

PARENT ADVOCACY AFTER EPILEPSY SURGERY



1. GET READY:

Your child needs you to be their advocate. Be prepared for the IEP meeting to maximize your time with the team. Good special education services are expensive, and resources are limited. You may wind up battling the school district for the services your child needs. To prevail, you need information, skills, and tools.

2. GET EDUCATED:

- ☐ **Become an expert in your child.** Understand all areas of your child's disability (review the IDEA eligibility categories). Keep up with current research on your child's disability, and be prepared to cite names of studies, dates, and names of researchers. Keep copies of this research and bring it with you to IEP meetings.
- ☐ **Know your child's rights** under the law Individuals with Disabilities in Education Act - IDEA) and the IEP process: Referral; Assessment; Identification; IEP development; Placement (LRE).
- ☐ **Know the components of the IEP:** present levels of academic and functional performance (PLAAFP); goals; statement of special education & related/supplementary services; program modifications, accommodations & assistive technology needs; Functional Behavior Assessment and a Behavior Intervention Plan, if warranted; testing (participation in statewide/ standardized testing); dates; inclusion amount; progress & reporting on progress, Extended School Year (ESY); transition; and finally, placement.
- ☐ **Understand assessments:** First, you must obtain a comprehensive evaluation in all areas of suspected disability. You need to know what assessments to ask for and why. Research every assessment tool: Is it the appropriate measure for your child and purpose? Was it administered appropriately? Was the assessor qualified to assess your child? **Remember: what your child cannot do drives the goals!**
- ☐ Know how to make a spreadsheet to **chart your child's progress** (or lack of progress) by comparing measurable data from year to year (or more frequently, if warranted).

- ☐ **Know how to write a baseline for each goal** from the present levels of academic and functional performance (PLAAFP).
- ☐ **Learn the meaning and purpose of scores** from standardized and informal tests. Can you interpret standard scores, t-scores, z-scores, percentiles, confidence intervals, etc.? (If not, consider working with an experienced advocate to help you.)
- ☐ Learn about all aspects of your child's disability and the proven methods of teaching based on their condition and needs.
- ☐ **Know the law:** what constitutes a FAPE; implications of Endrew F.; timelines for evaluations/reevaluations; how to make a written request for assessment in one or more specific areas; what are SMART goals and objectives; what constitutes a valid IEP; the legal foundation of IDEA; and your state code of regulations related to special education. These are your *rights*.
- ☐ **Learn key advocacy strategies.** Find your local Special Education Advocacy organization and attend training, research via reputable websites, get professional advice, and communicate with other parents and advocates regarding effective advocacy strategies. Key strategies to know include:
 - ☐ **Prior Written Notice (PWN)**;
 - ☐ the Rule of Adverse Assumptions;
 - ☐ how to use tape **recording** and **thank you letters** to clarify issues;
 - ☐ how to deal with a challenging IEP team member;
 - ☐ how to file a complaint; and
 - ☐ what is due process.
- ☐ **Understand the IEP process and the key personnel in your school district:** How are IEP meetings scheduled and run? Who is the ultimate decision maker for your child's special education division? Get to know that person (often the director of special education) and help them understand your child's unique needs and what types of support they need. Be collaborative..
- ☐ **Review your child's records carefully.** If you don't have everything, request (in writing) the missing documents or your child's entire file well ahead of your IEP meeting.
- ☐ **Review and understand:**
 - ☐ Your child's IEPs (current and previous, including 'draft' IEPs);
 - ☐ Results of your child's most recent evaluation(s), including those conducted by professionals not employed by the school (such as a pediatric neuropsychologist or other doctors) from the past three years;
 - ☐ Report cards, recent class papers, tests, and teacher comments;

- ☐ Reports of progress toward annual goals in the current IEP (should be reported as often as report cards, usually 3-4 times per year) and the data used to measure that progress.
 - ☐ Did your child fail to make the expected progress?
 - ☐ Are any goals being 'repeated'?
 - ☐ Might be a FAPE violation and indicate insufficient support, services, or wrong type of instruction.)
- ☐ **Learn how to disagree** with the IEP team. If you disagree with any part of any assessment, do not hesitate to request an IEE (independent educational evaluation at school district expense) or obtain an independent assessment. Know the procedures and legal obligations of the school district regarding IEE requests.
- ☐ **Review outside records** (notes or records from medical providers, independent assessments, regional center assessments, etc.). Ask the team to consider these records in developing your child's IEP.

