

# Advocacy

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# Maine Parent Federation



## Information Disclaimer

The purpose of the information packet is to provide individuals with reader friendly information. We believe that a good overview is a realistic one. For this reason we have included a variety of information that may include the more difficult characteristics of a diagnosis or topic along with medical, educational and best practice information.

All information contained in this packet is for general knowledge, personal education and enrichment purposes. It is not intended to be a substitute for professional advice. For specific advice, diagnosis and treatment you should consult with a qualified professional.

When this packet was developed, Maine Parent Federation made every effort to ensure that the information contained in this packet was accurate, current and reliable. Packets are reviewed and updated periodically as changes occur.

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## Disclaimer

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# Advocacy

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## Advocacy

### Advocating for Your Child - Getting Started by Pamela Wright, MA, MSW -

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Website: [www.wrightslaw.com](http://www.wrightslaw.com)

#### Why Advocate?

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 needs. 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 in 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 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.

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### ***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 a "free appropriate public education" that includes "specially designed instruction . . . to meet the [child's] unique needs . . ." (20 U.S.C. §1401)

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.

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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 to 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.

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### Your Assignment

#### *Plan for the Future*

What are your long-term goals for your child? What do you envision for your child in the future?

If you are like most parents, you are focused on the present. You haven't given much thought to the future.

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 be adults who hold jobs, get married, and live independently.

If you have a vision about what you want for your child in the future, you are more likely to achieve your goals.

If you believe others will make long-term plans for your child and provide your child with the necessary skills to be an independent, self-sufficient member of society, you are likely to be disappointed.

#### *Answer Questions*

What do you want for your child? What are your goals for your child's future? Do you have a master plan for your child's education?

If you want your child to grow up to be an independent adult, what does your child need to learn before he or she leaves the public school system?

What do you want?

#### *Develop a Master Plan*

If you are like many parents, you don't have a master plan. You don't know where you are, where you need to go, or how to get there. Do not expect school personnel to make long-term plans for your child -- this is your responsibility.

Begin by thinking about your vision for your child's future. What are your long-term goals for your child? What will your child need to learn? What services and supports will your child 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)
- \* 3-hole punch
- \* Highlighters
- \* Package of sticky notes
- \* #10 Envelopes
- \* Stamps

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- \* Calendar
- \* Journal
- \* Contact log
- \* Small tape recorder

In this article, you learned about lay advocates and educational advocates, and about limitations on teachers and special education staff in their ability to advocate. You learned that parents are natural advocates for their children.

You learned about basic advocacy skills -- gathering and organizing information, planning and preparing, documenting, problem solving, and negotiating. You have a list of supplies to help you advocate.

You learned that you must plan for your child's future. A plan is like a roadmap. When you have a plan, you know where you are, where you need to go, and how to know when you arrive.

### **The Parent's Journey From Emotions to Advocacy**

On your journey from emotions to advocacy, 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.

### **Wrightslaw: From Emotions to Advocacy - The Special Education Survival Guide**

This article is based on a chapter in [\*Wrightslaw: From Emotions to Advocacy: The Special Education Survival Guide\*](#) by Pamela Wright and Peter Wright.



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### From Emotions to Advocacy: The Parents' Journey

by Pamela Wright, MA, MSW

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Website: [www.wrightslaw.com](http://www.wrightslaw.com)

Worry. Sadness. Fear. Guilt. Helplessness. Anger. Confusion. Disappointment. More worry.

Parenting has always encompassed difficult periods — times when parents feel concerned and confused — sleepless nights when they worry about how well they are fulfilling their responsibilities to their children. Raising a disabled child "ups the ante." Meeting the complex needs of the child with a disability can be extraordinarily difficult, frustrating, emotionally draining — and expensive!

Parents of disabled children understand one crucial fact—that only by obtaining an appropriate education will my child have a real opportunity to lead a fulfilling, productive life. Unfortunately, statistics about the outcomes of special education programs will not alleviate your concerns.

Researchers have found that most special education programs fail to confer adequate educational benefit to many of the youngsters they are designed to serve. The statistics are sobering:

- 74% of children who are unsuccessful readers in the third grade are still unsuccessful readers in the ninth grade. (*Journal of Child Neurology*, January, 1995)
- Only 52% of students identified with learning disabilities will actually graduate with a high school diploma. Learning disabled students drop out of high school at more than twice the rate of their non-disabled peers. (*Congressional Quarterly Researcher*, December, 1993)
- At least 50% of juvenile delinquents have undiagnosed, untreated learning disabilities. (National Center for State Courts and the Educational Testing Service, 1977)
- 31% of adolescents with learning disabilities will be arrested within five years of leaving high school. (*National Transition Longitudinal Study*, 1991)
- Up to 60% of adolescents who receive treatment for substance abuse disorders have learning disabilities (Hazelden Foundation, Minnesota, 1992)
- 62% of learning disabled students were unemployed one year after graduation. (*National Longitudinal Transition Study*, 1991)

A meaningful education will help turn these figures around.

#### Emotions: Energy Source or Achilles Heel?

*"The pure rage that stems from an unredressed injury can be more fearsome than that produced by the original wrong."* (Gerry Spence, respected attorney-litigator and commentator on civil rights in America)

John sat on the couch in my office. His face reddened and his fists clenched as he talked about his son Chris and his contacts with the teachers and administrators at Chris's school:

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"My son is 13 years old and he still can't add simple numbers. He can't add 15 and 9. He can't read either, and he's been in special ed since he was six years old.

"This year they put him in regular classes with some sort of collaborative teacher—they say that's how they teach LD kids at his school, and that's all they can do. And now he's failing everything—everything! Last grading period—four F's and one D. The only thing he's passing is Science."

As I sifted through several inches of disorganized documents that John brought to the meeting, John continued: "And when I complained that he isn't learning, they told me it's my fault because I'm not making him do homework! Do you know what a nightmare homework is? He's exhausted when he comes home from school — where he hasn't learned anything. Then he has to spend two or three hours doing papers. It's a nightmare. A real nightmare . . .

I continued to skim through the documents — old standardized tests, letters from Chris' teachers, school papers, report cards, IEPs from the first grade to the present — all mixed up. No current psychological or educational testing. John's voice raised in anger: "Pam, you don't understand. They lie. They blame kids for not learning when they are not teaching . . . And they are stupid. They can't teach, they can't do anything. They are morons! And I told the principal that when I met with him last week . . ."

Tragically, John's case is not an isolated situation. This father's frustrations and fears had driven him to explode and demean school personnel. His reaction — an angry outburst — gave him short-term relief from his intense feelings of frustration.

Did his explosion and insults lead to the development of a more appropriate educational program for his son? Of course not. Will it be more difficult for John to work effectively with school personnel in the future? Definitely. Will Chris be the ultimate loser? You bet!

