



# Things to Think About!



By Brandan Atkin

## Finding Services and Support Systems

By Linda Jorgensen

Last week I received an email from a Mother requesting some assistance. Her child was recently diagnosed with an unusual disorder and while she was given plenty of information regarding her child's physical condition she was also told she would need to obtain "extra help and support". However, no one told her what that was. She relates, "I have a fist full of hand outs that don't make too much sense and felt like I was given a pat on the head and told to go find what I need. I still don't quite understand my child's diagnosis and have no idea what 'extra' help or support I'm supposed to ask for. Do you know? "

### Quick Guide to Finding Help.

1. Contact doctors, school district representatives, and other local contacts to find a support group.
2. Talk to parents who share the same questions and concerns as you do.
3. Use the internet, libraries, and physicians to research your child's disability. Learn all you can.

Be sure to check out the state and federal links under Medical Information/Research Organizations on the SNRP webpage.

If there is anything that is not discussed in our newsletters and you would like to see it discussed, or you would like to be added to our newsletter mailing list, please contact us at [snrproject@hotmail.com](mailto:snrproject@hotmail.com)

I must admit my first response was to chuckle. Sometimes I wonder what some physicians are thinking. Give a diagnosis, hand the parent a bunch of information with instructions to be sure to change the oil every 6 months or 50,000 miles, whichever comes first. Everything should be covered in the handouts. Sounds simple, doesn't it? Unfortunately it isn't.

Before we collectively throw our hands in the air in total surrender let me say this. The most important factor in finding the information you need is to first understand your child's diagnosis. This is literally a "find what works best for you" situation. If you don't know what to expect you won't know what to ask for.

### Educate Yourself About Your Child's Disability

If you're like the mother noted above you've been given some basic information to start with. Grab a notebook, something to write with and find yourself a quiet corner to read the information your physician has handed you. As you read be sure to jot down questions you may have.

If needed, schedule another appointment with your physician. The best strategy I recommend is, ASK QUESTIONS! If you are not sure you understand what your physician is telling you, ask them to repeat it or explain it in such a fashion you can understand. And don't limit your question asking to just your family physician or pediatrician.

There are many places you can go to get good, quality information. Most University Hospitals or Medical Centers have medical libraries attached to their facilities. Go to the information desk in the lobby and find out from the clerk where the medical library is. Most have professional

librarians to assist individuals who are looking for information. Parents should be able to locate references regarding any of the medical diseases, procedures, diagnoses, etc. that might be seen in that facility.

Online information sources can be found in the SNRP Resource Links, National Resources under **Medical Information/Research Organizations**. Check your state Resource links for local information sources as well.

Once you have educated yourself about your child's specific needs you are in a better position to find what you need in your community.

## Parent Support Groups

Parents of children with special needs are a unique group of people. Sure there are differences, not everyone has a child with the same diagnosis for one thing. But there are commonalities too. We all face varied medical problems, behavioral issues, financial strains, insurance tangles, communication problems, relationship issues, shall I keep going?

Given all those commonalities other parents can also be your best source of information. Once you've done your homework regarding your child's diagnosis, what to expect and treatments needed, your next course of action is to find out about services and programs in local schools and in your community. Your best resource? Other parents. Have questions about Early Intervention programs? Find a parent who uses one. Need information about your local school district? Find a parent who has a child attending that school. In short, join a Parent Support Group.

It may take a few phone calls before you locate a group but there are several places to call. If you need help locating a parent group try the following offices:

- Your pediatrician's office. **Before you leave your Physicians office request a recommendation for community Early Intervention Programs, Therapies, local programs and Parent Support Groups, etc.** Many physicians will have contact information at the front desk. Be sure to ASK!
- Special Education Coordinators at your local School District Main Office

- State Department of Services For People With Disabilities regional offices
- Parent Education staff or the staff Licensed Clinical Social Worker (LCSW) at your local children's hospital

Use online or local support groups to gain information quickly. Talk to other parents while you all sit together in the waiting room or attend programs at school. I've picked up more useful information about local programs and agencies that way. Keep a pencil and a small pad of paper in a purse, pocket, backpack, etc. for jotting down notes and contact information.

## Find Local Programs and Agencies

While SNRP provides basic Resource Links for every state, there is no one place to find every government or private support program in every community. We do our best to start parents off in the right direction but it is important for each parent to find a support group, build a rapport with your Physician and ASK questions. You'll be glad you did.



"A pocket full of marbles to replace the ones you're sure to lose"