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ABSTRACT

This brief guide for parents of children with disabilities offers tips on being the child's advocate. Parents are first urged to believe in their child, believe in their own intuition, and educate themselves. They are also encouraged to: (1) document events and encounters including both objective facts and subjective response, (2) document and negotiate effective telephone calls, (3) support telephone calls with effective letters, (4) attend and advocate for the child in meetings, (5) utilize legal representation or alternate dispute resolution means when necessary, and (6) use anecdotes to illustrate major points. The guide concludes by urging parents to pick their battles and congratulate themselves for each achievement. (DB)

ADVOCACY -- TAKING CHARGE: HOW TO DO IT

by Helen Reisner and Jenifer Simpson

According to Webster's dictionary, advocacy is *active support for a cause* or *to speak in favor of* or *to defend (someone)*. For parents of children with disabilities, it is speaking up on behalf of your child to ensure his or her needs and rights are met. It is often confronting authority. Sometimes, it is simply getting out there and fighting for your child's rights. Here are some tips that will help you become your child's best advocate!

REMEMBER:

The squeaky wheel gets greased.
Information is power.
Believe in your child.
Believe and trust in your own insight and intuition.
You are the change agent. You can do it.

Believing in your child is essential. No doctor, therapist, teacher, or anyone knows your child better than you do. You have lived with your child with a disability longer and more intimately than anyone else. Only you have the long perspective. The big picture. Trust that knowledge.

Believing in your intuition is being able to trust yourself and those feelings you have. A hunch is usually a sign, follow your hunches.

Educating yourself is critical. You do not have to become a walking encyclopedia about disability law but, it is very important to learn what your child's rights are before you can fight for them. There are many sources of education and support in your state. There are advocates in your state -- at United Cerebral Palsy affiliates, the Protection and Advocacy agency and at parent training centers. They are your allies and will prepare and support you. The more skills and information you learn the better you can advocate.

OTHER TIPS:

1. <u>Documentation</u> -- Keep a notebook.
You must write down facts and keep `a paper trail.' There are two different kinds of facts. One is objective and the other is subjective.

Objective facts are the name, telephone number and title or position of the person you talk to. Don't be afraid to ask. Say "*Just a minute, please, I need your name and title. I'm writing this down.*"

Facts are listing the questions you ask and writing down the given answers. Put quotes around answers. Ask the person to repeat themselves or say "*I heard you say that you do not think Jesse can be in your day care center because he has a wheelchair. Is that what you said?*" Write it down. It is okay to say that you are writing the response into a notebook.

Advocacy con't.

If you get an answer you don't agree with, don't understand or you know is wrong, say so. Always ask for the statement to be sent to you in writing. Say, *"Please send me a copy of that in writing."* You make this request when you are talking with educators, insurance companies, Medicaid, a community agency, hospitals, landlords, restaurant owners and others.

Keep a file folder or box or drawer for the written replies and paperwork you will receive. If you have time, organize it either chronologically or by subject.

Subjective facts are your thoughts about either a person or an event that occurred. Did the person act friendly? Ignorant? Were they willing to talk with you? Were they evasive? Just jot down a couple of words or sentences to remind you what kind of conversation you had.

Remember. Keep your notes on facts and opinions in one place, either on a computer or in an organized notebook. This is a quick and easy way to make sure that your notes are not here and there, but easy to find. Over the years, you'll see why having your notes together is a time-saver. Date your notes and thoughts.

2. Phone calls -- Write the date, time, name and title, and telephone number of the person you are talking with in the notebook.

Write ahead of time the questions you will ask leaving space for the answers you get. Realize that a phone call can be forgotten -- or denied.

Try to talk to the `power' person or the person who has the critical information you want. It may take a while to get to the person who has the authority to state policy so persist in trying to reach a person of authority. Call an agency and say, "*Who is the person responsible for putting together the IEP team*?" "*May I speak with the policy expert on the Medicaid state plan?*" "*Who is it who determines the transportation schedule for school buses*?" "*Who is the expert on assistive technology funding in our school district?*"

If you don't know what an IEP is or if you don't know if your child is eligible for Medicaid, that is the call you need to make tomorrow.