The intense emotions experienced by parents often become their "Achilles heel" as they attempt to obtain an appropriate education for their child. When the local school system fails to provide the child with that critical "special" educational experience or offers "too little, too late," many parents are shocked and angry.

These parents feel betrayed by the one system which they had trusted to help with the difficult task of educating their handicapped child. Once lost, trust is hard to regain. As Gordon, the father of a fourteen year old learning disabled boy erroneously diagnosed by the school district as "seriously emotionally disturbed," explained:

"One of the great tragedies of parental disillusionment is that even if we finally find a good educational program, we know that our child has been damaged by people within the school system. We don't know how severe or enduring the damage will be. The feelings of betrayal are often so strong and bitter that there will never be any trust by the parents."

### **Grieving: The Loss of the "Perfect Child"**

Children enter our lives with excitement, anticipation and joy. We have high hopes and great expectations for this new life. How do we process the new reality—that this much-loved child has a serious "life disability?" Or that this disability may negatively affect our child's ability to live a productive, satisfying, independent life?

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Parents must mourn the loss of the "perfect child" before they can become effective advocates.

Amy is a seven-year-old child who was diagnosed with autism. Her mother Karen recalled:

"As parents, we are at an enormous disadvantage. When we discover that our child is disabled, we are in shock and grieving. We don't know the laws or even that there are laws. We don't know about the IDEA. We don't know that we have any rights. We just trust for the first couple of years. Then something happens which causes us to become a little suspicious and we begin to look into things . . . and the worms come pouring out of the woodwork."

Mourning is the natural, necessary and healthy process that begins when you learn that your child has a disability. If not handled appropriately, the mourning process can continue for years. You need to come to terms with your loss and mourn the hopes and dreams that may never be realized. In common with other major losses, mourning encompasses predictable emotional stages. Typically, parents move back and forth between these stages, especially in the early months and years following their child's diagnosis.

### *Shock and Denial*

"I don't believe it. He is just a late bloomer. All the boys in our family had to repeat grades. And look at us—we did okay!"

Millions of adults have undiagnosed, untreated learning disabilities and attention deficit problems. If they are fortunate, they find a "good fit" in their choice of work and are successful, despite their disabilities. Yet, most learning disabled adults lead lives that are deeply affected by sadness, disappointment and frustration.

Undetected, unremediated learning disabilities are causally connected to many other serious life problems—from juvenile delinquency and substance abuse to severe marital problems, domestic violence, and chronic unemployment. Typically, learning disabled adults develop negative views of themselves as lazy or stupid — or worse.

Most of these adults — numbering in the millions — have developed a strong, pervasive sense of having failed. From their perspective, they failed to live up to their own expectations and the expectations of others. Their negative view of the self and their identity as a failure permeate all areas of life, leading to interpersonal, socio-emotional, marital, vocational, and legal problems.

If parents continue to deny the seriousness of their child's problems, these problems will not be appropriately treated, the child will not receive appropriate educational remediation—and the child is very much at risk for becoming another tragic statistic.

Unfortunately, parents who are in denial may find willing co-conspirators within the educational system. In some school districts, teachers are under a gag order by school administrators, forbidden to share their concerns about your child or to provide you with the information that you need about the child's lack of progress. In other districts, school administrators who have the lowest referral rates for special education services receive special commendation.

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### *Anger*

"I just wonder how the psychologists and special education directors who so systematically work to deny educational services to our kids can face themselves in the mirror every morning . . ."

Intense feelings must find an outlet. Parents of disabled children have lots of intense feelings — including anger. Typically, these parents also feel frightened, helpless and out-of-control. To assert some sense of control, they may attempt to assign blame for their child's problems — onto school personnel, the child, their partner, themselves, God, bad luck, or fate.

To avoid feelings of guilt and sadness, some parents externalize their emotions, blaming or faulting someone or something for the problems their child is experiencing. Sometimes this blame is warranted. As we will see in Mariah's case, when parents believe they have been betrayed by the educators in whom they placed their trust, their anger and sense of personal outrage can be intense.

Mariah is a nine year old child with at least average intellectual ability. When she was two years old, a brain tumor was detected. Over a period of years, Mariah endured painful surgeries, chemotherapy and radiation therapy. These treatments saved her life, but left her with multiple handicapping conditions, including learning disabilities, orthopedic and speech problems, and an attention deficit disorder.

Mariah's school district offered to provide a minimal level of special education services to this child. First, by using a "discrepancy formula," they refused to provide any special education services aimed at remediating her learning disabilities, claiming that she had not fallen far enough behind to qualify for services.

Later, using a novel argument, they argued that Mariah was not eligible for services under the "Traumatic Brain Injury" classification because her brain injury was caused by a tumor, not "acquired" from an external injury. Not surprisingly, Mariah's parents were shocked and angry.

Mariah's mother, Elizabeth, spoke of her two year battle to secure appropriate special education services for her daughter:

"I wake up in the morning and begin making phone calls. The laundry sits along with other relics of normal life. The school district is so good at what they do—setting up roadblocks and denying educational services—that it is consuming my life just to get an IEP for my daughter. I didn't know how the system worked for the first couple of years. I just kept going from place to place, getting evaluations which I gave to the school. I thought that once they understood what Mariah needed, that would be it. Was I ever wrong! All those evaluations were just 'filed.' Period!"

Elizabeth's soft voice held a strong undercurrent of contempt:

"When I sit and think about the undeniable fact that my child was not provided with an appropriate education for years, not as a result of 'blundering' or 'poor judgment,' but intentionally, and that we were manipulated by intentional double-talk, my blood just boils."

"Why is this type of thing different from any other scam? If school district personnel deprive children of their

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legal rights through the use of double-talk, flimflam, fraud, deception . . . this should be a crime under the law, and they should be held personally responsible for their actions!"

Some parents are angry about the hard choices — and the sacrifices — that must be made. That these choices and sacrifices are often difficult, is attested to by comments made by the father of two disabled youngsters: Both parents being able to work in their fields, or one having to stay home because the children's needs are so great.

- Having to choose between one kid getting mental health care, or the other kid getting speech therapy.
- Being in crippling debt, or merely being in tremendous debt.
- Losing a retirement fund that was built up over 24 years or losing a college fund that was built up over 17 years.
- Having to choose between a psychiatrist or a psychologist solely on the basis of cost.
- Having to choose between marital therapy for the parents or bankruptcy.

Tough choices.

### *Sadness and Guilt*

Other guilt-ridden parents internalize their feelings, turning their anger inward and blaming themselves for the child's problems. Anger turned inward leads to depression. And depression, with attendant feelings of inadequacy, helplessness and hopelessness, leads to emotional withdrawal.

