

INTRODUCTION

When our son James was diagnosed with a learning disability, my wife and I experienced a myriad of emotions. The most common emotion, however, was one of confusion and being overwhelmed. Where to go, what does this mean, did we cause this, and can it be cured? Most important was “What role can we play in being sure that he can still succeed, both in school and in life?”

We searched many Internet sites, spoke to teachers, social workers and medical doctors, and read lots of books and pamphlets. When considered collectively, all of these sources helped us to assist in the development of his Individual Educational Plan (IEP). Each state has its own procedures for design and implementation of the IEP, but they are all based on a number of common federal laws, including the Individuals with Disabilities Education Act Amendments of 1997 (IDEA), the Mental Health Parity Act and the various laws governing discrimination.

I hope to provide a practical guide to the process for you, the *parents*, written from a parents’ perspective. I feel that best advice comes from those who have lived through the tears, fears and hopes of caring for a special needs child. This guide is written primarily for those with children in grade school and high school who require special services. Since my experience has been that the system is intended to provide all qualifying children services, yet is funded to provide services to a significantly smaller number, parental involvement is the key. To take part in the process you must understand it and understand the role you can take in it.

THE PROCESS

A. Identification and Assessment

If you suspect that your child has a barrier to learning, the first step is to confirm or deny the existence of the problem. If, for instance, you suspect a learning disability, such as dyslexia, delayed learning, hearing or visual impairment, ask for testing to be done by the school explaining that you suspect a problem which is impairing his or her ability to learn.

If you suspect a medical condition, speak to your family doctor and ask for a complete physical including hearing and vision. You may be amazed to find that a barrier to your child’s learning exist in a simple physical affliction you just missed on your own. An objective exam, for instance, identified that a very dear friend of ours had a child who was legally blind. Who knew this happy child had this challenge when he functioned so very well at home? Glasses and an IEP helped this child to succeed in school with minimal accommodations for his disability.

If, however, you suspect that your child is trying as hard as they can and are still not succeeding, please, do not accept a teacher’s assessment that “he is just not focused” or “he can do the work if he tries”. It may not be so, and the longer the child tries their best and fails, the more self esteem damage occurs. You are the parent and know your child best. At this point you should inform the school, *in writing*, (*Our motto with everything is to put it in writing – all correspondence – if it is not in writing – it did not happen!*) that you suspect a learning disability maybe present and you want the child tested in a reasonable amount of time (usually 10 days). You do not have to identify the disability to test for, simply describe the symptoms you see and those that have been reported to you and ask for objective testing to be done and for you to be provided the results in writing.

B. Obtaining and Interpreting Results

The testing you have sought out should produce written results such as an audiogram or vision screening result for a physical exam, or, a written result of testing for educational testing. The results will almost always identify the test given, the “normal limitations range” and your child’s results. Study them carefully. They contain a wealth of data.

Discuss with the tester exactly what was found and what, if anything can be done to assist your child if any data varies from the established “norm”.

Carefully consider any recommendations for medication, such as Ritalin, Adderal or other medicines very carefully, but do not make any commitments at this time. You should allow yourself enough time to digest

any results and recommendations and conduct your own research if necessary. I will provide some great resources for conducting this research at the end of this book. I strongly encourage you to conduct your own information gathering on the diagnosis given or deficiency identified. It will help to make you a much stronger advocate later on.

C. The IEP Meeting

If testing reveals a learning disability or physical impairment, an IEP meeting will be scheduled. You will normally be asked to come to the school and meet with their Child Study Team. This meeting is exceptionally important, as it is designed for everyone in the room to discuss how to meet your child's needs. Normally present are the regular and the special education classroom teacher, a psychologist, a learning consultant and a representative from school administration (who is familiar with the process). This is in addition to you, the parent. Keep in mind that you need not attend alone and generally have the right to bring an advocate or someone else of your choosing. I would recommend to anyone that they not go alone. The amount of information exchanged at these meetings can be overwhelming, and I recommend you bring a family member or trusted friend to help you to stay organized and take notes. If you can not do this, bring a tape recorder, but announce its presence before the meeting begins.

To prepare for the IEP meeting, you should, at a minimum:

Prepare a list of any medications your child is taking and their side effects. This can be obtained from your pharmacist. This is very important, as medication side effects may need to be accommodated for in the plan. Common accommodations might be more frequent water opportunities for children taking diuretics or lithium for bi-polar disorder. More frequent bathroom breaks may be needed to counter urination problems associated with some drugs. You may need the school nurse to administer Ritalin or insulin at lunch. Get it out in the open now, so it can be discussed. Will your child require the use of an inhaler? Tell them. All school systems have their own rules for handling medication so it is better to identify the need early.

