



# How to advocate for more resources for your child

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Compiled by Laura J. Warren, TxP2P

I get many phone calls from parents who are struggling with their early childhood program, school, or insurance company to get the services they feel their child needs. I decided to ask the experts on these subjects – parent professionals who deal with these questions every day – people I go to or send parents to when I don't have the answers. It finally dawned on me that I could get the word out to more parents by putting it in this format. I hope it helps!

## *When Working with an Early Childhood Intervention Program:*

By Susan Prior, Information & Training Support Coordinator, ECI State Office

If your child is receiving services from an Early Childhood Intervention (ECI) Program and you are not happy with the services or feel your child requires more, follow the steps listed below to help resolve your concerns:

- When your child enters the program, you and your team members from your program will develop an Individualized Family Service Plan (IFSP) of what the services will look like based on your child and family needs. You are a very important part of that team and you have the right to receive answers to any questions you may have. You need to ask!
- Sometimes parents and ECI staff disagree. It is important for you to talk with the person you disagree with. If that is not possible, talk with your service coordinator and/or program director. If you are not satisfied, you can call the State ECI office at 1-800-250-2246 and ask for help resolving your disagreement.
- You have the right to ask for a change in your IFSP whenever your child has met a goal, isn't progressing or the plan is not appropriate. Your program is required to review your IFSP with you every six months and more often if needed.
- Most importantly, keep communication going with your program.
- Know your rights! Refer to your ECI Handbook or call the ECI State Office at 1-800-250-2246 if you have any questions.

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## *When Working with your Child's Special Education Program in Your Local ISD:*

By Rosemary Alexander, PhD, Parent and School Support Team, Austin ISD

Having your child covered by IDEA, the federal law that mandates special education services, is a great opportunity. Your child has the chance to receive the supports and individualized education he or she needs while you, the parent, have a chance to be involved in the decision making process regarding your child's educational services. IDEA provides you with a way to be a part of the educational team and voice your concerns, what might work best to help your child succeed, and your vision for your child's future.

However, to take advantage of these opportunities, parents must know about IDEA, understand the decision-making process, and learn how to be successful advocates for their children. Here are a few pointers for being an effective part of the school team:

- Stay in communication all year.

Get to know your child's teacher through chance encounters, phone conversations, and informal meetings.

Set up a regular communication system, such as a notebook, a checklist, regular phone calls, etc, that keep both school staff and family informed about routine concerns and events.

Volunteer at the school or ask how you can help from home.

Acknowledge through small gifts or treats that you appreciate the efforts of school staff.

- Get ready for IEP meetings (called ARDs in Texas ).

Keep a copy of your child's IEP (Individual Education Program) and latest evaluation handy. Know what it says.

Before the annual ARD or IEP meeting, meet with the teacher and other key service providers to look at the current IEP and discuss how to change it for the next year.

Get to know IDEA and the IEP process. Check out the following websites:

[www.advocacyinc.org](http://www.advocacyinc.org), [www.thearcoftexas.org](http://www.thearcoftexas.org), [www.nichcy.org](http://www.nichcy.org), and [www.wrightslaw.com](http://www.wrightslaw.com).

Go into the IEP meeting with a clear idea of the issues and what outcomes you want from the meeting.

Take a picture of your child or have your child attend the meeting. Provide a written statement from your child of what he or she would like to say to teachers, or have him or her say it directly.

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- Act carefully and thoughtfully when disagreements arise.

If you and school staff run into disagreements or hard feelings, take a deep breath and step back from the situation. Do not explode, but rather find someone outside of school to hear your story and sympathize with your emotions.

Write down what you are mad about, but also what you would like to see happen.

Find out what your school-system hierarchy is—who is the key person at each management level. Find out who allocates resources and can make a difference.

Now take action. Write letters and talk to the right people: start with the person closest to the problem, and then if you do not get help there, talk to the person next up the line.

Approach each meeting or phone conversation as a business meeting, with a business-like attitude.