A tearful young mother sat across from me in the office. Kim's nine year old son Justin had been diagnosed with a learning disability in reading and language (i.e. dyslexia) and attention deficit hyperactivity disorder (ADHD) nearly three years ago. Now in the fourth grade, Justin continues to have great difficulty reading, despite having received three years of special education services.

Justin's temper outbursts at home had intensified—the family dreaded the frequent rages during which he turned his anger on himself and family members. His mother was overcome with feelings of guilt, inadequacy and depression. She saw a psychiatrist who had placed her on antidepressant medication.

Kim had experienced similar problems in school. She reversed letters and syllables and "read from right to left" for many years. As an adult, her dyslexia was diagnosed. Kim's school failures had induced in her a pervasive sense of shame. Unlike her son, she became overtly withdrawn and depressed.

Kim's own complex blend of personal history and emotions had created a compulsive need to apologize-for taking up my time, for not understanding what various educational tests measured, for being depressed, for being a "bad Mom."

Based on the results of Justin's earlier evaluations, which clearly identified his dyslexia, coupled with his ongoing inability to decode words, I urged Kim to contact her son's school. Justin was in need of a more intensive program of remediation. Kim requested the meeting, which was also attended by the principal.

That afternoon, my answering machine contained a lengthy message from Kim:

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"Pam, I had the meeting. They were really mad at me. Justin's LD teacher kept telling me that she gave Justin extra time and that she worked really hard with him. She even permits him to sit in the front of the room."

"I felt bad. I told her that I really did appreciate what she was doing for Justin. I told her over and over that I knew she was doing everything she could for him. I think I need to meet with her again . . . When I told them that you thought Justin needed more testing about his dyslexia, they got upset. They asked me why I was talking with you. It's like they felt that I didn't trust them or something."

"When I tried to talk about Justin's dyslexia, the principal sat back in his chair and rolled his eyes. The principal and the LD teacher started talking and laughed. I know they were angry. I wanted them to know that I really appreciated everything they were doing for Justin, it wasn't that I was ungrateful but . . ."

Remember John and his son Chris, earlier in this article?

John's inability to control his anger and frustration caused him to react in a way that would have negative consequences for his son Chris. Like John, Kim approached the school to request additional services for her child.

What are your thoughts about Kim's approach?

Like John, Kim's emotions are her Achilles heel. Unlike John, Kim is a conflict-avoider — polite, unassertive, afraid of authority figures, and terrified that she will anger or offend others. By being conciliatory, is Kim functioning as an effective advocate for her son? Are the school personnel at Justin's school likely to accede to her request for additional testing? Has Kim persuaded the school officials to develop a more intensive program to effectively remediate Justin's dyslexia?

Sadness is a normal part of the mourning process. Guilt, sadness and regret often merge into a painful tangle of emotions. In Justin's case, his mother's feelings of shame about her own learning disabilities and her lack of self confidence, combined with her pattern of conflict avoidance, made her an ineffective advocate for her child.

### *Acceptance and Emotional Resolution*

Many parents try to avoid experiencing feelings of sadness and regret, preferring to remain angry. Given the pain inherent in sadness and regret, this is an understandable impulse. Yet, it is essential to mourn the loss of the "perfect child." Mourning the loss is not the same as repudiating your child or finding him less worthy of your love. Instead, it is part of the process of acceptance and resolution which will free you to move on.

### **Roadblocks on Your Journey**

#### *The Intimidation Factor and Transference*

At a parent support group meeting, I listened to the following exchange between two fathers. Both men had children with learning and attentional problems.

The first father, a businessman who specialized in marketing and sales confessed:

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"I always feel anxious and intimidated when I go to school for a meeting about my daughter. I start to feel anxious before I even get there. By the time I get to the parking lot, my stomach is in knots. I feel completely intimidated. When they ask me what I think, I don't know what to say. Being speechless is usually not a problem for me!"

"I know my daughter is not learning. I know she is falling further and further behind. I know that I'm very worried about her, but I don't know exactly what they need to do differently. I'm not a teacher. I don't know what to say—aren't they supposed to be the experts?"

The other father, a respected physician and father of two handicapped kids, responded:

"Boy! Do I know that feeling well! There is something about the process -- this team business where you sit around a table and it's just you, the parent, on one side, and six or seven school people on the other.

"I always feel intimidated when I go to a meeting at the school. I feel like I did when I was about eight years old and had to go to the principal's office. I was in big trouble then and I feel like I am in big trouble now!"

People are intimidated in different situations and contexts. Many of the decisions made for handicapped children are made by "teams" or committees. It is not unusual for IEP meetings to include five or six — or more — school district representatives — and one parent.

These meetings are held at the school — unfamiliar ground for most parents. Given these dynamics, it is not surprising that most parents feel intimidated. And how do people respond when they feel intimidated? Some respond with anger and defensiveness. Others wilt under the pressure.

If the parent also had difficulties in school, old negative memories and emotional reactions will often color his or her present feelings about schools, teachers, authority figures, and school meetings. The transference of emotions from past situations to present circumstances occurs in all areas of our lives. This transference can be positive or negative.

Remember Kim? Because her dyslexia was undiagnosed and unremediated, her personal experiences in school were predominantly negative. These past experiences led to negative expectations—which contributed to her fearful, conciliatory responses toward the educational "experts" at her son's school.

However, if the parent experienced school as a helpful, supportive place, then positive feelings and expectations will tend to transfer to the current situation. These parents expect that the school will be a helpful environment for their handicapped children.

### *Getting "Stuck"*

Because the mourning process involves intensely painful emotions, many parents try to avoid it by minimizing or denying their feelings. Others get "stuck" in one phase — and fail to complete the process.

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Like people who see themselves as "victims" of divorce, these parents remain angry, bitter, guilty, or depressed for years — or for life. Mired in negative emotions, they accomplish little of value for their child. You must not let this happen to you.

Failure to deal with reality causes other problems. As we have seen, when parents remain in denial and refuse to acknowledge that the child's problems are serious, their child will not receive necessary educational services. Parents who obsess about the transgressions perpetrated by the school system often "burn out" without achieving anything that is of true value to the child.

However, there is another serious danger that many parents of disabled children face. Little has been written about this danger in the parenting and advocacy literature but it is of great concern.

### *Overprotectiveness*

Attempting to suppress feelings of personal guilt and external blame, many parents become overprotective of their child. Unable to protect the child from the disabling condition, they attempt to protect him from other difficult or challenging areas of life.

The development of overprotectiveness, fueled by pity and guilt, may be the biggest mistake that any parent can make in raising a child with a disability. Overprotective parents unwittingly create chronic dependency and "learned helplessness" in their children — a mindset that will often persist throughout that individual's life.

### **Paul**

These children grow up to be adults who believe that they "can't" do things. Let's look at the case of Paul. Paul is a young man who was diagnosed with learning disabilities while a young teen. He received special education assistance and finally graduated from high school.

