

Advocating for Your Child—Getting Started

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Good special education services are intensive and expensive. Resources are limited. If you have a child with special needs, you may wind up battling the school district for the services your child requires. To prevail, you need information, skills, and tools.

Who can be an advocate? Anyone can advocate for another person. Here is how the dictionary defines the term “advocate”:

ad-vo-cate verb, transitive. To speak, plead or argue in favor of. Synonym is support.

1. One that argues for a cause; a supporter or defender; an advocate of civil rights.
2. One that pleads on another’s behalf; an intercessor; advocates for abused children and spouses.
3. A lawyer. (The American Heritage Dictionary of the English Language, Third Edition)

An advocate performs several functions:

- Supports, helps, assists, and aids
- Speaks and pleads on behalf of others
- Defends and argues for people or causes

DIFFERENT TYPES OF ADVOCATES

Special education advocates work to improve the lives of children with disabilities and their families. You are likely to meet different types of advocates.

Lay Advocates

Lay advocates use specialized knowledge and expertise to help parents resolve problems with schools. When lay advocates attend meetings, write letters, and negotiate for services, they are acting on the child’s behalf. Most lay advocates are knowledgeable about legal rights and responsibilities. In some states, lay advocates represent parents in special education due process hearings.

Educational Advocates

Educational advocates evaluate children with disabilities and make recommendations about services, supports and special

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education programs. When educational advocates go to eligibility and IEP meetings, they are acting on the child’s behalf. Some educational advocates negotiate for services. Others are less knowledgeable about special education law and how to use tactics and strategies.

School Personnel

Teachers and special education providers often see themselves as advocates. Teachers, administrators, and school

staff often provide support to children and their families. But because they are employed by school districts, school personnel are limited in their ability to advocate for children with disabilities without endangering their jobs.

Parents

Parents are natural advocates for their children. Who is your child’s first teacher? You are. Who is your child’s most important role model? You are. Who is responsible for your child’s welfare? You are. Who has your child’s best interests at heart? You do.

You know your child better than anyone else. The school is involved with your child for a few years. You are involved with your child for life. You should play an active role in planning your child’s education.

The law gives you the power to make educational decisions for your child. Do not be afraid to use your power. Use it wisely. A good education is the most important gift you can give to your child.

As the parent of a child with a disability, you have two goals:

- To ensure that the school provides your child with what

the law says is a “free appropriate public education” that includes “specially designed instruction...to meet the [child’s] unique needs...”

- To build a healthy working relationship with the school.

WHAT ADVOCATES DO

Advocacy is not a mysterious process. Here is a quick overview of advocacy skills.

Gather Information

Advocates gather facts and information. As they gather information and organize documents, they learn about the child’s disability and educational history. Advocates use facts and independent documentation to resolve disagreements and disputes with the school.

Learn the Rules of the Game

Advocates educate themselves about their local school district. They know how decisions are made and by whom.

Advocates know about legal rights. They know that a child with a disability is entitled to an “appropriate” education, not the “best” education, nor an education that “maximizes the child’s potential.” They understand that “best” is a four-letter word that cannot be used by parents or advocates.

Advocates know the procedures that parents must follow to protect their rights and the child’s rights.

Plan and Prepare

Advocates know that planning prevents problems. Advocates do not expect school personnel to tell them about rights and responsibilities. Advocates read special education laws, regulations, and cases to get answers to their questions.

Advocates learn how to use test scores to monitor a child’s progress in special education.

They prepare for meetings, create agendas, write objectives, and use meeting worksheets and follow-up letters to clarify problems and nail down agreements.

Keep Written Records

Because documents are often the keys to success, advocates keep written records. They know that if a statement is not written down, it was not said. They make requests in writing and write polite follow-up letters to document events, discussions, and meetings.

Ask Questions, Listen for Answers

Advocates are not afraid to ask questions. When they ask

questions, they listen carefully to answers. Advocates know how to use “Who, What, Why, Where, When, How, and Explain Questions” (5 Ws + H + E) to discover the true reasons for positions.

