This Q & A article is from BDSRA’s “Ask An Expert” Facebook Chat in the BDSRA Closed Facebook group for parents and caregivers.

\*Please note: the information contained in this material is intended to provide

basic information to Batten families and caregivers. It is not intended to be, nor is it, specific legal or education advice for individual children.

Parents and caregivers should consult the child’s teacher and/or school administrator prior to changing education plans, accommodations, or daily activities.

“Individual Education Plans and Classroom Strategies”

Featured Expert:

Jo Willer, Retired Educator and Batten Grandmother

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Q: Wondering if you have a good checklist--mental or otherwise on getting the most out of school meetings on IEPs?

A: I have sat in on Kate's IEP and I always try to have Ellie come with Kate's strengths and Ellies's concerns for the next school year or for whatever is going on right now. I always encourage her to bring documentation with her from outside therapists or doctors. At the conference, we talked a lot about behavior and accommodations. These are very specific to each child. Whenever, I try to help parents I suggest to them that they talk about what their child needs, not what they as parents want, but what the child needs. It is always best to keep the focus on the child and what the child needs. When talking about strengths of your child, it could be as simple as what they like or prefer to do, positioning, what their eyes follow, how you stimulate the child, such as with brushing, how you involve or include the child at home. Strengths can introduce and familiarize your child to the staff.

Q: Do you send the IEP team information about the child's medical status ahead of time or just bring that material with you to the IEP meeting?

A: If a parent has documentation or doctor recommendations ahead of time, it is good to bring them to the conference. If there are reports, then those could be sent prior to the conference so that they have a chance to read them ahead of time. You can also bring anyone to the conference that you want, so if a physician or therapist can send a representative then, you may bring them, you do not need permission or even need to tell them ahead of time. We had a doctor that could not attend the IEP meeting but she was able to call in on speaker phone and talk with the team and answer medical questions. That's possible as well.

Q: What if a child is progressing and it's beginning to look like they need a one-on-one aide in the classroom; how do parents go about getting one for their child?

A: If you believe your child needs assistance, do your homework. Be prepared to answer the reasons why. I used to tell teachers to defend such a request to me because what they were asking for was approximately a $15,000 expense. So, be prepared to say why----generally, an assistant is necessary whenever personal assistance for rest rooming is needed, or if there are safety or mobility concerns, or serious medical concerns, such as seizures or suctioning. Always refer back to it being a safety or medical concern in order for the child to benefit from their appropriate education.

Q: How about keeping a daily log? What types of records should caregivers keep in order to help them have documentation at the school meeting?

A: One way to keep your teachers informed with your child's activities and issues is through the use of a daily notebook. I would recommend that this travel back and forth daily, and that someone at the school take responsibility for it. The purpose is to share life with each other that revolves around the child. For the parents, this is critical because it gives the family something to talk about with the child, especially when the child is non-verbal. Insist on this practice and keep your end up. Share what kind of night the child had, seizures, sleep, appetite, etc. Things that might affect them at school the next day. If your child gives off, cues, you should try to alert the teachers to these individualized cues to help your child.

Q: What advice can you give parents to manage the emotional piece of school meetings?

A: I think it is always a wise thing to take someone with you to your first few IEP meetings or if you are expecting a difficult one. These meetings can be draining emotionally, and someone else can go as your note taker, and also as a support to you. You can bring anyone you want to. You can bring an advocate, if you want, and you don’t have to let the school know ahead of time. When I went to Kate's first IEP it was a little touchy when we were trying to establish her speech services. Ellie didn’t want to ruffle feathers because she has to live there, but I knew what they were pushing was not right and I was able to step in and say that while what they were recommending was convenient for their schedules and themselves, it was not in Kate's best interest and it was not what she needed. The principal agreed with me and so we added speech time into her IEP.

Q: My daughter is hospital homebound her IEP is her teacher comes here to our home 3 days a week for an hour each time. OT, PT and speech 2 times a week for an hour each time.   
In the past (almost) year she hasn't received speech. What steps should I take to make them abide by the IEP?

A: If it is in the IEP I would call the principal and tell them that they are not following the IEP. This is a violation of the IEP document. Before you do that though: I would look closely at the IEP, and see if it is a consultation to Brianna or is it a direct service? If it is a consultation only, are they consulting with the teacher or therapists? If it is a direct service, which is what it sounds like, I would first call the Principal; then I would call the Director of Special Education. They are the direct people responsible for the implementation of the IEP. You can also convene a Case Conference and request that certain people attend. Of course, put this in writing, and when you make your phone calls document what you say and what is said back to you. Many times, principals are pretty clueless about homebound. Our districts always referred homebound to special education department or a homebound coordinator for such services. They just didn’t know or understand this service. It is totally separate.

Other Notes:

We often times wrote up specialized medical health plans for kiddos like Batten kids. They were highly individualized, usually written with the nurse at the conference, including doctor recommendations, emergency plans, and numbers, down to the most minute details. It could describe seizures, meds, emergency meds, etc.

We had similar plans for transportation. Both of these types of plans generally included an outsider or a parent providing training. It also required that copies of these plans were kept on the bus in a folder, and in a folder on the teacher’s desk. There were also plans for a substitute. It was critical that these plans be available to the staff in the room. Copies of course were kept in the nurses file and with the IEP.

It is important to tell the teachers that since Batten is a regressive disease, maintaining skills is really progress. Teachers are pushed to have students progress, and sometimes their evaluations are related to progress, which for our kiddos is hard. So, be sure to tell them that maintenance is progress. And, as you establish goals, it is important to simply relate things to functional activities, and daily living skills, and the maintenance of language, understanding and awareness. The use of language is so important. I often see Kate listening to us and understanding what is going on. Just because she is non verbal, does not mean she doesn’t understand. We try to find ways to get her opinion.

I know some of our kiddos may have had recommendations for schools for the blind. As an administrator, I always hated making those recommendations and took them very seriously. I hated making that recommendation but the school for the blind could really impact some students tremendously. They could teach them orientation and mobility, they could show them braille in different ways so that the students really learned it. It is a hard decision to make, but sometimes, for a season, it is what is best for the child. And, as parents, I would again throw that spotlight on the child. It's all about the child, not us, as grandparents or parents. We don’t want them to go, but it could be necessary for a time.

Kate uses speech talk buttons. This gives her a voice. She can answer comprehension questions, make a choice about an activity or say her own opinion. These have been a good way for Kate to be included in events at school and in outpatient therapy. They were never used a lot at home but they could have been. Some schools get to "try out" assistive technology from equipment that is on loan from ATOhio. Each state has an Assistive Technology center/resource for schools to utilize. I believe most states do have libraries to borrow from. Some companies will let schools borrow to see if the equipment works for a specific child before purchasing it. This site has a listing of state AT projects: http://www.parentcenterhub.org/repository/ata/.

One other thing that we did to include kiddos, that was a part of their OT or PT was to give kids errands. For instance, they could push a wagon with stuff in it to the office. (heavy lifting or pushing is good for large muscles, and calming) This was a great PT exercise, or doing wall push ups was a great OT exercise. Taking walks and delivering things to a teacher or principal, is useful for mobility and being seen in the building, learning to greet others, learning the building, etc.

We also employed music therapist for our kiddos when I worked. She created songs for teeth brushing, taught how to use instruments that could transition into using spoons or forks, and taught skills from the teachers set to music. You might inquire if there is one in your area. Equestrian therapy is great for kids too. This would be more of a private PT activity but good for balance and core strength development.