3. GET ORGANIZED:

- ☐ **Create your own complete, organized special education file for your child.** Review these documents periodically and definitely in preparation for any school meeting. Organize your file to easily find needed documents (such as a 3-ring binder with numbered tabs and a table of contents, or scan and maintain an electronic file you bring on a laptop). Good records are essential to effective advocacy. This file should include:
 - ☐ A record of your contacts with the school;
 - ☐ A log of telephone calls and meetings, conversations, and correspondence between you and the school;
 - ☐ Copies of all assessment reports, IEPs, letters, and notes from teachers and doctors, medical records, therapist reports, test results and evaluations, report cards, progress on goals, any and all documents received from the school;
 - ☐ Audio recordings or transcripts of IEP meetings (If your state allows you to record your IEP meetings, then do so; if not, bring a friend to take notes).
- ☐ **Put It In Writing:** In addition to requesting all school records, get in the habit of writing everything down. **If you don't write it down, it didn't happen.** For example:
 - ☐ keep a log of behavior incidents or any time you are asked to pick up your child early from school;
 - ☐ include casual conversations in the hallway, parent/teacher conferences, and IEP meetings;

- ☐ keep a written log of every contact with the school team;
 - ☐ follow up any informal conversations with school staff via a note or email to thank the person you spoke to, summarize the issues that were discussed, and ask for clarification of any misunderstandings;
 - ☐ know your rights about amending your child's educational records;
 - ☐ become a good letter writer and make *all* of your requests to the school district in writing.
- ☐ **Prioritize Your Child's Needs:** Everything you want for your child is *not* equally important. **Make a list of what your child *really* needs**, what you want for your child (but may be willing to compromise on), and what would be nice to have but that you would be willing to give up. Consider what evidence you have to support each requested item (such as reports, assessments, experts, etc.). If you prioritize your issues and have facts and data that support what you want, it is more likely that the school team will take you seriously. Pick your battles. What is a must? What are you willing to let go of?
- ☐ **Write a statement of parent concerns.** Prepare a list of long-term goals for your child. Include their strengths and your academic, social, and physical/functional concerns. What are your child's educational needs, related service needs, accommodations, and modification needs? Make a list of evaluations you wish to discuss (or on which you base your concerns). The IEP must address everything listed as an educational concern. Share this statement with your IEP team in advance.

4. GET EXPERTS:

The only way to negotiate with the school for special education services is to ensure that the school district comprehensively evaluates your child. This evaluation must accurately represent ALL of your child's needs and abilities. You must have good experts, even if you have to pay for them. **What Mom or Dad wants doesn't matter, even though you know your child best!**

For a child after epilepsy surgery, there might be a long list of needed assessments. Prioritize your child's needs, but don't be afraid to ask for specific tests or recommendations from your child's evaluators. You need to know what the evaluations are testing and what the results mean. If you don't understand the test results, ask for clarification.

An independent evaluator may be a better option in certain situations. If you get an outside evaluation, bring the evaluator into the IEP meeting, even by phone, to explain their report to the district/IEP team and answer questions.

Inform any health professionals who have worked with or evaluated your child that you are preparing for an IEP meeting. Share your goals and concerns, and ask them to write letters supporting your concerns and ask them to participate in your IEP meeting by phone or in person.

5. GET CONNECTED

Develop positive relationships with school personnel to the greatest extent possible. Ask your child's team to explain things you do not understand. Take the high road. If a meeting is deteriorating, ask for a break or that the meeting be continued later. Good relationships will help ensure that the issues you bring up will be taken seriously. A positive relationship with school personnel accomplishes much more than an adversarial one.