Develop a list based on your research of accommodations your child may need to function in the classroom. Accommodation suggestions can be found near the end of this document, but may include asking for an extra set of books for a child with Attention Deficit Disorder, preferential seating in the classroom to allow better concentration, changing a schedule so the child attends the more academically challenging courses during periods of higher concentration or setting up a journal for the child to carry back and forth to school with notes from teacher to parent and parent to teacher.

Bring material with you on the disorder or condition your child has. Do not assume that the team is fully knowledgeable on your child's need. For instance, while they may have, as a group, dealt with children with Perceptual Impairments or delayed learning, they may not have extensive experience dealing with challenges like Tourette's syndrome or Bi-Polar Disorder.

Plan for your child to be involved in the process. To this end, you can help your child by preparing them to attend the meeting, talking with them honestly about what to expect, who will attend and why you are all meeting about this – and the reason is – YOU ALL CARE! These decisions will affect him or her and nobody should be allowed to lose track of the goal of providing *your* child the chance to succeed.

At the end of the meeting you should have, as a group, developed a plan to minimize the barriers to learning that exist for your child. Keep in mind, the plan must be put in writing and distributed to every teacher that your child will deal with.

During the meeting, try to keep in mind that every participant has their own agenda and their own approach to dealing with the plan. Some will be more cooperative than others, look to identify allies during the meeting and do not "get ugly" unless absolutely needed. Keep in mind that you are not asking for how many favors they can grant you, you are collectively brainstorming how to meet THEIR legal obligation to educate your child, accommodate for his handicap, and do it in the least restrictive environment needed.

There are a variety of placement options available for your child which are explained in later chapters of this document.

The plan must also be reviewed at least annually, but either you or the school can ask for a review of the plan at any time with 10 days notice. If you see something is not working, ask to look at it again and

realize you may not get it right the first time. The important thing is that it work for your child.

You will be asked to sign the plan. I do not recommend that you sign the plan at the meeting. While the team may advise that if you do not sign it, they can not implement it, you really want to look it over and be sure it complies with your notes. Lets face it, anyone can leave something off a document and it is better to get it right than to get it quick. This is your child we are talking about. Tell them you want to review it at home and return it as soon as possible. Do not delay, but take that extra day to get it right, comparing it to your notes and that of your companion at the meeting, making notes of questions if you see any and signing only when satisfied. **Make sure that everything you agreed to is written into the plan.**

D. Keeping them Honest

The best plans in the world are only going to work if they are followed. Although the school system has the responsibility to distribute the plan to all of the teachers, it is almost a guarantee that someone, somewhere, won't get the word. And your child could suffer because of it.

For example, my son's education plan indicated that because of his Perceptual Impairment, testing should not be done orally. He should be given the test in writing that the rest of the class received orally, ideally by the classroom teacher simply placing a copy of the questions quietly on his desk to read while answering, and if the test was too lengthy, he would be allowed to take the test before school, after school, at lunch or in the "Resource Room" when receiving special services. His classroom teacher made an independent decision that my son was "doing well enough in the class to take the test without accommodation" and gave tests orally. When my wife and I noticed a drop off in grades from 90s to 80s we asked him what was different and found this out. It needed to be corrected.

We called the Child Study Team and asked for a meeting explaining the challenge and asked that the classroom teacher be included in the meeting. After hearing his observations and considering his opinions we pointed out that a drop off in grades HAD occurred, that the plan was a legally binding document and that we expected it to be followed. He did not like it, he did not agree with it, but by stating this in the meeting, the school team had no choice but to reaffirm the binding nature of the IEP and to direct the teacher to accommodate the handicap.

I can not tell you how many times this has happened. Everything from not getting an extra textbook at the start of the year for one subject or another to counter Attention Deficit Disorder, to missed medications. You need to keep everyone honest. Trust but verify, Talk to your child, my son is now a young adult and we still talk every single day at 6pm to be sure the education process is on track. Keep in mind that at any time, after trying to work things out, if you feel that your child's IEP is not being followed or is inadequate; you can file a complaint with the your State Department of Education. My own experience with this process is that complaints are resolved very quickly in most cases; however, in major cases an arbitrator may be used to resolve technical differences. You can strengthen you request to change placement or ask for an additional accommodation to be considered many times with a note from your family doctor, explaining the need or a cited reference from a web site showing the benefit of this accommodation. Your state contact can be very easily found at an excellent site I found called www.wrightslaw.com.

