Parents Share Ideas For Educational Planning

Updated: July 13, 2009

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I often find myself talking to other parents of children with CFS about plans they have put into place for their child's education. Usually it is the case that I am making suggestions of modifications and accommodations that we have tried or heard of to assist the parent in enhancing their child's educational plan. But sometimes I have parents share ideas with me that leave me feeling that this is an excellent idea and I need to pass this one on. So that is what this month's column will do. I am passing on a few good ideas of plans that are in place in some schools in the US that may help you to jumpstart a new approach for your child's education. Please understand that while a program may work very well for one student it may not be an option for another. Not only do the regulations vary from State to State on what is required for a High School Diploma, but also it varies within each state, District to District. It has been the case in some instances, however, that an understanding and supportive parent has presented an idea to their district and because it was well thought out and doable it was accepted as a consideration for the child in that district. Just because it has never been done before, does not mean it can not be done now.

The first idea was shared with me last January in Seattle at the AACFS Conference. I was given a very interesting brochure from a mom of a high school boy with CFS who is earning part of his credits from a "Contract Studies Program." This is an independent studies program of the Bainbridge Island School District near Seattle. As the brochure states, "The Contract Studies Program is a personalized, individualized academic program supporting students in achieving their high school diploma. Central to this mission is establishing strong academic standards that meet the Bainbridge Island School District's graduation requirements." The program is used in grades 6-12 and involves an individualized learning plan where parents accept a central role in coordinating the daily operations of the plan. The school staff facilitates and evaluates the learning components of the plan and the student meets on a weekly basis with the staff to share progress and the time spent in learning. An advisory committee reviews the work to assure that it complies with the District's curriculum framework. Grading is done on a pass or no credit basis. The student who introduced me to this program was using it for his Physical Education Requirement. His mother stated that he was able to count short walks out in front of their home as a PE activity under the Contract Studies Program and many normal every day activities were included. I have talked to other parents who have used programs similar to this to help their child to earn credit in classes such as art, music, and computer skills. With a supportive school system it seems that there are many ways a program like this could be used. The brochure states that for more information on this program you can email Catherine Camp, Administrator for Alternative Programs at ccamp@bainbridge.wednet.edu or Penny Tyrrell, Secretary for Alternative Programs at ptyrrell@bainbridge.wednet.edu. They can also be reached at Contract Studies, 9530 NE High School Road, Bainbridge Island, WA 98110 (206)780-1646.

The second parent I talked to impressed me greatly by the amount of involvement that she and her husband had in the development of their son's IEP. As I have said in the past it is critical to the education of our children that we, as parents, develop a positive working relationship with the personnel at school. We may grit our teeth and scream at home, but at school we need to do all we can to build bridges and to develop a rapport with the staff that encourages ongoing communication and cooperation. I have been on both sides of our love/hate relationship with schools in the past, and I can tell you that it is not always easy. There are many emotional issues for the parent and when someone appears to not care or to try to understand, our worst sides can come creeping to the surface. I have always tried to maintain a positive, respectful attitude, even when I did not feel I was being understood. But in the end we have always prevailed. We have stuck by our requests and have been very determined at times to have our needs addressed, but we have tried to do so without antagonizing anyone. I cannot say enough about how important this is. To be your child's advocate is the most important role you will take on in this illness; their advocate at school, with doctors, with family, in the world. And if we do our job well, we will prepare our child to go into the world better prepared to be a successful advocate on their own behalf when the need arises. In reading the Individualized Educational Plan that follows I could see two parents who excelled as their son's advocate. They had learned the laws and knew their son's rights. They presented his educational needs in a way that made the teachers truly understand how his condition impacted his education and what the school could do to accommodate for his limitations. Now on to this boy's IEP and the areas I felt well addressed and worth sharing.