- ☐ Always inform the school at least five days in advance when you intend to record the meeting and if you are bringing others with you to a meeting.
- ☐ Share outside assessment(s) you wish to discuss with your child's IEP team at least a week before a meeting (and request the same courtesy from the school district regarding their assessment reports and draft IEPs).
- ☐ Have a professional appearance in IEP meetings, and do not bring treats. Save that for school events (when you can bring treats and supplies, and volunteer your time).
- ☐ Spend as much time in your child's school as possible and get to know school personnel well.
- ☐ Build a support team, to include:
 - ☐ Your child's case manager,
 - ☐ The social worker or nurse from your child's neurology clinic,
 - ☐ A representative from your local parent advocacy center (such as Family Voices, Protection and Advocacy, The Arc, or Disability Rights),
 - ☐ Support groups,
 - ☐ Friend or neighbor to come to IEP meetings with you,
 - ☐ A special education advocate or attorney, if needed.

IEP MEETING ADVOCACY TIPS

Before the meeting:

- ☐ Make a list of your child's recent assessments and all service providers who work with your child, both in and out of school. **If there are no current assessments, or they do not cover all areas of your child's suspected disabilities, then request a comprehensive evaluation well before the IEP!**
- ☐ Request copies of any **new** assessments at least five days before your meeting.
- ☐ Review (ask the school for any of these items if you have not yet received them):
 - ☐ All **current** assessments/evaluations (3 years or newer). Your child's **needs** (as described in each assessment report) become the **goals**, which then determine the services and other supports, and ultimately placement!
 - ☐ **The recommendations** from both the school and outside assessments.
 - ☐ The results of **state and local testing**.
 - ☐ **Report cards**.
 - ☐ **Progress reports** on goals (you should receive these as often as report cards, generally 3-4 times yearly).
 - ☐ The **data** and **work samples** to support reported progress on goals (what evidence do they have that your child made progress?).
 - ☐ **Behavior** and **attendance** records.
 - ☐ The **draft IEP with proposed goals**.
- ☐ Compare the *draft* IEP to previous IEPs. **Track progress/lack of progress on all goals.**
- ☐ Look at your **state's common core standards** for your child's grade level.
- ☐ Talk to your child's teachers, therapists, and medical team, and get their thoughts about your child's progress, behavior, attention, social skills, functional skills, or any other concerns.
- ☐ Visit your child's class or other school settings to determine if these settings are appropriate for your child.
- ☐ Make a list of the goals, accommodations, and services you would like to propose based on the evaluation and observation data.
- ☐ Research your child's **medical condition** and expected outcomes; learn about what evidence-based curriculum would be appropriate for your child. Print out the research papers and bring them to share with your team (or email them before the meeting). Print out all relevant PESA guides ([Cortical Auditory Impairment](#), [Vision After Epilepsy Surgery](#), [Education After Hemispherectomy](#), Quick guides, etc.).
- ☐ Know who is attending the IEP meeting and their roles.
 - ☐ Parents decide if the school can excuse a team member from the meeting.
 - ☐ A general education teacher is needed to help align goals with grade-level standards and discuss inclusion in general education settings with support.
 - ☐ Related service providers must attend to discuss their services and evaluations.

- ☐ A decision-maker who can commit the resources of the district must attend (generally the special education director or another higher-up in the district).
- ☐ Let them know you will **bring someone with you to the IEP meeting**. This could be your spouse, neighbor, babysitter, private therapist, someone else who knows your child well, or a trained special education advocate.
- ☐ Make notes about what you'd like to discuss at the meeting.
- ☐ Make a list of your child's strengths and needs to add to your statement of parent concerns. Send your **parent concerns statement** to your child's team in advance and make sure that it is added to the IEP.
- ☐ Let the team know in advance that you will **record the IEP meeting** (if this is allowed in your state, check your state education code)

During the meeting:

- ☐ **Be prepared** with questions and facts you want to share with the team.
- ☐ **Discuss strengths** – both your child's and what is working well in the school setting.
- ☐ Take good notes, **audio-record the meeting**, or have someone be your note-taker.
- ☐ **Have support**: bring a friend, advocate, or independent assessors.
- ☐ **Manage your emotions** – avoid blaming or crying if at all possible.
- ☐ **Be flexible** – there may be multiple ways to solve a problem. Pick your battles.
- ☐ Keep the discussion focused on **your child's needs**.
- ☐ Eliminate the word “best” from your vocabulary. Your child is only entitled to an “**appropriate**” education based on their unique needs.
- ☐ **Trust your judgment** — sharing knowledge of your child is crucial. You know your child best. Remember that **you are an equal member of the IEP team**.
- ☐ **Don't be afraid to ask questions**. You have a right to participate in the process, meaning you need to understand it. Interrupt or stop the meeting if needed.
- ☐ Start by discussing all of the assessment data (including **progress on last year's goals!**) to develop a robust PLAAFP outlining all of your child's needs.
- ☐ A person of knowledge about each evaluation (generally, the person who did the evaluation) should present their findings and answer questions. The school psychologist may have meaningful suggestions based on your child's cognitive profile and processing, for example.
- ☐ Link your child's identified needs specifically to goals and services: which needs will be addressed by which goals, accommodations, and services. Be sure to discuss progress on previous goals before moving on to this year's goals.
- ☐ Your child may need specific accommodations or modifications to access the curriculum. Both the general education teacher and special education teacher should be part of this discussion to address both classroom environments.
- ☐ Make sure all services, accommodations, and other agreements are written into the IEP using specific language.
- ☐ Document in the meeting summary, meeting notes, or **Prior Written Notice (PWN)** the issues you feel strongly about and your requests. Review the summary as a team before you leave the meeting.

- ☐ Be sure to get a copy of the IEP and the meeting notes to take home to review. Take the time to check that it is accurate and contains everything you agreed to in the meeting. Review it with a friend, spouse, or advocate if possible.
- ☐ In some states, the parent must sign IEP approval. You don't need to sign the document at the meeting – you can sign for “attendance” only and take the IEP home to review.

After the meeting:

- ☐ **After every IEP meeting**, summarize the discussion and your understanding of what the IEP team agreed to provide for your child. Send this summary with a polite letter thanking the IEP team for their commitment to your child's education, and re-state any action items or promises made during the meeting.
- ☐ There are two ways to sign the IEP: **approve the IEP** in full, or “**with exception**.” If there is something that you believe is missing, if you disagree with a service or want a goal changed, etc., then list those exceptions, allowing the school to implement the parts on which there is agreement. Then immediately request another IEP team meeting to resolve the disagreement. (Note: not all states allow a parent to sign “with exception.” - check your state's education law!) It's helpful to provide a written explanation of your disagreement(s).
- ☐ If the school district refuses to provide any requested assessment, goal, service, accommodation, etc., ask them to give you **Prior Written Notice (PWN)** explaining the basis of their refusal. Look up what this should include, as it can vary from state to state. (Note: in some states, PWN is called NOREP or Notice of Required Educational Placement.)
- ☐ If the school district stated that something you requested for your child is ‘against district policy’ ask them, in writing, for the board-approved school district policy. District employees sometimes confuse procedures in the district with special education laws.
- ☐ If there is a disagreement about services, try to negotiate a settlement with the school informally (this is the simplest, least costly option) or find an educational consultant, advocate, or attorney representing children with disabilities. You can also consider filing a complaint with your state department of education.
- ☐ Share the IEP with your child's health professionals to get their feedback and help them better understand your child.
- ☐ Monitor your child's progress and call an IEP meeting any time you have any concerns. The IEP is a living document. Most state laws allow 30 days from when a parent requests an IEP meeting to hold the meeting. (always make your requests in writing!)
- ☐ Some complex children after epilepsy surgery may require 5 or more IEP meetings per year to discuss all of their areas of need, goals, and services. There should never be a limit on the number of IEP meetings.

Resources

[The IEP Process After Epilepsy Surgery – A Step-by-Step Guide](#) (Pediatric Epilepsy Surgery Alliance)

[Individuals with Disabilities Education Act \(IDEA\)](#) (U.S. Department of Education)

[How to Organize Your Child's IEP Binder](#) (Understood)

[How to Organize Your IEP Binder in 2023 \(and track IEP Goals!\)](#) (A Day in Our Shoes)

[Record Keeping Supports Parent Participation in Special Education Planning](#) (PACER Center)

[Resolving Special Education Issues: Keeping special education records](#) (PACER Center)

[Right to Obtain an Independent Educational Evaluation](#) (Center for Parent Information and Resources)

[Special Education Record Keeping Folders - Publications](#) (PACER Center)



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