

## FAMILIES AS ADVOCATES

### BEING A HEALTH ADVOCATE FOR YOUR CHILD WITH SPECIAL HEALTH CARE NEEDS

*Parenting a child with special health care needs is not easy. The thousands of members of Family Voices, most of us parents of kids with disabilities or chronic conditions, want you to know you're not alone on this amazing journey. We're there, too. And we know that the sooner we parents become knowledgeable and strong advocates for our children, the smoother life becomes for our entire family. Our advocacy tips focus on health issues, because that is the mission of Family Voices. But you can use these ideas at your child's preschool, child care center, classroom, in the community, and with your extended family and neighbors. Family Voices also has materials that describe how to advocate for other children by improving public and private health systems serving youngsters with special needs. We all begin, however, with one child.*

- Believe with all your heart that your child, like all children, is wonderful - even when she or he gobbles up so much of your time and energy. Tell all the world about this precious gift! Remember, though, that your child with special health care needs is not the heart of your family, but a **part** of your family, sage advice from veteran mom, Florene Poyadue.

- As soon as possible, make contact with another family who also has a child with special needs. Hearing from another parent who never sleeps, feels inadequate and is also frightened about the future will change your life. We know it's not easy to talk with a stranger about your child, but it's worth it. Most communities have a parent organization, that matches experienced fathers and mothers with new parents. Some groups bring parents together around a certain diagnosis, Cerebral Palsy, for example. Parent groups give peer support free, and help you learn all about this new world.

- Find out everything you can about your child's diagnosis from your pediatrician, early intervention program, parent group, local library, state program for children with special health care needs. Surf the Internet, where every imaginable diagnosis has a website full of information and resources. If you lack a computer or don't know how to surf, ask for help. Every community now has a location with free internet access. Family Voices has a list of Internet addresses.

- Learn about the hospitals, pediatric specialists, therapy centers, equipment banks, early childhood programs, and state and private agencies that your child will use. Ask other parents for advice about where to get the best care.

- Keep records and take notes of all phone calls, doctor visits, insurance bills, Medicaid notices, and forms related to your child. Request copies of

everything. Put this paperwork in one place - a box in the kitchen, a notebook, a bedroom drawer.

- Become an expert on your child's health insurance plan, whether it's through your employer or Medicaid, especially the benefits paid for by the plan. Make sure you ask lots of questions about how your health insurance works, and about any special seminars that might help your child.

- Insist that all your child's providers, from pediatricians to social workers, practice **family-centered care**, which acknowledges and supports families as they raise their children in their homes and communities.

- Develop strong partnerships with health and other professionals in your child's life, so that you can work together and use the expertise and skills each of you brings to the care of your youngster. It's especially helpful to have one professional who knows you, your family, and your child very well, and who will advocate with you as a partner.

- Know that **YOU** are your child's best advocate. No one else will do the job as well. Use all the information, contacts, friends and skills you have gathered to practice your advocacy firmly, but with kindness and humor. As your child grows up, teach her or him to be an advocate, or prepare a sibling or friend to do so. Because you won't be around forever. In the meantime, it's wise to take care of yourself.

- Ask Family Voices for help. Call us toll free (1-888-835-5669) or visit [www.familyvoices.org](http://www.familyvoices.org) to find brochures, books, and websites about linking parents, family-centered care, family-professional partnerships, fathers' networks, information in languages other than English, support groups, and more.

**NOW, GO FORTH AND ADVOCATE!!!**