First off I noted the length of the IEP. It is about 30 pages long using standard forms to check off things. If you look at IEPs from different districts, you may find one is a couple of pages and another is a book. Our district's run about 4-5 pages and keep things brief. They offer the same protections, but are just written up differently, so do not worry if your district is like ours. As long as the team has addressed all the parts of the IEP that is what matters.

In the aforementioned IEP 2 pages of background were included with teacher/tutor comments. In short paragraphs this boy's progress was outlined for the year, including his learning styles and how the illness impacted on his learning. I found this a remarkable and easy way to share with the teachers how this child's education is impacted by CFS. For Example one section notes, "John has a strong innate ability. The tutor reported that John does not like completing alternate projects because he finds it difficult to sit up for extended periods of time. The tutor found concentration to be his greatest weakness. During a week that John was not feeling well, she tutored him approximately 5-6 hours. During a good week when his energy level was better, she tutored him approximately 10-12 hours. Input from John's Grade 9 teachers describe John as alert and an active participate in class discussion when present on "good days." On "bad days" the teachers stated that he often put his head down on his desk. Subtle cues and teacher movement around the classroom were found to be helpful to allow him to stay on task. Attendance for the previous school year varied from term to term and from class to class."

On a separate page general information was shared beginning with a "good days" vs. "bad days" list. It states "The tutor reports that on a good day John is able to concentrate better, produce some written work, ask appropriate questions related to the material and work for approximately 2 hours with one to one instruction (while lying on his back 75% of the time). John's tutor reports that the following accommodations have been most effective on good days in the home tutoring environment: allow John to lie down, scribe, cues to keep him on task, condense material, open book tests, outlines, multiple sessions for tests. Following on this page were sections on Course Communication and how the work will be exchanged, and issues of Confidentiality as to John's health status, and The Role of the Tutor are outlined as to the type of contact and how often she will communicate with Special Education Teacher, classroom teachers and the Education Consultant. The final category deals with the testing and teaching modifications and accommodations and outlines why such things are needed.

At this point you may be saying that this IEP shares a great deal of personal information about the student, in terms of health, specific learning issues etc. Some schools may prefer to keep some of this information out of the IEP, and may even refuse to have it in there. I am just sharing with you the way this particular school has done it. However if your school is like mine, a much shorter IEP will be found. This too has it's benefits as it is easier for a teacher to review and see at a glance what is needed. A long detailed document may not receive the attention a shorter one may. But I still like John's IEP because I feel it makes this child's learning styles and habits a matter of the academic record. It makes it easier for a teacher or educator to pick up this IEP and to get a handle on why John needs these accommodations or modifications. In my opinion it would ease the task of the parent to continually need to be reeducating the teachers and staff on the impact of this illness on the child and the necessity for implementing the IEP. John's IEP continues to outline what modification is requested with a personal line on why it is needed. I personally LOVE this. As a parent I often find myself justifying areas of the IEP and explaining why parts are in there that may not be needed in Sept, but will be necessary come January. I plan to write up an addendum to my daughter's IEP that will include the information noted above on her personal learning characteristics and styles. I also plan to explain how the illness impacts her education and how and why we have accommodated for these areas.

John's IEP also does a fantastic job outlining the goals and objectives course by course. The IEP team copied the regular course requirements and made notations as to modifications for John such as omit requirement 5 & 6. The goals and objectives in our daughter's IEP are vague and I would like to use the format of John's IEP to amend our daughter's.

A third parent who I am in touch with via email offers a new perspective on tutoring. She suggests the concept of teaching by telephone. In her experience telephone teaching with brief sessions (making sure all systems are established like volume control and that the teacher understands the condition, etc) really WORKS! She states it is an option to consider in drastic cases. They have used this option with their daughter for the times they had previously had to cancel the tutor but later found their child feeling better. I also heard of an instance where a child had no tutor and a teacher/friend tutored her long distance over the phone until a real in home tutor could be found. The internet and email or instance messaging are other tools that our children may be quite comfortable with, and can adapt to use with teaching/homework. While these are alternatives to the normal one on one situation that tutoring provides I do not advocate that these be substitutes for this personal one on one contact. I guess the suggestion is to look outside the mold. If you have no tutor at all and the school is dragging their feet on providing you with one then an alternative approach is better than doing nothing. What works for one, may not work at all for another child. But if we are all willing to look at our individual child's strengths and weaknesses and to be creative, we may be able to come up with some new innovative ways to approach teaching, tutoring and homework.

