and held over the past several months in multiple locations around the country. Leaders from 5 additional states will be meeting in Texas this month. Funding was made available for these meetings by the Maternal Child Health Bureau (MCHB) through the Family Voices National Center for Family Professional Partnerships (NCFPP) along with funding from other sources. Multiple state and local partners, including staff of Title V programs, children’s hospitals, Medicaid programs, and many others participated in these meetings. Family Voices and Family-to-Family Health Information Centers (F2FHICs) planned and organized each meeting and report many benefits from these opportunities to learn from each other and from their partners. In next issue of Friday’s Child, Family Voices will share exciting findings from these meetings.



Editor's Note: We want to continue to acknowledge innovative activities of parent and youth. If you know someone who deserves special recognition for their leadership efforts, please send their stories to Melissa Vickers, Editor, Friday's Child, at Vickers@aeneas.net.

♥ Kids As Self Advocates Seeking Task Force Members



Kids As Self Advocates (KASA) is looking for disabled youth, between the ages of 12 and 18 to serve on an all-youth task force to give advice and opinions to the KASA Advisory Board and staff about what information and training youth with disabilities need. The Task Force will meet through phone conferences and work on all aspects of youth-led projects

If you or a youth you know is interested in applying for the KASA Task Force, please contact Naomi Ortiz, KASA Project Director at: ortizn@fvkasa.org or for any questions please call: (785) 273-3398. You can download the application at: <http://www.fvkasa.org>.

Application due date: June 13th, 2008.

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/tc/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.

NEWS FROM OUR PARTNERS



Congratulations to our friends and partners at the National Center for Cultural Competence, led by Director Tawara D. Goode, MA, for their recognition during National Minority Health Month-2008 by Health Power for Minorities. Other honorees included David Sather, MD, PhD, Director of the Center of Excellence on Health Disparities, Morehouse School of Medicine and the 16th US Surgeon General.



Gearing Up For Healthy People 2020

Every ten years, the US Department of Health and Human Services (HHS) maps out the health goals for the country. Plans are already underway to begin the task of identifying the topics and specific goals and objectives deemed important enough to become national priority.

This spring, HHS has been sponsoring 6 public meetings around the country to encourage people to give input on this important process. It is also possible to send in written comments as well. This is a perfect opportunity to make sure that the policy makers keep the needs of families and CYSHCN.

For more information about the process, the meetings, and to register written comments, please go to the Healthy People 2020 website:
<http://www.healthypeople.gov/hp2020/default.asp>.



News You Can Use: Resources and More

☑ Bright Futures: Family Matters-- Spring 2008 Newsletter Now Available.

The current issue of Bright Futures: Family Matters focuses on parent leadership—roles, opportunities, and avenues for training. From the opening article:

When parents speak out on behalf of their own child, the changes they request often help improve programs and services for all children. Riding the wave of a successful parent/professional partnership, or occasionally getting caught in the undertow of a failed one, may be the incentive to continue to work to change and improve services and systems. When parents take on this role, they are LEADERS!

Read more about various leadership roles parents take on—sometimes out of necessity rather than choice—as well as a listing of leadership training materials from such sources as the Johns Hopkins Bloomberg School of Public Health, the Minnesota Governor's Council on Developmental Disability, and the W. K. Kellogg Foundation. The quarterly newsletter is available on the Family Voices Bright Futures for Families website:

<http://www.brightfuturesforfamilies.org/pdf/FamilyMattersSpring2008.pdf>.

☑ Family Matters Promoting Health And Wellness For Children With Special Health Care Needs Family Booklet Now Available!

The Family Voices has published a NEW booklet designed to give practical tips to help families eat nutritiously, incorporate physical activity into daily routines, and limit screen time (TV, video games, computer). While the booklet is geared specifically for families with children with special needs, most of the tips and suggestions are applicable to all families—including adults. Suggestions are “doable” and include lots of websites for more information.