I tell you these things not because I think the systems for our children are there to harm them. They are not. Most of the teachers and professionals have the best of intentions and we have met some real gems. We do not need to become adversarial with them. However, the sad fact of the matter, based on my personal experience is that while a school district may actually have 100 kids who need services of one kind or another, they only have funding for about 65 or 70 of them. Your mission is to be sure that your child gets taken care of and the parent who advocates for their child to receive reasonable accommodations will get the services. Others may or may not.

I honestly believe that my children are a blessing. Any work I do on their behalf is worthwhile and I assume that you feel the same or you would not have gotten this booklet. I hope, in the near future, to develop a newsletter on Special Education topics written from a Parents point of view. If you would like to receive it, please, email me at Jim@theparentaladvocate.com and I will be happy to include you in this distribution. The newsletter will be published absolutely free of charge.

E. Great Comebacks

Frequently during meetings with the Child Study team comments will be made out of emotion, some good and some bad. Your objective is to keep the process on track so you can obtain the best services for your child under pressure, so thinking about the “what ifs” in advance has proven to be a lifesaver for me in the past. Here are some examples:

School: Your child’s grades are good/excellent

Comeback: Who are you comparing my child to? How do you judge that?

School: Trust Us

Comeback: We have a good relationship, but if my child transfers school during the year, the next school may not be as helpful as you are, I would feel better if this was written into the plan so there is no confusion. I am sure that you understand.

School: We don’t do that

Comeback: Really, not even if my child needs this to succeed? I thought that was against the law. Can I get that in writing?

School: This is the ONLY program we currently offer

Comeback: I guess that’s why they have an ‘I in IEP, to make it an individual plan, now how do we address this valid need?

School: Your child will be labeled. Why would you want that?

Comeback: The disease illness or handicap labels them, completing this process makes sure that my child gets the Free and Appropriate Public Education he or she is entitled to.

School: We are not sure your child needs additional help and longer

Comeback: I am not so sure that I agree. I think we are seeing improvements because of the accommodations that have been made. What do you base your recommendation on?

School: He or she must be more responsible or lacks motivation

Comeback: Ok, great, how do we teach him or her that?

School: He does not need Assistive technology (PC, Organizer, Tape Recorder, etc)

Comeback: I am not so sure, can I have the results of the FORMAL Assistive technology survey done?

(this must be done formally not informally and will generally be less costly for them to give than conduct the survey)

School: Aren’t you getting a divorce or having marital problems?”

Comeback: That really is not your business, lets stay on track for education please.

School” But you need to sign this now

Comeback: I don’t think that I can be legally compelled to sign and would certainly be more comfortable having my advocate review this with me. I will return it in 3 days at most. **(two hints here - #1 – keep your promise and return it ASAP, and #2 – if questioned about your advocate – do not disclose who it is – whether you have one or not)**

School: Oh, you have an advocate, we would be happy to work with him or her

Comeback: Thank you for your generous offer, but as a parent I would be more comfortable dealing with this process myself, after all, I will be making sure the plan is followed by the school. Besides, the advocate is there to advise me. **(this is great whether you hire an advocate or you are advised by a counselor or an internet support group.)**

School: If we do it for him or her, everyone will ask for it

Comeback: I really don’t think so, as this is an Individual Education Plan and I am sure you will discuss if it is appropriate for other students. Besides, we do not discuss his education plan outside of the family and the school and I am sure that you will not either.

ACCOMODATIONS

Below is a list of accommodations to be considered when preparing for an IEP meeting. It is by no means meant to be all inclusive and no child needs them all. I hope that upon review, they may be useful or give you ideas on what accommodations your child may need to become successful

FOR ANY DISABILITY

Preferential Seating in the Classroom (TO AVOID DISTRACTIONS)

Regular Progress Reports to Parent (MORE FREQUENT THAN REPORT CARDS)

DYSLEXIC STUDENTS/ PERCEPTUALLY IMPAIRED STUDENTS

Allow for submission of dictated homework – either use of parent as transcriber or taped reports

Do not force oral reading in the classroom without advance notice (Self esteem damage)

Untimed tests

Reduced homework load – a 1 hour assignment for a “Typical Student” could take 3 hours

Eliminate spelling tests in lower grades

Reduce copying assignments

Allow Assistive technology (Typing of notes, etc, Dictation software)
Ask for student to receive training in note taking and organizational skills
Consider books on tape – the school can provide or you can get them individually from the RFBD.ORG

BEHAVIORALLY DISABLED STUDENTS

Identify a key phrase for the student to use when he/she needs a “time out”
Identify a staff member, nurse or counselor for the student to report if agitated
Require the reinforcement of good behavior
Allow the student to take any medications in a “private setting” to avoid embarrassment
Consider allowing the student access to Mental Health counseling at the school.