This past year I also became aware of programs that are taught on line via computer that can help a child earn High School and College credits. As the online world spirals in our life there will be more and more options available to our children via computer if we are only willing to go searching for the programs that may assist them in their learning.

Sometimes as desperately as we want a public education to work out, it is just more headaches and heartaches than we can deal with. Sometimes there is so much animosity with the school, or the child is so ill, that tutoring or school attendance on a regular basis is just not possible. Or there may be an ill parent in the home and the role of advocating for the child with the school becomes an insurmountable task. In these instances some parents have opted for home-schooling curriculums. As one Mom of an 11 year old wrote to me, "I miss that exciting beginning of the new school year but I'm hoping that she won't have to start with high hopes and fail as she has every year since 2nd grade. She's sleeping nights and up days now but we don't know what she'll be able to manage. Being home is so much easier for her than going out, so maybe she'll be able to do a little more this way. We've got a Waldorf home-schooling curriculum, which I'm adapting for her to reduce the amount of reading and writing. I'm organizing it into short packets that she can do at her own pace and be able to finish. The school never got the idea of what to do with her. She said they were just waiting for her to snap out of it. She had a terrific home tutor for 3rd and 4th grade but she left. The one last year was not so good. We are not sure how the peer thing would work out at this stage either now that she is in Middle School. The kids seem to be less accepting when she does see them. She can see kids in a home-schooling group if she feels up to it. "

This mom also noted in another note "I've noticed that I am getting a sense of when she can and cannot work. It is as though a window is open for a time and then abruptly closes and no more can go in. She can now let me know this is happening, and as long as I don't insist she go on, we are ok. I can feel the difference as I work with her. The emphasis in school is to get the kids to do more and more work, but she can't do this yet. It reminds me of PT for many PWCs it's not a matter of increasing activity level but just doing what they can do without exhausting themselves. The other thing I've noticed is that she needs to learn in the ways that come most naturally to her. If she was feeling better, she would need to accommodate to the way things are presented but she just can't be that mentally flexible right now. For her, this means I have to focus on concepts and let her verbalize her ideas and fit new information into what she is thinking about. Since I tend to be a detail person, this is quite a challenge. "

I guess the bottom line of all these ideas is that, as parents, we need to really fine-tune our efforts as our child's advocates. We need to go the extra mile to really figure out what it is that our child needs to excel. Do they need an extra accommodation? Do they need a different approach to teaching available to them? And as parents do we know the answers? Do we know and understand our child's rights as they pertain to their education? Do we know their best learning styles or habits? Do they study better in a supine position or at a desk in the same place each day? Do they need moderate/natural lighting? Do they do better when they are read to as opposed to reading material alone? Are there things that can be done to their environment that helps them to be more productive? My guess is that most parents do not know the answers to all these questions. I encourage you to not only talk to the school and your child's teachers and tutors, but talk to your child. Ask him/her to tell you how they learn best. What helps, what hinders and what can you do to make things easier for them. I have found I learn much more from listening to my child, than by observing her. When asked she can be extremely articulate in explaining how she learns best and roadblocks that make things more difficult. I also find I need to write down what she says so that I can better present it to the teachers when the time arises. I do not have the illness, and as good days melt into bad and back to mediocre, I forget what she said. I for one am going to take the suggestion from this column's IEP of John's and put in writing many aspects of my daughter's learning strengths and learning styles. I hope you too have found some ideas to enhance your child's educational plan and have strengthened your resolve to assist your school in developing and implementing the best plan possible