



Utah Parent Center
Special needs, extraordinary potential

Information Sheet

Working with Professionals

Over 20 years ago, parent Cory Moore, speaking directly to professionals, wrote: *"We need respect; we need to have our contribution valued. We need to participate, not merely be involved. It is, after all, the parent who knew the child first and who knows the child best. Our relationship with our sons and daughters is personal and spans a lifetime."*

This sentiment echoes throughout the parent literature and in the hearts of parents everywhere. Not surprisingly, many of the materials written by parents for other parents offer insight into how you might work together with professionals for the benefit of your child and family. The best relationships are characterized by mutual respect, trust, and openness, where both you and the professional exchange information and ideas about the best care, medical intervention, or educational program for your child. Both you and the professional need to speak clearly and openly about issues facing your child and listen carefully. Indeed, both of you have important expertise to share.

You, for example, have intimate knowledge of your child with special needs. You live with and observe your son or daughter on a daily basis and can contribute invaluable information about his or her routine, development, history, strengths, needs, and so on.

The professional, too, has specialized knowledge to contribute—that of his or her discipline. Often you must rely upon the professional's judgment in matters that are critical to the well-being of your child.

Thus, there should be mutuality in the parent/professional relationship. This can take time to develop and may require effort from both parties. To that end, many parent writers suggest:

- If you are looking for a specialist with whom you can work well, ask other parents of children with disabilities. Often, they can recommend a good speech or physical therapist, doctor, dentist, or surgeon.
- If you don't understand the terminology a professional uses, ask questions. Say, "What do you mean by that? We don't understand."
- If necessary, write down the professional's answers. This is particularly useful in medical situations when a medication or therapy is to be administered.
- Learn as much as you can about your child's disability. This will assist you with your child, and it can help you participate most fully in the team process.
- Prepare for visits to the doctor, therapist, or school by writing down a list of the questions or concerns you would like to discuss with the professional.

Utah Parent Center

230 West 200 South
Suite 1101
Salt Lake City, UT 84101
801.272.1051
1.800.468.1160
info@utahparentcenter.org
www.utahparentcenter.org

- Keep a notebook in which you write down information concerning your special needs child. This can include your child's medical history, test results, observations about behavior or symptoms that will help the professional do his or her job, and so on. (A loose-leaf notebook is easy to maintain and add information to.)
- If you don't agree with a professional's recommendations, say so. Be as specific as you can about why you don't agree.
- Do whatever informed "shopping around" is necessary to find a doctor who understands your child's needs, is willing to work collaboratively with other medical professionals, and with whom you feel comfortable.
- Measure a professional's recommendations for home treatment programs or other interventions against your own schedule, finances, and other commitments.

You may not be able to follow all advice or take on one more thing, feeling as Helen Featherstone did when she wrote, *"What am I supposed to give up?...There is no time in my life that hasn't been spoken for, and for every fifteen-minute activity that has been added, one has to be taken away."* Peggy Finston points out that *"most professionals won't be familiar with the sum total of our obligations and will not take it upon themselves to give us permission to quit. This is up to us. It's in our power to make the decision."*

In conclusion, it is important that the parent/professional relationship empower the parent to be a full participant in information-gathering, information-sharing, and in decision-making. However, it is ultimately up to you to decide what role(s) you want to take in this process and what role(s) you need help with.

It is helpful to know that families do, indeed, choose different roles in relationship to professionals. Some parents want to allow professionals to make most decisions about their child, others want to serve as an informant to the professional, some want veto power, and some parents want a shared role in the intervention with their child.

You are also free to change your mind about the role or level of involvement you may want or be able to assume regarding your child's services. You may find that you choose different roles at different times for different purposes. Be as direct as possible about what you want or don't want to take on in this regard.

Adapted from "[The Unplanned Journey](#)," a NICHD legacy resource at the Center for Parent Information and Resources