After being fired from dozens of jobs over a period of years, Paul enrolled in a community college where he took a night course. To his surprise, he was successful.

Encouraged by his unexpected success, Paul returned to college and, after several years of part-time study, graduated from a four year university with a degree in special education. Paul had decided to become a special education teacher.

Paul's teaching career had its ups and downs. He spent several fairly successful years in a small rural school system. Open about his learning disabilities, he asked for and received help from other teachers. Eventually, Paul obtained a job in the large urban school district where he had received his own education. He would be teaching elementary school children who had learning disabilities. He had achieved his dream.

But Paul had other problems which caused his dream to self-destruct. Pampered by over-protective parents, Paul had developed a personality style that was characterized by helplessness and a stubborn insistence on getting his way, coupled with a lack of empathy and an inability to see the perspectives of others. Paul firmly believed that his learning disability meant that he could not do certain things.



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In his new teaching position, Paul was expected to teach children all academic skills - from reading and spelling to math. Paul's learning disability was in the area of math. Despite his disability, the principal expected him to teach math. Paul refused. He also refused to accept help from an experienced LD teacher who offered to help him learn the necessary math skills. Paul's response was, "You don't understand. I'm learning disabled. I can't do math."

Eventually, Paul was terminated from his position. He moved back home with his elderly parents. His dream was dead.

### **Becoming an Advocate, Becoming an Expert**

There is an antidote to feelings of helplessness, hopelessness and despair.

As you come full circle, having experienced the denial, anger, guilt, and sadness that are the inevitable reactions of the loving parent, you will find that your emotions can be freed to use in a positive search for information and for solutions to the problems you face. You must transform your emotions into energy-the battle to obtain a good education for your child will be long and arduous. You need to conserve your strength and focus on what is important-obtaining an appropriate education for your child.

Becoming an advocate means becoming an expert. In the course of your journey, you need to learn all that you can about your child's particular disabling condition and how this condition can be remediated.

You must learn about evaluations — psychological, educational, neuropsychological, psychiatric neurological—and what these evaluations measure. Depending upon your child's unique problems, you may also need to learn about speech-language, physical therapy, and occupational therapy evaluations too.

In your advocacy journey, you will need two things-accurate information and support. This journey is more difficult if undertaken alone.

### Join an Organization . . . or Two

It is essential that you join disabilities organizations that represent your child's disability. These organizations represent a rich source of information and support that is invaluable to parents, regardless of the child's handicapping condition.

Hours before an eligibility meeting, a young mother wrote us this note which we received by e-mail:

"I am not nervous anymore. I am going into this hearing with a two-foot tall stack of reports and notes we have kept over the years. I have copies of the law and regulations that are highlighted and dog-eared. We have your articles-and a very firm resolve that we will leave no stone unturned in seeing that Joy gets the free and appropriate education necessary for her to become a happy, competent adult."

"We are not going to bang on the table. We are not going to threaten or yell. We are going to calmly listen to what they have to offer Joy, and tell them that we will do whatever it takes to see that this child receives the education that she is entitled to."

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"I dare them to deny her. If they do, we will need your help and I pray if you can't help us, you can steer us to someone who can. But, I am not nervous any longer."

*"I am determined."*

### Success Stories

These stories can have happy endings. Matt is a sixteen year old who has dyslexia. This is how his parents described their son's progress over the past two years:

"Matt is now well on his way to having a successful educational experience. His 'Learning Difference' is no longer disabling - he has acquired the skills to read and write. He is, at long last, beginning to hone and develop these very necessary skills.

"We are so proud of his success and efforts. It is hard to believe that this 16 year old young man was reading at the 3.8 grade level just two years ago. Testing completed a few months ago found that at the beginning of the tenth grade, Matt was reading at the 12.4 grade level And he is on the Dean's list! He is a competent, confident, literate, academically successful young man."

We asked Matt's parents how they would describe their own advocacy journey to other parents:

"BELIEVING that our son COULD overcome the obstacles to learning to read, write, manipulate numbers, "organize" his thoughts and actions. SEARCHING for and FINDING the correct educational approach that could remediate and help him to overcome his dyslexia (NOT merely teach him to "COPE") and a lot of HARD WORK on Matt's part."

"Parents must be patient and determined. There is no 'quick fix' or 'silver bullet.'"

### Emotions can be your worst enemy or your greatest ally.

If you are thinking of counseling, obtain it for yourself. Learn to use your emotions as a powerful driving force.

Understand that pity is a negative emotion — it is always destructive.

Our children can accept some blows from the system and survive. Ultimately, children grow and flourish by facing adversity — if they know that we understand them, support them, and believe in them!

problems ... and get better services for their children in [Success Stories](#).

### *Yellow Pages for Kids with Disabilities*

You need to learn about your child's disability, how the disability affects your child, and about appropriate educational and remediation techniques. Please read the [Yellow Pages for Kids User Guide](#)

The groups listed in the [Directory of Disabilities Organizations and Information Groups](#) are an invaluable

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source of information. You can learn about training and support groups by checking the [Directory of Parent Training and Information Centers and Community Parent Resource Centers](#)

### *Your State Yellow Pages*

Find educational consultants, psychologists, educational diagnosticians, health care providers, academic therapists, tutors, speech language therapists, occupational therapists, coaches, advocates, and attorneys for children with disabilities on the [Yellow Pages for Kids for your state](#).

Your [State Yellow Pages](#) also has listings for special education schools, learning centers, treatment programs, parent groups, respite care, community centers, grassroots organizations, and government programs for children with disabilities.

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## Advocacy

### Advocacy Rule #1: Write Things Down When They Happen!

by [Sharon D](#)

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Website: [www.wrightslaw.com](http://www.wrightslaw.com)

#### Preparing Documentation is Essential to Good Advocacy

Your goal at an IEP meeting is to initiate or obtain additional special education and/or related services for your child. A successful outcome at an IEP meeting depends on the documentation you make available to the team.

**You can't wait until the last minute to prepare documentation.** Documenting events and conversations later is never as effective or accurate as writing things down, in detail, at the time they occur. Here are some tips . . .

#### 1. Paraprofessionals

If your child has a crisis intervention paraprofessional or a shadow, provide that person with a small three subject notebook (5×8 size is perfect). Look for a notebook that has a pocket on each subject divider – that's even better. Have the paraprofessional document incidents that occur in the classroom, at recess, on the bus, etc., on a daily basis. These entries should include:

- the child's action,
- the paraprofessional's response, and
- the child's reaction to the response.

Each entry should be dated, time stamped, and signed. This log will support the need for continued service from the paraprofessional.

#### 2. Teachers

If you plan to request a paraprofessional for the first time, you need documentation that shows your child's need for this service.

Provide your child's teacher with a set of [anecdotal sheets](#). Ask her/him to keep meticulous records of everything that happens that provides support for the needed service. Each entry should be:

- dated,
- time stamped,
- and signed.

