



## The AMCHP Conference

The Association of Maternal and Child Health Programs (AMCHP) held its annual conference in Washington, DC last month. The theme was improving pregnancy and birth, with special plenary speeches from **Jennifer Howse** of the March of Dimes and **Marian Wright Edelman** of the Children's Defense Fund.

Over 30 family members participated in all aspects of the conference. Family Voices Network Members helped plan and carry out special aspects of the program for family members who work with state Title V Programs including **Grace Williams, Ruth Walden, Rodney Farley, Susan Colburn, Lyn Land, and Carla Sandwell** as Family Mentors. **Beth Dworetsky** was a Family Scholar.

Family Voices Network Members also participated in the first face-to-face meetings of the Family Advisory Group, the guiding body to AMCHP for increasing family involvement organizationally and in state Title V programs. **Ruth Walden** was elected to this group and will be the first family representative on the AMCHP Board of Directors, with **Susan Colburn** succeeding Ruth in this role. FV also participated in the Champions for Progress meeting of MCHB National Centers and regional breakfasts with family/professional teams from their states.

Family Voices Network Members **Juno Duenas** and **Lynn Land**, with staff members **Betsy Anderson, Barbara Popper** and **Nora Wells**, presented on various topics, including planning and using focus groups in research, Title V, Family-to-Family Health Information Centers, and the Data Resource Center's website. Additionally, **Patti Hackett** presented on transition issues.

Family Voices helped to bring a wide breadth of family participation and partnership to this important national conference!

### SPOTLIGHT

The CMS Grantees meeting was held in Baltimore from February 28 to March 2. Three Family Voices leaders presented during the panel discussions at the conference.

**Diana Autin**, FV NJ, offered the family perspective and how families help bring about systems change in her talk, "How Are the Grants Helping Consumers and How Are Consumers Helping the Grants?"

As part of "Supporting Family Caregivers," **Grace Sisco**, FV NC, shared firsthand how critical supporting family caregiving is for day-to-day living.

**Liz Hecht**, FV WI, addressed factors that have led to successful coalition building across disability and aging networks in "Facilitating Partnerships and Building Coalitions Across Aging and Disability Service Networks."

The information these colleagues shared is a snapshot of the expertise that's so evident in our Family Voices network. Thank you, **Diana, Grace and Liz** for continuing to spread the word about the value and need for family participation in systems change!

"Leaders are more powerful role models when they learn than when they teach." -**Rosabeth Moss Kantor**



## ReCap of FV Talk

This information is a summary collected from Family Voices Talk listserv

### Resources

#### Data Byte

From July through September, 2005, 32 Network Members in 30 states provided data on over 54,000 requests for assistance by phone, e-mail, mail, or in-person regarding health care issues for children and youth with special health care needs. Of these requests, 60% were made by families, and 40% were made by professionals. The category of information most frequently provided to families and professionals related to health care financing (27,555), including information about Public Health Care Financing (Medicaid, Home and Community-based Waiver, SCHIP, Title V, or SSI - 21,434); health related services in IEP/504 plans and EI (5,541); private insurance (580). During this quarter, Family Voices Network Members also reported distributing over 300,000 newsletters and nearly 84,000 printed materials (bulletins, fact sheets, brochures, etc). Family Voices network members also reported participating in a total of 2,254 meetings attended by 115,194 families and professionals.

**(NOTE: The reported data represents work supported by funds from a variety of sources including F2F HIC and other federal grants, state grants, foundation grants, fundraising and volunteer work.)**

#### CAHMI DATA RESOURCE CENTER ON CHILD AND ADOLESCENT HEALTH UPDATES

Check out these new features and aspects of the Data Resource Center interactive website that provides easy access to national data on children with special health care needs!

<http://cshcndata.org/desktopdefault.aspx?topic=gettingstarted>

<http://cshcndata.org/desktopdefault.aspx?topic=gethelp>

Step-by-step instructions on using the interactive data query, planning and conducting searches, and using data query results.

<http://cshcndata.org/desktopdefault.aspx?topic=statedatasets>

Available in either SPSS or SAS format, these cleaned and labeled datasets contain Interview results for 750 CSHCN in each state. Many new variables, key state indicators and MCHB outcomes measures are included.

<http://cshcndata.org/anonymous/Dataquery/DataQuery.aspx>

State and national data results on a variety of issues.

### News & Stories

<http://www.asbj.com/specialreports/0305SpecialReports/S1.html>

The Medicated Child. *Thanks to Barbara Popper.*

[Health Insurance Scams: How Government Is Responding and What Further Steps Are Needed](#)

[Insuring the Healthy or Insuring the Sick? The Dilemma of Regulating the Individual Health Insurance Market—Findings from a Study of Seven States](#)

Recent publications from The Commonwealth Fund.  
*Thanks to Trish Thomas.*

[HTTP://www.Kaisernetwork.org/daily\\_reports/rep\\_index.cfm?hint=3&DR\\_ID=28764](HTTP://www.Kaisernetwork.org/daily_reports/rep_index.cfm?hint=3&DR_ID=28764)

HHS Agrees To Give New York More Medicaid Funds if It Implements Changes to Program. *Thanks to Barbara Popper.*

<http://www.nihcm.org/CMHReport-FINAL.pdf>.

Paper: overview and policy considerations for advancing child and adolescent mental health. From NICHM Foundation. *Thanks to Karen Anzola.*

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