First meet informally to resolve the problem, then have an ARD to write your new decisions into the IEP.

Ask for more testing to get a more accurate picture of your child's needs and abilities.

Bring in tangible evidence about your child's abilities and needs, such as videos of your child doing things he does not do at school or participating with friends outside of school; make a strong case for what you are asking for your child.

Think before meetings about areas where you are willing to compromise and where you cannot compromise.

Keep your poise and focus on issues, not personalities, facts not feelings. Do not look for revenge but try to solve problems. Keep the school team looking at long-term outcomes for your child: what's really important for him or her to learn before graduating from school? What will make this child successful after graduation?

If all else fails, find out about mediation and due process.

Consult [www.feta.com](http://www.feta.com) for many more advocacy and conflict resolution suggestions.

Teach your child to participate also.

As your child gets older (around middle school), start to involve him or her in the IEP process as much as possible. Guide your child to be a "self-advocate," able to describe his or her disability and the accommodations needed.

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Encourage your child to make choices at first about little things, then about more important issues.

Give your child opportunities to speak for him or herself in a variety of situations.

Work with the school team to coach your child to speak up in the ARD meeting, even to lead it as he or she gets older. Begin to help your child to think about the future, what work to do, where to live, and how to find friends—the elements of a good transition plan for the future.

Good luck in the process of building a team with school staff and in building a positive, productive relationship with your child's school.

### *When Working with your Insurance Company:*

By Leah Rummel, Executive Director, Texas Association of Health Plans

I receive many calls from parents having problems navigating their insurance to obtain services for their children. I have found over the years that navigating the system has become more complicated due to the unending arrangements physicians and providers have with the insurance company. Most of these are not known by you, the parent, but affect how you can receive services.

My first advice to parents is:

- Ask for case management. If your insurance company has case management ask for it or insist to have those services. Your life will be much easier if you only have to deal with one person at the company whose job is to navigate the system for you. Case managers have been known to find alternatives to services that may not be covered by the insurance, get approval for services that may be less expensive but more appropriate to your child, find other resources available in the community for your needs and suggest equipment, specialists or the latest technology available for your child that you may not know about.
- Read your policy. Never be without your policy. Your policy will tell you what is covered and how much your costs will be from the coverage. Most people who call me do not have their policy, do not know if they have a HMO or PPO, and do not know if their policy is a self-funded ERISA plan or a fully insured regulated plan. Ask your employer for a copy of the policy and find out if it is an HMO, PPO, Point of Service Plan or EPO. Find out if your plan is a self-funded plan regulated by the federal government or a fully funded plan overseen by laws in the State of Texas . The rights of members and the benefits are usually better in a fully funded plan.

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- Know your rights. You always have the right to appeal a denial; you usually have a right to have an independent review for medical necessity cases and you have the right to sue your insurance company if they have incurred harm. You have the right to information concerning your policy, and the list of physicians and providers on the network. You have the right in most cases to never be charged more than the deductible or co-payment for services with in-network physicians or providers and you have the right for help from the Texas Department of Insurance. Their toll free number for assistance is 800-578-4677 (in Austin , call 512-463-6169).
- Do not be afraid to ask for services. Many people I talk with will not ask for services. I always recommend asking for what you want. The worst that a person can say is no. Also, when you get a no, do not be afraid to go to their supervisor, and then theirs, or to the Texas Department of Insurance. A large percentage of appeals for denied cases are overturned.
- If you have a choice of insurance companies, pick carefully . If your company has a choice of insurance companies to choose from, pick very carefully. You need to take into consideration which physicians your child uses regularly and if they are on the network, what services your child uses regularly and what level of reimbursement those are paid for by the insurance company, whether network restrictions can work for you and how much out of pocket can you afford. You can also ask other parents about their experiences with the insurance company or look at their complaint record at the Texas Department of Insurance.

Remember to ask for help when you do not understand your policy.

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