Include the child's action, the teacher's response, and the child's reaction to the response. If the child is taken to the principal's office, staple a note from the principal with information about what happened to the anecdotal report. Two to three weeks worth of reports are usually sufficient to validate the child's need for this service.

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If you plan to request additional services for your child, provide your child's teachers with a set of anecdotal sheets at the beginning of the school year. [Download Anecdotal Form](http://www.wrightslaw.com/blog/anecdotal.form.doc) at <http://www.wrightslaw.com/blog/anecdotal.form.doc>

For example, if you will request speech therapy, ask the teachers to write notes regarding times when articulation errors affect the child's academics (i.e., poor spelling as a result of producing sounds incorrectly, etc.). If your child has a language problem, ask the teacher to document times when these problems arise (i.e., in reading comprehension, context clues, cloze, etc.).

You can use anecdotal sheets to document a child's needs for other related services ... occupational therapy services, physical therapy services, and counseling.

### 3. Parents

It is your job to keep a careful record of all tests. Don't highlight information in evaluations. Use Post-it notes to write comments or call attention to specific information on tests and other important documents. Make copies of tests and quizzes with the Post-it notes attached.

**When you attend a meeting, have your documentation ready to go. Anecdotal sheets** should be in a sealed envelope (sealed by the teacher before giving them to you). Ask the team to make copies for you. Your **log book** should be presented for the team's review, but you should take it back at the end of the meeting. The team can make copies of any entries they want as part of your child's record. Present your **duplicate tests** in a folder so they are part of the record.

If you present proper documentation that supports your request for a service, the team's respect for you is likely to increase. They are more likely to acknowledge that your child needs the service, and conclude the meeting in your favor.

Good luck!

## Advocacy

### 10 Ways to Be an Effective Advocate for Your Child

By [Geri Coleman Tucker](#)

Used with permission by Understood

Website: [www.understood.org](http://www.understood.org)

As a parent, you are your child's best education advocate—until he's old enough and informed enough to speak up for himself. You know your child's strengths and challenges, and you can help identify and push for the resources your child needs to succeed. Here are some tips to help you advocate for your child at school.

#### **Keep a paper trail.**

Make sure to [keep copies](#) of all report cards, progress reports, evaluations, educational assessments, IEPs, medical records, homework samples and other documents. They can provide insights into your child's learning issues and how much progress he's making. Take notes at important meetings and keep copies in a file.

#### **Study up.**

Read and attend workshops. [Get insights from parents](#) whose children have learning and attention issues. This way you'll be familiar with your child's challenges and possible ways that schools can help.

#### **Build relationships.**

Get to know your child's teachers as well as the school psychologist, speech therapist and anyone else who can help you help your child. [Building relationships](#) with these people will help keep the lines of communication more open. There's less of a chance of misunderstanding if everyone knows each other.

#### **Ask questions.**

It's important to work with the school, but make sure you're in agreement before you give your approval. Don't be afraid to ask for clarification, request further testing or challenge the school's decision regarding services. It's a good idea to submit in writing any requests for additional testing. Keep copies of these requests that include the date you sent them. It might also be helpful to keep a log of whom you spoke to and when.

#### **Stay calm.**

Remember that the teachers and other school staff members involved are there to help, even if you disagree with them. The process will go more smoothly if you listen and keep an open mind. Make a list of the topics you want to cover in important meetings. Take deep breaths. Consider bringing a friend or relative who can take notes for you and help keep you steady.

#### **Remember that you're in control.**

Parents should never feel pressured by school staff to make a decision. Ultimately, you're in the driver's seat. So while it's important to be receptive to the school staff's thoughts, don't agree to something you think goes against what's best for your child.

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### **Know the law.**

Learn about [your child's rights](#) to a [free and appropriate public education](#) (FAPE) under the [Individuals with Disabilities Education Act](#) (IDEA). Your child might have the right to extra time on tests and other [accommodations or modifications](#). Keep informed about your school's legal obligations to provide your child an evaluation and other services. You can also request that the school provide a parent advocate to help you during important meetings.

### **Talk to your child.**

Understanding what your child is experiencing in school is essential to advocating for his needs. For example, the 30 minutes he's supposed to spend each week with a speech therapist might only be 20 minutes because the therapist keeps showing up late. Asking your child detailed questions will also help him understand what it is he needs. This will help him [advocate for himself](#) when he's older.

### **Know the lingo.**

Find out whether the speech therapist and other service providers are “pushing in” (working with your child in the classroom) or “pulling out” (taking your child to a separate location). This is important because your child may say he didn't go to speech that day, but it could be that the speech teacher pushed into the classroom.

### **Attend meetings regularly.**

[IEP meetings](#) and [parent-teacher conferences](#) are obviously good opportunities to get an update on your child's progress, but there are also other times. When teachers host a publishing party so kids can showcase their work,

this is a good time to see what's been going on in the classroom. PTA meetings may provide insight into curriculum changes. The PTA can also help push for weekend test prep and other resources that could help your child.

## Advocacy

### 11 Tips on Informal Negotiation Strategies

By [Andrew M.I. Lee](#)

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Website: [www.understood.org](http://www.understood.org)

#### **Give the school the benefit of the doubt.**

The vast majority of schools and teachers want the best for your child. Keeping this in mind will help you establish a collaborative atmosphere for any negotiation. It's important not to create a disagreement where there really isn't one. Starting with this mindset will help you identify possible allies among teachers and school employees. And it will help you better apply other negotiation strategies.

#### **Be prepared for the meeting.**

The more prepared you are, the better you can negotiate. At a minimum, know the basic details of the meeting. Where will it be? What time? Who will be there? Beyond basics, make sure to understand your child's learning and attention issues, his rights, how he learns and what helps him thrive. Before the meeting, write down your goals and the points you want to make. This shows the school that you're prepared and know your rights.

#### **Be polite and respectful, but firm.**

It can be frustrating if your child is struggling and the school doesn't seem to be able to help. Nevertheless, it's important to be polite and respectful to school personnel. Bringing food or coffee to the meeting can help things start off on a positive note. If you personally attack a school employee, chances are the employee will be reluctant to help you. At the same time, be firm about your child's needs.

#### **Understand the school's interests.**

Sometimes the school doesn't have the staff or training needed to help your child. In an informal negotiation, make it a point to understand the school's interests and limits. By understanding what the school wants and can do, you can avoid miscommunication and be in a better position to negotiate. Sometimes, the school is willing to give your child what she needs, but only in a certain location or with a certain program.

#### **Make sure the school understands your interests.**

A misunderstanding can delay the services that your child needs. So it's important to make clear to the school how you want to help your child. If you want to improve your child's behavior, say so. If you're concerned about reading skills, tell the school. A school that understands your child's needs may focus on solutions, rather than just resisting your requests.

