

**FAMILY-TO-FAMILY HEALTH INFORMATION CENTERS:
HELPING FAMILIES MAKE GOOD DECISIONS ON BEHALF OF THEIR
CHILDREN WITH SPECIAL HEALTH CARE NEEDS**

BACKGROUND: There are at least 12 million children in the United States who have special health care needs. Most are cared for at home by their families. Because their children have complex medical conditions and disabilities, parents must find good, objective information in order to make informed health care decisions for their children. Public and private health systems serving our vulnerable children are complicated, confusing—and keep changing! For example:

- Many children are enrolled in managed care systems which: 1. Have little experience caring for youngsters with chronic health conditions and disabilities; 2. Frequently change a child's longtime primary provider or pediatric specialist; 3. Have few financial incentives to provide quality care to our children.
- Children covered by private employee health plans find their benefits shrinking, especially for specialty services, therapy, equipment, behavioral health services, home health care, and some medications.
- Medicaid's EPSDT pediatric benefits package is important for millions of our children. However, many states ignore or barely provide important EPSDT benefits, and some states are considering ways to limit EPSDT benefits.
- SCHIP, the State Children's Health Insurance Program for uninsured children, sometimes provides coverage that is inadequate for our children's needs, often with unaffordable co-pays and deductibles.
- There is great confusion and controversy about who pays for therapy and other education-related health services in public schools and community early intervention programs.
- Thousands of poor children with serious disabilities are no longer eligible for SSI cash benefits that help their families keep them at home. Some have also lost Medicaid eligibility. Because the SSI eligibility process is so daunting, thousands of other potentially eligible children never even make it through the application phase.

QUESTIONS, INFORMATION, DECISIONS: As we look for the best, most cost-effective medical and related services for our vulnerable children, we ask many questions, especially when our child is first diagnosed, or when we move or change employers, including:

- Where can I get information to help me choose a health plan that's good for my child with special health care needs as well as the rest of my family?
- Where can I get assistance to understand which services my present health plan does and does not cover?
- Is there a way to keep my child's longtime pediatrician when my job requires that we switch insurance plans?
- Does my new HMO have a primary provider with expertise in children with complex health conditions?
- Who can help me find a way to pay for my child's expensive medications?
- Where can I find safe, affordable child care for my child, whose medical condition requires trained caretakers?
- Is there a place in town that fixes wheelchairs? Loans equipment? Makes ramps for homes?

PROBLEM: Families cannot find answers to their questions and objective, family-friendly, culturally sensitive health information to help them make good health care decisions.

SOLUTION: Family-to-Family Health Information Centers! In every state! Run by experienced parents, and supported by private and public funds. Family Voices has helped many of our volunteerNetwork members, all of them parents, develop Family-to-Family Health Information Centers around the country. To date, twenty-five Family-to-Family Health Information Centers have been funded. We accomplished this with the support of short-term grants from The Robert Wood Johnson Foundation, the federal Maternal and Child Health Bureau's Division of Services for Children with Special Health Care Needs, as well as the Center for Medicaid/Medicare Services at the federal Department of Health and Human Services. The U.S. Congress has also shown considerable interest in this problem through the pending Family Opportunity Act/FOA.

Questions? Please contact Julie Beckett (319/365-0227 or waivermom@earthlink.net) or Janis Conallon (202-537-6046 or j-rcon@starpower.net).