



SUMMER IS HERE!

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Well, here we are again. It is June, hot, dry and getting ready for summer. Your local family care council has addressed meetings, a web-site and newsletter so we kind of know how to do that now.

What we haven't done is make much of an impact on our legislators.! That is something that we really need to do. After all, that is where all of the money comes from. And if you talk with the legislators, we are not even on our radar screen. We have to change that! We need to start taking our representatives to task regarding the care of our folks. So, this election period ask the folks who are running where they stand on the issue of supporting our folks.

QUESTIONS FOR OUR LEGISLATORS

One thing that we need to do is develop a list of questions that all candidates will be asked to answer. if we can develop this list, get it to the candidates and then print their answers in our newsletter, we will be better informed about who to vote for. But-t-t-t.... We need that list. And for that, we need your input.

Email suggestions to me at ppearson1@mindspring.com.

Here are a few things to think about:

1. Would you consider introducing legislation to form a "board of directors" to aid in providing direction for APD?
2. Would you consider introducing legislation to amend the state constitution to guarantee specific minimum services for the developmentally disabled?
3. How would you address the current APD waiting list for services?

NOW IS THE TIME

Presented as a community service by, Susan Crum, B.S., M.S., Ph.D.

Special Needs Coach
Able2Learn

Email: Able2learn@live.com
Voice and Fax: 863-471-0281

School is now out for the summer, but many parents ended the year with IEP's for their children that they signed, but still feel do not adequately address all of their children's special needs. In these cases, I would like to recommend that summer is the perfect time to revisit these issues. The key to successfully negotiating a more appropriate IEP at this time is preparation.

The advantages to calling an IEP meeting yourself over the summer include having the opportunity to prepare, being in the position to select the agenda, and choosing a time when school staff have little opportunity for pre-meetings and attempts to coordinate their position.

Preparation

list your concerns and desired interventions

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First, make yourself a list of aspects of your child's handicapping condition(s) that you feel are not adequately addressed in the current IEP. Write down specific examples of how you feel this addresses your child, and use examples from what you see at home and in the community this summer. This is valid because the goal of education is not to equip the child to function within the school setting, but to equip the child to be a self-sufficient and independent adult who can be a contributing member of society. Next, list the interventions or accommodations you that you feel would be appropriate. Then, head to a good library and find all the peer review research articles you can supporting your position

Share your list with private providers

Share your list of concerns, desired resolution and the relevant peer review articles with your child's pediatrician, psychologist, psychiatrist and other private therapists. Ask each if they concur and if so ask them to write a letter supporting your requests and indicating why the things you are asking for are appropriate for your child. For example, let's say you want your child to receive feedback based attention training. After reading the research you have shared your speech therapist con-

curs that this would be helpful for your child. Then, she might write a letter stating that your child's progress in improving language pragmatics and auditory comprehension is significantly impeded by his inability to attend to auditory stimuli even in the one on one therapy session for more than a few minutes at time, therefore, it is necessary for CHILD to receive attention training to improve his ability to benefit from the related service of speech as well as to make meaningful progress in the general education curriculum. Your psychologist might write about your child's level of impulsivity and how it has resulted in disciplinary actions on the school's part for the past year and is likely to contribute to continued behavior problems unless addressed through feedback based training as your child has not had sufficient benefit from medication therapy to date. Your psychiatrist might write that given the negative side effect's CHILD has experienced from a range of medication trials, medication no longer represents a viable alternative for him, and therefore, he recommends feedback based attention training.

Gather your team

Now you are ready to gather your team. This should include the child's mother and father (even if divorced), any grandparents residing in the area, older siblings, aunt, uncles, cousins, scout leaders, youth ministers, and so forth. Share the letters from your pediatrician, psychologist, psychiatrist and therapists, as well as the research articles (or annotated bibliographies) with everyone. After everyone has an opportunity to read everything, invite them to your home for a meet-

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ing. At this point explain, that you will be asking each person to serve as an advocate for your child at an IEP meeting which you are requesting to address these issues. Give them a copy of your proposed agenda with your concerns and desired resolutions.

Then clearly explain their role under IDEA. Explain that Both the Individuals with Disabilities Education Act (IDEA), Section 34 C.F.R. 300.344 (a) (6) and Policy 2419: Regulations for the Education of Exceptional Students, Section 5.1.2. State that parents (and school districts) have the right to invite individuals who have knowledge or special expertise regarding the child to serve as additional members of IEP meetings. The determination of whether the individual possesses the required knowledge or special expertise regarding the student as described in paragraph (a) (6) of Section 34 C.F.R. 300.344. (c) Is made on a case-by-case basis by the party (parents or district) who invited the individual to be a member of the IEP team. Therefore, knowledge is defined by the party who is inviting the specific individual(s). Since you believe these individuals gathered at your kitchen table have important knowledge about your child, and are inviting them they will be full and equal members of the IEP team when it meets.