When you make a call, leave pleading and begging behind. Simply say, "*Hello. This is Jane Doe calling for Mr. Sampson.*" Period. You can say, "*My son can't see very well and has cerebral palsy. What are the steps I must take to get him enrolled in an extended school year program?*" or "*How and where do I apply for Social Security for my disabled son?*" Be as direct as you can with your initial request.

You do not need to explain your story or request in detail to everyone. You don't have to give the medical terminology for your child's disability. Just keep it simple and straightforward. And keep it to the facts. It is easy to begin to explain the ins and outs of what you've been through: however, save that for your friends, family and support groups. Deal with administrators and service delivery people in a businesslike manner.

If the person is not available, simply say, "*Please ask Ms. Claims Supervisor to return my call. My number is --.*" If a message is requested, <u>and</u> you may volunteer to leave one as well, make it strong and to the point. "*I am calling about the bus picking the kids up an hour early each day*" or "*I'm calling about the teacher who called my daughter `retarded',*" or "*I'm calling about my son's application into the summer recreation program.*"

Ask when you can expect a return call. Write that down. If you don't get a return call when you should have, call back.

Call back if you don't succeed in reaching the right person the first time. Ask, "*Who should I be talking to, then?*" If they seem unhelpful or to be avoiding you, write it down. Keep a record of these referrals and if they are passing the buck, say so: "*Look, I'm getting annoyed. Mr. Blank referred me to Ms. Specialist who referred me to you and now you're referring me to Mr. Blank!*"

If you are given approval over the phone, be sure to say thank you and ask for written confirmation to be sent to you the next day. File this with your other documentation.

3. <u>Letter Writing</u> -- After the phone call, sit down and write a short letter which states that you just talked and this is what transpired on the phone. Keep it as objective as possible by stating the facts. At the top of the letter reference the subject, e.g., "**Re: Occupational Therapist Still Not Hired,**" or "**Re: Second Request For Payment of Physical Therapy Sessions.**"

To give your letter real muscle though, there's a simple technique called `cc' or `carbon copy.' This is at the very end of the letter and it's to let the recipient know that you mean business. You `cc'your letter to their boss, or the agency head that administers the program. Using two or more cc's can be useful: you can `cc' an advocacy organization such as the national UCPA office or the affiliate, or the parent training center, and your state legislators or U.S. Senator or Representative.
Don't worry about whether or not your Congressperson cares or not. They do. This is one 'cc' that will do more good in the long run than any other. The people who amend, authorize the funding or change the laws of the land need information from you. If there is no law or regulation, they can make new ones. Your voice is very important. They need *you* to keep *them* informed.

4. <u>Meetings</u> -- If a meeting is scheduled at a time you can't attend, ask for it to be postponed. Propose an alternative time.

If you know you are going to be late, call and let them know.

Be sure you know the purpose of the meeting. This will establish what your role is and will help you focus on what your child needs to have happen.

Be prepared. If you are going to change the IEP, have your suggestions in writing, preferably typed, with extra copies.

Take a moment at the start of the meeting to write down the name of everyone in the room and their title. Don't hesitate to ask "*Just a minute, how do you spell your name?*"

Advocacy con't.

Bring a tape recorder if you want to. Bring a friend or advocate for support. Introduce the person.

If you don't understand something that is happening in the meeting, or emotions flare, ask for a break. Say "*I think I need a break. I'm going into the hall for ten minutes.*" Use the time to collect your thoughts.

Avoid being in a position where you swear or will regret later words you used. Take notes during the meeting if you can.

If the meeting is `going nowhere' say so. Propose another meeting.
If substantial gain is made during the meeting, write a follow up letter clarifying what you think was decided or happened. "CC" all the attendees or others who are interested in the outcome.

