

FINDING HELP

Check out the Resources Section (IV). When asked, these are some of the things parents said were helpful to them (special thanks to Michael Schwartz, Michelle Westmaas, Bonnie Haggerty, Lisa Weir, and Jeanne McMullen for their input)

Other Parents:

Finding/getting help from *other parents* has been the most beneficial to us if for no other reason than knowing we are not alone in our struggle. *A good way to contact other parents is through the CHARGE listserv. See the website www.chargesyndrome.org for a link to the list. Going to the biennial conferences is another good way to network with parents.* Ask the nurses or doctors if they know of another family you can contact.

Early Intervention:

Try to find early intervention from birth. Our hospital identified Patty from the PICU and they came to the house once a week from the time she was sent home. *Ask the **hospital social workers** about early intervention or Birth to Three program referrals.*

Parent to Parent:

Parent to Parent is a wonderful organization that provides parents with assistance in areas that only a parent of a special needs child can know about. They have coordinators who can match up parents with other parents with similar struggles. These parents can provide assistance with educational battles, insurance battles, emotional support, and much more. They have a national 800# as well as regional chapters throughout the country.

Educational consultants and Case Managers

Identify educational consultants and case managers as early as possible. *Again, hospital social workers may help. Also try calling your local school district special services program.*

Community Agencies:

Finding community agencies. Look through your phone book blue pages page for page under "Human Services," paying particular attention to the headings like "Services for the Disabled." Your local Easter Seals, ARC, and Parent to Parent Chapter can also steer you to your providers of early intervention resources. Request any pamphlets any organizations you speak with have. Often they have pamphlets that can steer you towards other services such as respite or legal aid.

Danny has been getting services through the school district, Easter Seals, the Regional Center (for developmentally disabled persons) and California Children's Services. *All states have similar programs, including DeafBlind services.*

Ask Lots of Questions:

Ask questions and follow up on programs, even those that don't sound like they would help (at first). For example, several people at the hospital told us to register with California Children's Services, and one doctor even referred us there. I didn't think we would qualify because of our income, but I made an appointment anyway. Sure enough, we make too much money for their main program (which would have been of little interest to me anyway since we have health insurance). But on the way out, the eligibility worker said, "the only thing you would qualify for is occupational therapy and physical therapy." When I got home, I started to think that that "only thing" could be a very helpful thing. I called back (it took a few calls on my part) and got Danny in a therapy program that has been a big help.

Ask about other services:

Ask each agency if they have any other programs, do they provide, e.g., speech therapy, respite care, etc., or do they know some agency that would. Some of these agencies are worried about their budgets and don't volunteer info unless you ask. Some will even lie or say know if you don't ask exactly right, so it helps to ask around a bit.

DeafBlind services:

Every state has DeafBlind services. You can find out more from DBLink and NTAC (see at Resources)

Special Education services:

In most states, special education services start at birth or age three – long before “school age.” One place to start is to get a copy of the federal IDEA law and your state's special education regulations. The state document should be free at your request from the State Board of Education. I read several books on IEP law, parents' rights, how to advocate, etc, but I can't recall any titles. I searched on Amazon.com and Barnes & Noble.com then took the titles I found to the local library. They got them for me through the inter-library loan system (we're in a small rural community). Another source I used for access to reading material was my local special ed and early intervention offices and our state spec ed library clearinghouse.

Request your first case study and IEP meeting as soon as possible. Plan to discuss the team's findings and ideas and then adjourn. Take time to mull it all over, research some more, and reconvene when you are armed with all the info you need to get what your child needs. This strategy worked well for me, but that's because it fits my personality.

Parent Training:

I learned a lot from reading but also found parent trainings to be essential. Find out who would sponsor these trainings in your area. If you can get on the right mailing list, you will be aware of advocacy trainings, parent retreats, etc. I met many professionals who have served as wonderful sources of information by networking at various trainings.

Go to advocacy workshops to learn and network. Contact Parent to Parent and go to their social functions. You'll learn through your contacts the people and agencies who are particularly helpful for their families and who do not

Press the professionals for as much information as you can. Social workers are often overworked and will often dedicate their limited time to the families that they deem "most needy" so you really need to effectively communicate exactly what your needs are and keep on them for answers.

Other Financial help:

The things most helpful have been Family Support Services (FSS) funds which in some form are in every state. These funds can defray respite costs and assistive technology costs. The FSS case manager can be instrumental in helping us obtain emergency respite care. *Ask the hospital or other social workers about these programs.*

Other helpful things:

The Massachusetts loophole (nationally known as the Katie Beckett Waiver) and the Health Insurance Premium Plan (HIPP) program. Through HIPP, the state of Pennsylvania pays the private health care premiums of KB waiver recipients when private healthcare is available through the parent's employer at less cost than the waiver (saving us much \$\$\$).