Further explain that since you, the parent has invited the them to participate in the upcoming IEP team meeting, each of them is considered by the law to be an IEP team member and each of them may assume an active role in the review and development of the student's IEP. Their job is to ensure that his/her recommendations and decisions are made with respect to the individual educational needs of the student and/or views of the parent and not with respect to what the district has available, staffing schedules or what is convenient to the district.

Let them know that the nature and extent of their role should be determined by you, the parent, and that you will be communicating in writing that they will be attending and are to be considered equal members of the IEP team

Explain that the focus of the meeting for all team members, regardless of their role, will be student or parent-centered with regard to determining the student's unique needs and how those needs can be met through the development of a more appropriate IEP. Ask each to be prepared to share stories that illustrate when they have seen the difficulties or behaviors you are concerned about and want

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addressed by the team. Ask each to support your specific requests for methodologies or accommodations based upon what you have shared with them and what they have read. Then, ask if anyone has questions about what you are asking for, or suggestions for other things they feel should be included in the IEP

Involve your child

If your child is capable of understanding the issues, tell your child about your concerns, and what you believe will help your child. Get your child's opinion about whether she/he feels these will be helpful; and if not what they feel they need. If you feel that something such as neurofeedback is needed, but your child doesn't want this intervention because they fear being signaled out as different let your child know that because you love and them and want to equip them for adult life, you have to do what is best for them. Then, focus on their fear of being different. Get some books on their disability intended for children and help them understand their disorder. Help them think about ways to tell peers about their differences, and when they are important and when they are not. Ask if they want you to come into their school to talk about the types of differences people

have in how they learn and interact. You can even approach the school to ask for disability sensitivity to be included school-wide. Sometimes you can address this issue through other avenues. For instance, my Girl Scout troop had a number of girls with disabilities. When the girls were planning projects and dividing responsibilities, we always talked about each person's strengths and weaknesses and who could most easily handle a task, and who wanted to try it even if it was a challenge, and whether or not they would like assistance from a peer. The more situations your child is able to discuss their differences with peers and the more opportunities they have to learn that many people have such differences, the better your child's self-acceptance and advocacy will become over the long run.

Permitting your child to attend this IEP meeting is another such opportunity. Your child will know ahead of time what is being asked for, and that all the people in his or her life who care for him or her will be there to support them. You can insure the child that he or she is free to speak up and correct teachers or school staff if they say something the child feels is not accurate. You can even role play your child telling school staff what they struggle with and what they feel will help them. Besides, this is a good opportunity to demonstrate the impact of the disabilities you are speaking about. I sat in one meeting with a parent and her then 15 year old autistic child who the parent continually complained spoke in whispers; which the district had always denied. When team members could hear the child at the IEP meeting, they finally had to add speech along with goals to increase vol-

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ume to the IEP. In another case, when the district was denying ADHD and the impact of hyperactivity, the child got up in the middle of the meeting and pulled the fire alarm causing the whole building to be evacuated. It was pretty hard after that for the district to argue that there was no ADHD or that it didn't impact. So, if feasible and practical, take this opportunity to involve your child in this IEP meeting.

Your Special Needs Coach or advocate

If you have a special needs coach or advocate, have them attend this meeting to explain any test data, and answer questions your team has about procedures. This should be the person who takes the lead in facilitating this parent requested IEP meeting with the school. This avoids the district diverting away from the parent's primary issues, and the parent speaking out of emotion or anger. Thus, the special needs coach or advocate is the one to keep the focus on the child's needs and how to best meet them. In fact, under the law, the special needs coach or advocate is permitted to speak in place of the parent at the meeting as long as the parent is in attendance. To have your special needs coach or advocate assume this role, however, you will need to delineate this to the district in writing when you request the meeting. Understand that you, the parent will still receive the procedural safeguards and prior written notice and sign parental consents, but your special needs coach or advocate can raise

your concerns, respond to questions and direct the flow of the meeting.

Sometimes districts attempt to say that they can only speak to the parent. This is not true. If you as the parent has determined that the advocate has knowledge or special expertise regarding your child and have invited this individual to serve as a member of the student's IEP team, then the special needs coach or advocate is a participating member of the IEP team and the school personnel must work with that person, you, your spouse and all the other members of your team towards a consensus. They should not unilaterally dismiss your ideas or those of the people you have invited to the meeting. If a disagreement occurs during the review and/or development of the student's IEP with any IEP team member and the dispute cannot be resolved, the county school district has the ultimate responsibility to ensure that the IEP includes the services the student needs in order to receive a free appropriate public education. In this case, you and all the other people you invited can put your concerns in writing both to the director of special education to ask for mediation; and when appropriate to the State Department of Education if you feel the violation is district wide, or to the district's ombudsman as a precursor to going to OCR if you feel there has been a form of discrimination.