5. Legal Representation Or Alternate Dispute Resolution -- You can hire a lawyer later if you need to or if you opt to utilize a formal Alternate Dispute Resolution process if it's available or offered. Your state has a Protection & Advocacy agency and your county has a legal services office.

With your documentation and knowledge of the facts and a feeling about what is going on you will save time and attorney's fees, and personal aggravation, by having your records straight. You will also know a great deal and be able to figure out if the mediator or lawyer is competent and knowledgeable about disability issues. You **cannot assume** that the Domestic Relations lawyer, that you used for your divorce, for instance, also understands how Special Education law works or that an appointed mediator, for instance, knows what a Personal Assistance Services caregiver is.

Like all professionals you will be involved with, they are paid for their expertise and services and it is **you** who hires or consults **them**. Always get several referrals first and then "interview" the professional if possible, to see if you can work with them. Again, trust your intuition and observations. You can say "*I'm shopping for an (attorney) (doctor) (dentist) who understands disability. I'll get back to you when I decide what to do.*"

6. Use of Anecdotes -- Anecdotes are stories to make a point. They are used to give examples. This is a particularly useful tool if you meet face-to-face with an elected representative or are asked to testify at a public hearing or public meeting or are writing a *Letter To The Editor* of a newspaper. People remember anecdotes. For example, if you want to complain about unresponsiveness or insensitivity of the school system to your child, you could talk about your child's IEP goals and explain how they are not being implemented. OR, you could say,

> "*My son Sean is in regular kindergarten. He can't talk. He uses sign language and a machine which talks for him when he pushes buttons. The teacher asked the children to bring in a favorite stuffed animal at story sharing time. Sean brought in his Snoopy, who he carries with him all the time. When it was his turn, the teacher wouldn't let him use his voice machine. She said it was disruptive and distracting to the other children. She has not learned his signs, so no one understood what he was doing with his hands. Sean stood in front of the class, silent. The teacher and children stared at him for a while and then she instructed him to sit down. He threw himself to the floor and had a temper tantrum.*

Advocacy con't.

The teacher told the aide to take him out of the room for "time out." She then reported that Sean was becoming a problem child in her class and asked the principal to work out a behavior modification program."

A story in short declarative sentences is easier to understand than going into a lot of detail and opinion. Find a powerful story to make your point, and use it.

Advocacy is its own reward and there will be always be something to advocate for in this imperfect world. Accept that you cannot win all the time and that many goals may take months or years to reach. Give yourself a break now and again!

Pick your battles. You'll have ample opportunity over the years to fight many, so choose them and space out your energy. And be creative -- there is no limit on the tactics parents can choose as they advocate for what it is right for their child with a disability. One parent may leaflet all the teachers' mailboxes to argue for inclusion of their child with Down syndrome into a regular education classroom and win; another parent may launch a full-scale litigation effort to win. Different circumstances require different actions and strategy on your part.

With each achievement, no matter how small, take a moment to congratulate yourself for a job well-done. Have a party with your family or friends when you finally get Medicaid to pay for the specially-adapted toilet seat, when you secure SSI for your child, or you get the `okay for payment' for extended school year over the summer. Share the gladness of the moment when your child gets on the bus with his sister to go to the neighborhood school, or your young adult daughter with disability gets a job after a year of searching.

You'll know you are an advocate when you feel like you have had to decide between being popular or being respected. In the long run, being respected will do more for your child than trying to keep everyone pleased. This might sound like we're suggesting you have to fight for everything and be combative. We are not saying exactly that. We are saying, however, that as you work to make sure your child's legal and social rights are won --because, unfortunately, they are not automatically provided or extended to your child -- you will feel and act differently. And it will be worth it!

It is your right, your responsibility and your duty to speak up and out! We thank **you** for **your** efforts! We all gain when your child gains.

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