#### **Know your "best alternative to a negotiated agreement."**

The term "Best Alternative to a Negotiated Agreement" (BATNA) comes from the best-selling negotiation book *Getting to Yes*. Your BATNA is your best option if you can't reach an agreement with the school. For



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example, if the school doesn't agree to the reading program your child needs, is sending your child to [private school](#) the best option for you? Or is it mediation? Knowing your BATNA helps you figure out whether or not to accept a school's offer.

### **Focus on mutual problem solving.**

Informal negotiations can break down when schools and parents focus on *winning*, rather than focusing on the interests of the child. Get around this by setting up your discussion with the school as mutual problem solving. Work with the school to identify the issue and then ask how you can work together to solve it. If the school proposes a solution you don't want, emphasize how the proposal doesn't solve the issue, then redirect the conversation back to problem solving.

### **Help the school save face.**

Sometimes when a school says it won't do something, it can get stuck in that position—even if school employees realize later they're wrong. Look for solutions that help the school "save face." For example, if the school's already rejected one type of therapy, ask if there are other therapies available. You may be surprised when the school suggests one that is just as good. Also, never gloat or brag if you get what you want.

### **Support your negotiation with objective data.**

If you're trying to get a school to give your child a particular service, you're more likely to succeed if you support your request with data. For instance, if your child struggles with math, what are his current math test scores? How have other students improved in math with this service? How did your child respond when he tried out the service? This makes it more difficult for the school to say no.

### **Follow up negotiations with letters.**

After a meeting, send a polite letter or email describing what was agreed on. It can be helpful to make this a thank-you note. Begin by expressing appreciation, then detail your understanding of the meeting. Even the best-negotiated agreement can fall apart if you and the school later disagree on what was said. Even if no agreement was reached, it's important to make a record of how you are working with the school to find a solution.

### **Take time to think about an offer.**

If a school offers services, you may be tempted to accept on the spot. This can be a bad idea if you don't have time to fully consider the offer. If you feel any discomfort, don't hesitate to ask the school for time to think it over. Having a few days to consider the offer and ask others about it may help you make the right decision.

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### **Assertiveness is equally important at work as at home.**

If you become known as a person who cannot say no, you will be loaded up with tasks by your colleagues and managers, and you could even make yourself ill.

### **Being Aggressive**

By being aggressive towards someone else, their rights and self-esteem are undermined.

Aggressive behavior fails to consider the views or feelings of other individuals. Those behaving aggressively will rarely show praise or appreciation of others and an aggressive response tends to put others down. Aggressive responses encourage the other person to respond in a non-assertive way, either aggressively or passively.

There is a wide range of aggressive behaviors, including rushing someone unnecessarily, telling rather than asking, ignoring someone, or not considering another's feelings.

Good interpersonal skills mean you need to be aware of the different ways of communicating and the different response each approach might provoke. The use of either passive or aggressive behaviour in interpersonal relationships can have undesirable consequences for those you are communicating with and it may well hinder positive moves forward.

It can be a frightening or distressing experience to be spoken to aggressively and the receiver can be left wondering what instigated such behavior or what he or she has done to deserve the aggression.

If thoughts and feelings are not stated clearly, this can lead to individuals manipulating others into meeting their wishes and desires. Manipulation can be seen as a covert form of aggression whilst humor can also be used aggressively.

### **Different Situations Call for Different Measures – or do they?**

You may find that you respond differently — whether passively, assertively or aggressively — when you are communicating in different situations.

It is important to remember that any interaction is always a two-way process and therefore your reactions may differ, depending upon your relationship with the other person in the communication.

You may for example find it easier to be assertive to your partner than to your boss or vice versa. However, whether it is easy or not, an assertive response is always going to be better for you and for your relationship with the other person.

## Advocacy

### 10 Common Myths about Your Child's Rights

By [Lyn Pollard](#)

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Website: [www.understood.org](http://www.understood.org)

When it comes to your child's legal rights, knowledge really is power. But there are a lot of misconceptions about the rights of kids with learning and attention issues. Learn the truth behind these 10 common myths.

#### **Myth #1: Only a lawyer or educational advocate can protect your child's rights.**

**Fact:** It's true that hiring a [special education](#) lawyer or advocate can be very helpful when advocating for your child. However, as a parent, you also have the ability to protect your child's rights. In fact, one of the purposes of the [Individuals with Disabilities Education Act](#) (IDEA) is to give parents a voice in their child's education. Get tips on [how to be an effective advocate](#) for your child.

#### **Myth #2: There aren't any good local resources to help you navigate special education law.**

**Fact:** Every state has at least one [Parent Training and Information Center](#) (PTI) where you can learn about your child's rights and how to advocate for her. PTIs hold training sessions and help answer parent questions. Depending on your area, there may be other resources as well. Some schools, for example, have a special education parent committee. If you're stuck and can't seem to find support, plug into [our community](#) and ask fellow parents how they connected to local resources.

#### **Myth #3: If your child qualifies for special education in one state, she'll qualify in all states.**

**Fact:** Every state must follow federal law, including IDEA. But states can set their own rules in some areas, including special education eligibility. States (and even school districts within states) may have different standards for deciding if a child is [eligible](#) for special education. The bottom line: Your child may qualify for [an IEP in one state](#), but not necessarily in another.

#### **Myth #4: Your child needs a diagnosis before a school will evaluate her.**

**Fact:** A medical diagnosis by a doctor can give you insight about your child's issues. However, your child doesn't need one to be evaluated by the school. You have the right to ask for an [evaluation](#) at any time. The evaluation process is designed to identify children who have disabilities, which may include learning and attention issues like learning disabilities and [ADHD](#).

#### **Myth #5: Your child must go through RTI before getting evaluated by a school.**

**Fact:** Some schools use [response to intervention](#) (RTI), a schoolwide approach to helping struggling students. If done well, RTI can be beneficial for your child's learning. However, you can ask for an evaluation for special education even if your child currently receives services through RTI. You don't need to wait. (This [memo](#) from the U.S. Department of Education tells schools they cannot use RTI as a reason to delay an evaluation.)

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### **Myth #6: You can ask for an IEP or a 504 plan evaluation, but not both.**

**Fact:** Depending on your child's issues, either an [IEP](#) or a [504 plan](#) can be an option. As a parent, you can ask the school to evaluate your child to see if she qualifies for either. You don't need to limit your request. In some schools, these evaluations will be done together. Since struggling students have a wide range of needs, asking for an evaluation for either may allow you and the school to explore different options. Here's a [sample letter](#) for requesting an evaluation.

### **Myth #7: Children with ADHD can only get a 504 plan, not an IEP.**

**Fact:** Children who have [ADHD](#) may be able to get special services through an IEP. However, not every child with ADHD is eligible. Conditions like ADHD can be covered under the "other health impairment" category in IDEA. Get more details on [when kids with ADHD may qualify for an IEP](#).