OTHER ACCOMODATIONS I HAVE WITNESSED TO BE OF VALUE

The email address of a school contact (usually the teacher)
Having the school conduct an “in -service” training on your child’s disability
Supplementing or replacing a single subject with Resource Room Assistance
Rearranging classes at the High School Level to allow the student to take more academics at
Most productive time of day, with Physical Education and lunch at less productive times.
Allowing for a reduced class schedule when depressive episodes occur
ANYTHING needed to accommodate the use of medication (think – susceptible to diarrhea, dehydration,
lithium tremors, etc)
Providing a laptop for student use in class and at home (At the schools expense)
Development of a planner or use of a Palm Pilot device for those with ADD so assignments are not
forgotten.

PLACEMENT OPTIONS

Each child with a disability is entitled to the education in the Least Restrictive Environment (LRE)
Necessary. This can be critical depending upon the age of the child, as tearing them away from or isolation
from their friends or other sources of validation and self esteem are critical considerations to their overall
well being.

Placement options, pretty much in order are:

- 1) Regular Classroom placement with accommodations – basically allowing them to be where they
are with some minor modifications to the curriculum, like not timing tests etc.
- 2) Regular Classroom placement with some resource room placement – maybe just help with math if
the disability hinders processing of numbers or calculations.
- 3) Classroom Placement with a Paraprofessional – this can be beneficial if your child requires intense
help staying task focused or needs reinforcement. Basically the system can provide an aide to
focus on your child, who may also help out. Sometimes called inclusion classes.
- 4) Self contained classes – Essentially a Special Education Teacher provides instruction in the
school system without travel, much smaller classes, no changing of classes. This can be fantastic
for a child with ADD or emotional problems who is overwhelmed when they make the big jump to
Middle or High School.
- 5) Out of District Placement – usually a special needs school where the child is transported to the
school by bus or van. Emotionally disturbed children can be placed temporarily here where more
support services are available. Also, specialized schools are available for the blind and retarded.
Your district should be able to identify several to choose from if needed, but I have also found the
National Association of Private Schools for Exceptional Children www.napsec.org to be a
tremendous resource for this service. They are free and willing to help. A rare combination.
Keep in mind that another, usually temporary option, you and the team, in conjunction with your family
doctor or psychiatrist, can consider placement on Home Instruction. This allows your child to remain at
home with the teacher coming to him or her. While it is used frequently for disabling illnesses or injuries
like broken hips, I have found it to be a godsend during periods of clinical depression. My own child found
it more manageable to focus on subjects for the 1 hour per day of tutoring rather than attend school. It
gave him breathing room to allow the depressive slump to pass.

RESOURCE ORGANIZATIONS I HAVE FOUND USEFUL

Attention Deficit Disorder Association <http://www.add.org>

Child and Adolescent Bi-Polar Foundation <http://www.bpkids.org>

National Institute for Mental Illness www.nami.org

The Parental Advocate www.theparentaladvocate.com

LD Online www.ldonline.com

Dyslexia Parents Resources www.dyslexia-parent.com

WRIGHTSLAW (Extensive Library) www.wrightslaw.com

Association for Comprehensive Neuro Therapy (Tourette's site) www.latitudes.org

Deaf Resource Library www.deaflibrary.org

Foundation for the Blind and Dyslexic (Books & Textbooks on Tape) www.rfbd.org

Determine your child's learning type www.howtolearn.com

National Center for Learning Disabilities www.nclld.org

Parents of Bi-Polar Kids www.geocities.com/enchantedforest/1068/

Department of Education Memo Outlining the Rights of Children with ADD

<http://www.add.org/content/legal/memo.htm>

A copy of the law on Special Education (IDEA) can be downloaded from the Department of Education at:

<http://www.ed.gov/offices/OSERS/OSEP/Policy/regulations.html>

Many of these organizations host bulletin boards and newsletters. They tend to center on parents sharing experiences with each other, the method which has worked best for me in dealing with James' needs.

Again, if you find something I left out, please drop me a line and let me know. Also, as the newsletter comes into being (again, totally free), if you would like a copy, please email me at

jim@theparentaladvocate.com and I will be happy to include you in the mailing. I will never, ever, release your name and email to another person.

Thanks for reading this ebook. I sincerely hope you will find it useful in helping your child to get the help they need and to navigate the system. If you have a question, please, email me, I will be happy to share my experiences with you. You can reach me at jim@theparentaladvocate.com.

Please visit my website www.theparentaladvocate.com