



YOU ARE AN ADVOCATE FOR YOUR CHILD WITH SPECIAL HEALTH CARE NEEDS!

Parenting a child with special health care needs is not easy. The 40,000 members of Family Voices, most of us parents, want you to know you're not alone on this challenging journey. We're there with you! And we've learned that the sooner we become advocates — informed strong voices for our children— the smoother life becomes for our child and family. The following advocacy tips, based on years of experience from hundreds of families, focus on health, which is the mission of Family Voices. You can use these tips with your child's doctor, hospital, clinic, therapists, preschool, child care center, classroom, community, and with extended family and neighbors. Always begin, of course, with one child...yours.

1. 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 the entire world about this precious gift!
2. As soon as possible, connect with another family who also has a child with special needs. Talking with a parent who also never sleeps, feels inadequate, and is frightened will change your life. Meet the parent sitting next to you at a clinic or school meeting. Most communities have a parent organization, usually listed in the phone book that brings experienced fathers and mothers together with new parents. They'll be your best teachers in helping you navigate this new, strange world.
3. Learn everything you can about your child's diagnosis — from your pediatrician, early interventionist, therapist, or other parents. Look up the diagnosis on the Internet. If you lack a computer or can't use one, ask another parent, a teacher, or a teenager for help. In every community there is a place, perhaps a library, with free Internet access. Find out about services for your child — special clinics, pediatric specialists, therapies, equipment, early childhood programs, and state and private agencies. Inquire about financial eligibility, free services, and, most important, where to get the best care.
4. Keep records. Of all phone calls, doctor visits, insurance bills, notices, and forms related to your child. Always take notes, including date and person you spoke with. If you're not a good note taker, bring a friend who is, or use a tape-recorder. Request copies of everything. Put this paperwork in one place — a box in the kitchen, a notebook, and a bedroom drawer.
5. Become an expert on your child's health insurance plan, whether private or Medicaid. Know the benefits covered. Read everything from your insurance company, managed care plan, or Medicaid.
6. Develop strong partnerships with the professionals in your child's life. Your expertise about your child will help your child's professionals practice family-centered care. Find one professional who knows you, your family, and your child very well, and who will advocate with you as a partner.
7. Know that YOU are your child's best advocate. No one else can do the job as well. Use all your information, contacts, friends and skills to advocate with kindness and humor. Teach your child to be an advocate, or prepare a sibling or friend to do so, because you won't be around forever. And please take care of YOU, so that YOU stay healthy.
8. Then, help another family. Learn to be a parent-to-parent supporter. Ask a parent group how you can be involved. Work with other families and professionals to improve care for all our children.
9. Look to Family Voices for assistance. Visit our website, www.familyvoices.org, or call us toll free, 1-888-835-5669, for brochures, books, websites, diagnoses, legislation, state parent groups, information in languages other than English, and training conferences.

NOW, GO FORTH AND ADVOCATE!