### **Myth #8: A 504 plan can only offer accommodations, not services.**

**Fact:** It's a common misconception that a [504 plan](#) can't include services. But it's not true. The [U.S. Department of Education](#) has made clear that a 504 plan *can* include school services. However, it's important to remember that the services a 504 plan offers may not be the same as those available in an IEP. Here's a [useful chart](#) for understanding the differences.

### **Myth #9: If your child has an IEP, the school must give her a superior education.**

**Fact:** Children who qualify for special education have a legal right to a [free appropriate public education](#) (FAPE). But the right to FAPE doesn't mean that your child's education should be superior to that of other students. Public schools are required to provide an "appropriate" education. Courts have used the following analogy to explain the [meaning of FAPE](#): A child with an IEP is entitled to a reliable and serviceable "Chevrolet"—not a luxury "Cadillac."

### **Myth #10: Your child can only get services in a special education classroom.**

**Fact:** Special education isn't a *place*. It's a range of *services* to address your child's unique needs. As a legal matter, your child has the right to receive services in the [least restrictive environment](#). This means, when possible, she should be in a general education classroom. Today, many schools offer a combination of services, curriculum, and [accommodations](#) for children. One example is an [inclusion classroom](#).

## Advocacy

### 8 Steps to Better IEP Meetings: Play Hearts, Not Poker

Used with permission by Wrightslaw  
Website: [www.wrightslaw.com](http://www.wrightslaw.com)

As an attorney, arbitrator, mediator and loving mother of an autistic daughter, I have a unique perspective on the process by which families prepare their children's Individualized Education Plans (IEPs).

The IEP meeting, required by federal statute, is convened at least once a school year to plan an educational program that is tailored to the needs of each disabled child. The child's "team" attends the meeting: teachers, therapists, parents, school administrators, and any other invited parties.

So far, our family has had success with Amanda's education in our district. She has been fully enrolled in standard district programs - Early Childhood and then grade-school inclusion - and has made significant educational gains. We have been able to get the district to agree, with minimal or no conflict, to provide all the services we felt she needed in her IEPs.

Over the years, many parents have told me battle stories about their children's IEPs. They comment on how "different" Amanda's experience has been from theirs, even within the same district. Maybe so.

Certainly, my daughter's innate abilities have emerged, and in so doing, have given her more skills as she goes. Success truly breeds success. I can take no credit for the marvelous daughter God gave me.

However, Amanda would not have been able to be successful if the right opportunities were not available to her. This is where good advocacy can make all the difference.

### Advocacy v. Parenting

Advocacy is by its nature, a cerebral activity and involves great thought and creativity. Parenting is by nature a visceral activity that involves great emotions and heavy decisions.

I know first hand how the feelings that come with children, especially disabled children, overwhelm and confuse us. No words can adequately explain the dread and anxiety that accompany us everywhere we go. We belong to a select club, an elite group of people, who speak a foreign language ("IEP", "OT", "PT") other parents do not know. We emit sensitive radar that only those of our own kind can detect, often with one look.

For the sakes of our children, we must strive to be patient with those whose experiences have not given them access to our perspective. It is our duty to lead these people to a fuller understanding of the beauty and ability within our children. To do this, we must become effective advocates.

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### **Learning About Rules and Strategies**

Good advocacy often works like a game. I do not suggest that advocating for the needs of special needs children is trivial. It is just that the method of getting what you need from a school administration has rules and strategies that are often quite predictable.

If you learn and apply these rules, you can reduce the risk that is inherent when you negotiate for educational benefits. I liken this to the difference between poker and hearts.

### **Playing Poker . . .**

Poker is a stimulating game of wager. The fun, the skill and the whole game is in the bet. In truth, the cards make only a marginal difference to the outcome of the hand. It is not what you have in your hand that matters as much as what the other players think you have.

Every hand is a winner, and every hand is a loser. By manipulating the other players at the table, making them believe what you want them to believe, you win the bet. You do not really need to have a strategy for the cards: if you understand people, the cards will play themselves.

### **And Playing Hearts**

Hearts is different. Hearts is all about having a strategy for the cards: how you play the cards given to you. What the other players think or feel is less important than getting them to play their cards in the order you want them to!

Yes, there is minimal bluffing, but at tremendous risk. This is because everyone is paying attention to the cards, not the players. However, the rules of the game give talented players a chance to unload their worst cards at little or no jeopardy to themselves.

In fact, the best hand at hearts is the worst hand played skillfully! If you have a wretched hand, and take every trick, you end up winning the round! Moreover, even if your round goes badly, the game keeps going, hand after hand, until all hands are played.

### **Thinking Like a Poker Player**

Many parents and advocates involved in IEPs use "poker" language to describe the process. They have come to believe that districts, overall, do not act in good faith when setting IEPs, and that they will cheat.

They do not want to "tip their hand" or "show their cards". They talk about the personalities of the school administrators and staff. Are they bluffing? What are their cards? Are they holding back? Do they care about my child? Do they care about disabled kids in general?

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When parents feel like they have to battle educators for benefits, they lose confidence in those educators. When parents lose confidence in their educators, those educators (who are often acting in good faith to do an extremely difficult job) feel unappreciated.

A siege mentality sets in, lines are drawn, and the parties toss therapies and interventions onto the table like chips. They wager with the child's needs, but rarely does the child walk away with any of the pot. This is why playing poker at an IEP does not work for the children.

### Learning to Make Deals

Like hearts, advocating in an IEP might take many deals. The players, sometimes with competing goals, sit down year after year and look at their hands.

What progress has the child made in school? What skills does he or she have now? What are the demands of the next grade? How well equipped is the district or the staff to meet these needs? What resources do the parents have?

Most of the answers to these questions are known to most of the parties at the table. Unlike poker, which allows for more uncertainty to sweeten the bet, IEPs leave little to bluffing.

Either the child has abilities in certain areas, or he does not. Either she can attend in a regular education setting, or she cannot. Either the staff is prepared to deal effectively with this particular disability or they are not. And so on. A skillful advocate, like a skillful hearts player, knows when and how to play certain facts in the file so the child does not bear an undue burden in the education process.

### Eight Steps to Better IEP Meetings

Here are eight steps for parents to learn. These steps will help the parent negotiator minimize conflict when dealing with good-faith district negotiators. They will also help you prepare a solid case when negotiating with district personnel who are acting in bad faith.

#### 1. Make every attempt to sustain relationships.

Like the many hands in a hearts game, IEP negotiations play out over time. A game of cards is always more enjoyable when played in a group that likes and respects each other. Try to get to know and personally connect to the other team members.

Whether or not we personally like our child's teachers, school psychologist, school social worker, principal or other administrative personnel, we are stuck with them unless we move. If we move, we will be stuck with new school officials with whom we have conflict. Or new, difficult people will be promoted into established positions.

