

Advocacy!

Parent Assertiveness and Advocacy

Some parents shy away from speaking up ... because they fear they will be labelled as troublemakers. No one can make promises about labels, but when your child's welfare is at stake, whatever label you may be given needs to be relegated to the bottom of the list of important issues.

One of the greatest barriers that parents face in trying to get what their child needs is the lack of effective assertiveness. Most of us have not been taught these skills, which are simple but take a great deal of courage, support, and belief in our own control of our lives.

Often, the parents who do not eventually get good services or accommodations for their children are the ones who let the professionals decide what is right or needed, regardless of the fact that doing so has led them to the current situation they are in.

Effective assertiveness means thinking and deciding for yourself what your child needs, and making a commitment to do whatever it takes to see that they get it.

A Place to Start

1. Get all our child's records - school, medical, and psychiatric. Read them. Highlight and/or flag any pertinent information.

School

There may be several files you need to get. The main office has the regular school file. Some schools keep discipline records in a separate file. You will need to ask. If your child is in Special Education, the teacher responsible for the IEP (Individual Education Plan) keeps a separate file. Also, there will be another file at the district's Special Education office. Related "services personnel" (i.e. school psychologist) will also have records of instruction for their particular services.

Medical and Psychiatric

You have a right to these records, and the information in them is often valuable.

2. Get copies of relevant legislation and other materials that help explain them. Read the laws - spend all the time you possibly can reading them. Highlight any pertinent information related to your child's situation. Know your rights. Attend workshops to understand them and meet others who are

using them effectively. Learn to use the language in the laws. State the legal references in your letters of documentation. This helps others take you seriously instead of dismissing your requests.

3. Prepare a written plan of what you want and need for your child. Relate them to your rights under the law. Organize documentation that supports your opinion. Be sure to prioritize them, so that you can stay focused on what really needs to be accomplished first (Some thoughts and ideas on preparing for IEP meetings are given below).
4. Approach each new person as if they are there to help you. Give them the chance to try to make things right. Do not go in with an attitude of blame and hostility - they haven't let you down yet.
5. DOCUMENT, DOCUMENT, DOCUMENT! Start documenting everything that is said to you. Put all requests in writing and ask for a written response. If it only happened verbally, it never happened (e.g. in a court of law). Keep a notebook for all phone conversations. Follow up meetings with a letter stating your understanding of what was said and agreed to. Keep these letters focused on the facts and try to leave emotions out of it. Be sure to state clearly what you are asking of them and a deadline for response. Always end them with "If I

have misunderstood anything, please contact me in writing within 10 working days", and perhaps a nicety stating how you want to work with them. Be prepared - people may find this hostile and adversarial. In reality, it is the smart thing to do. Read the letters to someone else before sending them (there are tips on letter writing below).

6. If you are not getting satisfaction, go up the chain of command, in the correct order, unless it's an emergency. Document every attempt to resolve disagreements regarding what your child needs. Make the commitment to go all the way to the top if you have to, and let others know your intentions (on a 1:1 basis, not in a meeting). Let them off the hook - tell them you understand they will not go with you. This is something you, as a parent, must do without their assistance.
7. Assertiveness is NOT the same as aggressiveness. In spite of the tremendous stress that we are usually under, we must find the support we need to be able to deal with our anger in another arena (such as a parent to parent support group) - not when dealing with professionals. Documenting and using the chain of command and all formal complaint, grievance, and mediation avenues available to us are the expected and appropriate ways to address disagreements in any business situation. All child serving systems are businesses.

Navigating Meetings

Some thoughts on preparing for IEP or other nightmarish meetings:

1. Read your child's entire school, medical, and psychiatric files. Don't overlook this step. Believe it or not, there will be many helpful observations that you can use to justify what you're asking for. Or at the very least, there may be incorrect assumptions that are constantly made about your child's "choices" or intentions that you need to be prepared to relate to his/her abilities if appropriate.
2. Know your bottom line for what your child must have to succeed. Ask for more and be prepared to negotiate. Knowing your rights is crucial - you may be able to get what you really need by leveraging against what you have a right to demand but are willing to give up.
3. Meet with the most supportive persons on the team beforehand, preferably in a neutral location if they're willing (coffee shop, etc.). Share with them everything you feel needs to be addressed in the meeting and try to gain their agreement. You'll feel much better in the meeting if you know at least somebody is on your side, and they'll hopefully be vocal to the team that what you're asking for is reasonable. Even if they can't agree, at least you'll know the opposition beforehand!
4. Make sure you have your child's understanding if not agreement to the things you will be asking for. Be VOCAL to the team that you are your child's voice! They probably will not believe it unless you tell them often.
5. Request the IEP meeting in writing. Give three dates and times that you will be available. State who you would like to be there, and let them know who you will be bringing. Be sure to ask them to schedule at least one or one and half hours for the meeting. Ask for confirmation in writing (see letter writing tips below).
6. Prepare an agenda. Prioritize the issues to be discussed, so that if you run out of time you know you will have achieved the most urgent. Organize your documentation - be prepared.
7. If the members of the team do not seem to be aware of your child's history, diagnosed difficulties, or are recommending things that have already been tried and failed, think about reading at least parts of your child's file with them during the meetings. Don't assume they're dismissing years of professional documentation. Perhaps they haven't had time to read all. If you read it together, at least you'll know further denial of these facts are indeed intentional.
8. Make sure you tell them everything that you are doing for your child! Leave nothing out