The booklet is based on findings from a three-year research project, conducted by Family Voices in partnership with Tufts University School of Medicine, Public Health and Family Medicine, and funded by the Centers for Disease Control and Prevention. The project combined focus groups, an online survey of over 800 families, and mentoring by Mentor Parents. Recommendations for parents were based on the Bright Futures Guidelines for Health Supervision of Infants, Children, and Adolescents, the US Department of Health and Human Services Healthy People 2010 Goals, as well as ideas from nutrition specialists and families themselves.

Copies of the booklet are available for \$3 from the Family Voices National Office, 2340 Alamo SE, Suite 102, Albuquerque, NM 87106, phone 505-872-4774 or toll free at 1-888-835-5669.



"We all should know that diversity makes for a rich tapestry, and we must understand that all the threads of the tapestry are equal in value no matter what their color."

-- Maya Angelou

NETWORK NEWS

**Diana Autin (NJ),
featured panel participant**



Diana Autin, Executive Co-Director of Statewide Parent Advocacy Network (SPAN) of NJ and Family Voices Board and Network Member has been invited to participate in an upcoming event sponsored by the Eagleton Institute of Politics at Rutgers University. This community forum, *State Government and Immigrant Integration: Goals, Models and Programs*, will bring together directors of state immigrant/refugee service bureaus and experts on immigrant integration to consider state government responses to changing demographics and community needs. Diana Autin, as a member of the Board of the NJ Immigration Policy Network and a dynamic advocate for children's health, will share her expertise on families of children and youth with special health care needs from diverse cultures.

Congratulations Diana Autin!

“Families, Clinicians, and Children and Youth with Special Healthcare Needs: A Bright Future” . . . Family Voices article in April 2008 Pediatric Annals Journal

The second of a two-part issue of the Journal of Pediatric Annals, featuring the newly revised Bright Futures Guidelines for Health Supervision of Infants, Children, and Adolescents, includes an article written by Family Voices leaders Polly Arango, Betsy Anderson, and Nora Wells. The article describes the role of families in the health care of their children with special needs. Beginning with an historical perspective and a discussion of the need for ongoing well-child care for all children, it also describes the role of the family in a Bright Futures' approach that includes families as vital partners in their children's health:

Families expect their child's clinicians to be experts in their fields. We count on them to know what they are doing, to be honest about an unknown outcome, to have access to outside expertise when needed. Physicians count on families to openly share information, concerns, and skills as decisions are discussed, peer to peer, before important decisions are made. This team decision-making implies that all parties share the same information and will be honest about what they can and cannot do. It also implies that families will provide honest feedback if we are not able to follow a treatment or decide to explore further treatment options. This is true whether the mutual decision is about a therapy, a delicate surgical procedure, or an effort to serve healthy after-school snacks. (p.219)

Contact the Family Voices National Office (888) 835-5669 for a copy of the article.

Other News & Resources

CMS Presents Satellite Broadcast: “Health Implications Of Caregiving”

The Centers for Medicare and Medicaid Services (CMS) is hosting a satellite broadcast on June 25th, from 1:00-2:30pm EST, entitled “Health Implications of Caregiving.” The broadcast will include an open microphone question and answer period. It is important that caregivers of children and youth with special health care needs be included in this discussion, not just the caregivers for the elderly. For more information and to register for this event, go to <http://www.blsmeeings.net/caregivers>.

Sooner SUCCESS Family Partnership

Families sometimes express needs that reach beyond their communities. This is why the Sooner SUCCESS Family Partnership involves families at the State, Regional and Local Level. The Family level is the most critical to the program and all stops are pulled out if a family expresses a need for a service that doesn't exist within a community. Learn more about Sooner SUCCESS (State Unified Children's Comprehensive Exemplary Services for Special Needs), a program of the University of Oklahoma Child Study Center at the University of Oklahoma, at <http://devbehavpeds.ouhsc.edu/ssfp.asp>.