The hope, however, is that if you have clearly stated your child's levels of performance, areas of disability and how

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they are manifested and impacting upon your child's learning, along with the desired resolutions and why they are appropriate and how they are supported by research, having had ample time to review all of this, the school personnel should be more amenable to collaborative working towards meeting your child's needs than they would if you had not provided them with the objective research supporting your position and the time to read and digest that information. Moreover, when you can match the district personnel in terms of numbers of people attending who have knowledge of your child and knowledge of the issues and desired resolutions, the process becomes much less one sided and much more collaborative.

Obviously, even though school has just ended, this is the time to begin this process because it will probably take you a month to write out your concerns and desired resolutions, read the literature, make copies, gather your team and educate them. When this is completed, you will need to write the school requesting an IEP meeting to address the items outlined in your attached agenda; which you need to copy along with the research to all school members of the team. Only after they have scheduled the meeting and sent you an invitation delineating who the district is inviting, will you write to indicate who your special needs coach or advocate is and the role they are to play, as well as who each of the

person's of knowledge of your child are (family members, neighbors, scout leaders, minister and so forth) and the fact that you have invited them to be full and equal members of the IEP in modifying your child's IEP through collaboration with the district members and group consensus.

Length of meeting

When you send the letter to the district, specify that you want ample time to address all these issues; and let them know exactly how much time you think may be needed; specify the number of hours you want them to set aside for this meeting. Remember, this is the summer so the district should not be backed up with a lot of other annual IEP meetings or triennial, nor do staff have the regular school year responsibilities, therefore they should be able to accommodate your request; and if they read the material you provide ahead of time and work collaboratively with you and your team members, the process should go faster.

In any event, plan for a long meeting. Bring a tape recorder with plenty of tapes, an extension cord and backup batteries. If you have one, bring a laptop so you can take notes. Tell everyone to wear comfortable clothes, to bring a snack and some water, as well as paper and pencil to take notes or a laptop. Let everyone you invite understand that your intention is to remain in the meeting as long as it takes to resolve the presenting issues; so that they can all plan ade-

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quate time for the meeting.

Don't be put off

When you write the school district to notify them of your objections to the current IEP and your desired resolutions, since it is summer, they may try to delay. One delay tactic is to say that you agreed to the current IEP. In that case, indicate that you agreed with reservations, but upon further research and in view of your child's current functioning you now recognize that the IEP is definitely not appropriate, and therefore it is your responsibility per Congress to advocate for your child by reconvening the IEP team to address these issues. Indicate in this letter that should the district fail to schedule a team meeting within ten calendar days of the date you hand delivered this notice, they may consider this same notice as your formal request for mediation. Include in this letter that as the director of special education knows, an appropriate IEP designed to ensure your child meaningful progress must be in place for the first day of school, and that reconvening the IEP team is not dependent upon school vacation or holiday schedules. Make certain the letter includes all the information required for mediation – your child's name, date of birth, address, school, grade, classification, placement, your name, address, and phone number. Copy this letter to the State Department of Education to add some pressure for them to schedule promptly.

Webinar:

Maneuvering the Special Education Labyrinth: Effective parent advocacy skills from day one

By:

Susan L. Crum,
B.S, M.S., Ph.D., NCSP ,
Special Needs Coach

Where: From your home computer
When: Thursday, July 10 and Thursday July 17
Time: 8:00 to 9:30 pm
Cost: \$75.00
Registration: Email Able2learn@embarqmail.com with REGISTRATION in your subject line. We will email you back a pay pal invoice and then the URL to go to at the specified dates and times.

This Webinar is interactive. You will be able to see and hear Dr. Crum as well as type or verbalize your questions to her. This seminar has information both for parents just beginning to deal with special education, as well as for those who have been struggling with the district for years.

SUPPORT OUR LIBRARIES

Our latest donation to the Volusia and Flagler Libraries is "The Special Needs Planning Guide" - how to prepare for every stage of your child's life by John W. Nadworny and Cynthia R. Haddad. **Check it out!**

FCC UPCOMING MEETING SCHEDULE

- 9/11/2008—APD office, 210 N. Palmetto Ave., Suite 312 Daytona Beach, FL 32114 .
- 11/13/2008 -3-5pm , APD office, 210 N. Palmetto Ave., Suite 312 Daytona Beach, FL 32114
- 10/9/2008—New Smyrna Beach Library - 1001 Dixie Hwy, New Smyrna Beach, FL 32168—(386) 424-2910
- 12/11/2008—APD office, 210 N. Palmetto Ave., Suite 312 Daytona Beach, FL 32114 .

Area 12 Family Care Council
210 N. Palmetto Ave., Suite 312
Daytona Beach, FL 32114