that relates to school - if you don't tell them they often assume that you are doing nothing and asking them to do everything. Whenever possible, have your commitments attached to the IEP as well (anything can be attached),

9. This usually helps me the most - meditate on these ideas for weeks, days, and minutes before the meeting:

- “No” only means that this person does not have the authority to approve what I’m asking for. I must leave this meeting and go a step higher. There is a reason why I must go higher - even if I can’t see it today. If I believe in what I’m asking for, never accept no until I’ve exhausted all possible avenues. In almost all cases, I can only lose if I GIVE UP!
- Remind myself of what my child’s future may look like if I give up. I like to convince myself that the worst will surely happen - if I believe it, it really lights a fire under my butt. Pessimism can have its advantages.
- If someone is belligerent to me, I remember that other people’s anger has nothing to do with me and it is self-centered for me to think I really mean that much to them.

10. What frustrates me is how long it takes to convince people to do what is effective. There must be some methods to bring people

to this understanding and agreement sooner! I’m thinking that it has to do with being as completely honest as we can be about our fears, assumptions regarding their motives and intentions, and how far we are prepared to go.

There is an excellent discussion of “hidden agendas” and honesty in the book, *When Society Becomes an Addict*. This is not the same as the many different approaches to “team management” that professionals are promoting. Those approaches never really seem to get to the heart of the matter. They may talk about worst fears, but not about realistic fears for today - right now. They never leave room for the rest - assumptions, expectations, possibility of legal action and more importantly what steps will precede that. These are the issues we really need to talk about.

Writing Effective Letters

Tips on letter writing and documentation:

- 1.** Writing letters (documenting) is just one part of this whole process. It is not the solution or the answer in and of itself. But it is a critical part of getting what you need.
- 2.** Don’t be concerned about failure - this is a LEARNING process! You only get better by doing, and you learn from your mistakes. Most of us start out feeling this is an

impossible task, but it does get better if you keep on doing it.

3. Try to be as direct and concise as possible, but don't worry about perfection. What's important is that you get it written down. They will have the opportunity to correct any miscommunication in their written response. And don't try to document the entire conversation - only the issues that are important to you.
4. Whenever possible, keep it to a maximum of one or one and a half pages. Try to address only one issue per letter. Nobody reads or understands a long letter with lots of issues.
5. This is an opportunity to re-direct your sadness and anger! Put that energy into positive action. First drafts will usually be full of emotion - it is often healing to get these feelings out. Then re-write it stating the facts as you understand them, without the emotion.
6. Learn to identify what you want to see as an outcome. Ask directly for it. Make your expectations clear.
7. Remember - these letter writing principles apply to all situations you are dealing with. It can be equally effective when dealing with education, medical, mental health, and other social service agencies as well.

8. Letters make communications clearer. They can be used to achieve any of the following and more:

- to clarify what was said to you, or what you said
- document what was said to you, or what you said
- document agreements or disagreements
- justify your stand
- state your change of mind since your last discussion or meeting
- apologize when you may have been out of line
- let someone's supervisor know when they have been responsive, respectful, or otherwise provided satisfactory services (Don't forget to acknowledge any and all positives!).

9. Keep track of timelines. How long do you have to respond? How long do they have? Did you ask for a written response within a specified number of working days? Did you state that if you have misunderstood in any way to respond in writing to clarify, also within a specified number of working days?

10. It isn't always necessary to quote the legal reference applicable to your request or issue, BUT using the language as it appears in the law is often effective. Quoting the legal reference will be seen as adversarial, so I don't recommend starting with it. If just using the language found in the laws doesn't

get respectful response, then start quoting all references in all your letters.

11. Always end your letters with a positive statement about wanting to work with them to resolve these issues. If you ever go to court, hostile letters with little intention of trying to resolve will not help your case. And, truly, this really is what most of us want - we just want things to get better for our kids. Few of us REALLY want to fight. We fight hard enough just to get through every day

12. Don't waste too much time trying to resolve issues at the same level. Give it a reasonable try, but then go higher. If you "cc" your letters to the next level up, those up the ladder should be somewhat informed of the situation when you need to ask for their assistance. Some people prefer to "cc" their letters to two levels higher. Don't expect a response from a "cc"ed letter, though. It is just for the recipient's information. You haven't asked them for anything.

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