Identify Problems

Advocates learn to define and describe problems from all angles. They use their knowledge of interests, fears, and positions to develop strategies. Advocates are problem solvers. They do not waste valuable time and energy looking for people to blame.

Propose Solutions

Advocates know that parents negotiate with schools for special education services. As negotiators, advocates discuss issues and make offers or proposals. They seek “win-win” solutions that will satisfy the interests of parents and schools.

YOUR ASSIGNMENT

Plan for the Future

What are your long-term goals for your child? What do you envision for his or her future? If you have a vision about what you want for your child, you are more likely to achieve your goals.

Do you expect your child to be an independent, self-sufficient member of the community? Although some children with disabilities will require assistance as adults, most will grow up to hold jobs, get married, and live independently.

If you believe others will make long-term plans for your child and provide him or her with the necessary skills to be an

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independent, self-sufficient member of society, you are likely to be disappointed.

Do not expect school personnel to make such plans for your child—this is your responsibility.

Develop a Master Plan

Many parents don't have a master plan for their child's education. You may not know where you are, where you need to go, or how to get there. But after you've determined your long-term goals, it's time for the master plan and additional questions. What will your child need to learn before he or she leaves the public school system?

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What services and supports will he or she need to meet these goals?

Are you ready to advocate? Here is a list of supplies that will help you get started:

- Two 3-ring notebooks (one for your child's file; one for information about your child's disability and educational information)
- Three-hole punch
- Highlighters
- Package of sticky notes
- #10 Envelopes
- Stamps
- Calendar
- Journal
- Contact log
- Small tape recorder

JOURNEY FROM EMOTIONS TO ADVOCACY

Becoming effective on behalf of their children means parents must journey from emotions to advocacy. On this journey, you will learn about your child's disability, educational and remedial techniques, educational progress, Individualized Education Programs (IEPs), and how to artfully advocate.

You will learn how to present your concerns and problems in writing, prepare for meetings, and search for win-win solutions. You will learn how to use your emotions as a source of energy and power, and how to focus on getting an appropriate education for your child. 

Peter and Pamela Wright will be holding a special one-day parent seminar (separate registration required) at the 10th International Fragile X Conference. Contact the NFXF for more information.

Case Study of An Aggressive 4-Year-Old

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his caregiver and hit her. I got up and immediately sat him down next to me and said, "No hitting, time-out." I did not yell, but I was firm. Initially he got up, and I sat him back down, and repeated, "No hitting, time-out." He tried to get up again, so I sat next to him and kept my hand firmly on his shoulder. He tried to bite me, so I kept my hands away from where he could reach with his mouth. After approximately two minutes, during which he was still struggling, I lifted my hand and said, "You can get up now." He was very angry, and he immediately rushed to his caregiver and hit her in the face. What a perfect learning opportunity! I moved quickly to him, sat him down next to her and said, "No hitting, time-out." Now he was REALLY mad. He yelled and tried to bite me again. I moved my arm to a position that he could not reach, but I did not verbally address the biting. After two minutes he got up yelling and crying, went over to his caregiver, raised his hand, looked at me—and then sat down. He cried, but did not hit her.

That was about as good as it can get for only two trials. His hitting clearly did not disappear, but he did quickly learn the connection between hitting and time-out. His caregiver was very impressed with how quickly he was able to learn, so she and his nanny used the strategy and his hitting decreased. Both the nanny and the caregiver, however, were concerned about his crying during time-out. Following a discussion on the importance of managing his behavior, they agreed to use time-out as a part of his behavior plan. I was not in their home on a regular basis, so I do not know how frequently they used this process after I left. Reportedly they had success when it was used consistently.

The importance of this vignette is to show how quickly children with FXS can make the connection between the inappropriate behavior and time-out, and that they are capable of inhibiting these behaviors. It is also important to note that this family, as is typically the case, needed some initial support in developing and implementing the plan.

—Karen Riley