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In any event, we have to learn to work with people we do not understand, agree with, or get along with. They are there, and will be there all year, year after year. Getting personally angry with them, even if they deserve it, lead to hostility down the line.

Now hostility can have its place, as in a lawsuit or a Due Process Hearing. However, if parties get that far in their fights, any chance for a working relationship is dead. Since it is in the best interests of our children to have a cohesive team working towards a common goal, we as parents must take a leadership role in sustaining the team atmosphere.

We cannot lead a team we do not join.

It is not enough to come into a meeting, periodically and make demands; even legitimate, legal demands. **We** must model the behavior we want to draw out in our children's IEP team.

If we want the other team members to be patient, prepared, and educated about our child's needs, ***we must set the standard.***

**We** must be understanding of them and the demands on their time.

**We** must be patient with them as they learn our child's method of learning.

**We** must be prepared and secure helpful test results on our child's development, articles or other related materials, and then share them; and

**We** must be as or more educated about the objective realities of our child's disability so we can talk to other team members as peers.

Before we make any demands on a team member, we must ask ourselves, "Am I asking of this person something I have not done, or am not willing to do?"

If someone did something helpful, remember to say "thank you!"

When we can demonstrate that we are doing our part, it is more reasonable to press others to shoulder their responsibilities.

### **2. Keep the focus on the child's needs, not the district's resources or the parents' expectations.**

Under the Individuals with Disabilities in Education Act (IDEA), Congress set forth certain protections for children with special needs. At its core, IDEA is designed to make sure that disabled children have access to a "free and appropriate public education" in the "least restrictive environment".

The United States Supreme Court has been relentless in their insistence that IDEA may not be used to force a school district to "maximize" a child's "potential". If a child is getting a "meaningful educational benefit" and making progress that can be objectively measured, then most courts will conclude that IDEA has done its job - even if most parents would consider the results basic or minimal.

Most schools pride themselves on doing more than passing work for their students, even their disabled students. Clearly, those with the highest expectations for children are the parents. This is why we are here.



## Advocacy

Yet, many parents engage in the IEP process without having tangible educational goals, let alone a plan to accomplish these goals. Without a plan, the IEP, school staff, and parents will flounder.

Let me share an example. Our goal for Amanda is to teach her to function as an autistic person in a non-autistic world. We do not expect the District, or anyone else, to cure her autism. Each decision made for her - educational and otherwise - is shaped with this plan in mind. This simplifies things.

When we read a map, we have a starting point and a destination. We plan our routes and back-up routes from these two variables.

### *Get Independent Evaluations*

How do you know where you are beginning? Get the child tested and find out! Parents must obtain independent medical and/or developmental assessments for their disabled children! Without clinical data, there is no reliable starting point for the journey.

Yes, these tests are often burdensome and expensive. Do them anyway. Our children's abilities and disabilities are the cards in our hands! How can we decide how to play them if we do not look at them first?

These evaluations bring parents on board. They force parents to understand the precise nature of their child's disability, and in so doing, obtain the necessary information to formulate a cohesive strategy for dealing with it. This is especially true if the nature of the disability has a hidden educational impact.

IDEA only requires school districts to pay for special services like speech, occupational or physical therapy if doing so gives an educational benefit, not just a medical one. In other words, the disability has to effect learning.

I emphasize the need to have independent clinical medical, psychological, and /or educational or evaluations done -not evaluations through the school district or by a practitioner selected by the district. Because IDEA has provisions, which, under certain circumstances, require school districts to pay for evaluations (ostensibly to make the field more level for low-income families), many parents who can afford an independent evaluation fail to get one.

However, school district evaluations are still school district material. If there is a hearing or lawsuit, these tests are crucial evidence. Parents will have more faith in the truth of these tests when they choose the professionals who administer them. In the event that a test does not accurately reflect a child's abilities, parents who get these evaluations independently have a choice about whether to share this information with the district - something they could not control if the tests were done by the district.

These outside evaluations have another benefit in that they relieve the parties from subjective disagreements. The results speak for themselves. No one is to blame for this information. In fact, third-party reports give a willing school administrator a way to justify a difficult or politically unpopular decision to grant services.

## Advocacy

When Amanda was going into kindergarten, I wanted her to a full-day program with kindergarten in the morning and Early Childhood in the afternoon. Our district had a "policy" (read "budget issue") against this.

When I took Amanda to her yearly reevaluation at the University of Chicago Developmental Disorders Clinic (a nationally recognized leader in autism diagnosis and treatment), I was able to persuade the U of C team that Amanda required the full-day program. They gladly made this recommendation in their report.

This relieved the sympathetic school administrator (who granted the request) from having to make the judgment herself. After all, if her boss disagreed with her, he would have a much harder time disagreeing with the University of Chicago!

With independent reports, everyone is off the hook and can bring themselves, defense-free, to the great task of addressing the child's problems. Once we know where we are, we can decide how best to get where we are going. Once everyone has an objective sense of a child's abilities, they can develop a plan to teach that child.

### *Design Specific, Measurable, Realistic IEP Goals*

The IEP is designed to list specific educational goals for the child. Make sure the goals are realistic, specifically stated, and penned in layman's terms. As the school year unfolds, the team can look at these goals to objectively assess the child's progress. To this end, IDEA requires that the goals as they appear on the IEP form must be something that can be objectively measured.

Avoid generalized goals, as "Johnny will be able to attend in the classroom with increasing frequency". This phrase leaves Johnny's progress open to subjective evaluation. Disagreements about subjective evaluations lead to bluffing and defensive postures on all sides. Where does this leave Johnny?

If the goal read: "Johnny will be able to complete grade-appropriate class work during class time, up to 75% accuracy" the parties can evaluate what Johnny is doing in class and objectively measure this against the goal. If Johnny cannot finish a spelling test with his class with 75% accuracy, the team can agree on his inability to meet the goal.

This keeps the focus on Johnny and away from the other team members. When everyone can agree on the problem, it is much easier to brainstorm about new interventions that can help him learn, or whether the goal should be modified (e.g.: "...up to 50% accuracy", etc.).

### *Parental Expectations v. District Resources*

A word about parental expectations and school district resources. These competing interests are present in every IEP. They represent an inherent tension in disabilities issues. Parents want the best for their children. School districts have to provide basic services within a clearly stated budget.

Never ignore these dynamics in an IEP. They are always there, even if districts are not supposed to consider budgetary concerns when they formulate an IEP.

In negotiations, emotions are often the problems to be solved.

## Advocacy

Parents should never treat the school team as if they are sitting on limitless resources. School personnel should never forget the legitimate emotional investment each parent has in his and her child. Parents should attempt to occasionally see their child through the eyes of others. School personnel should try to be creative with what resources they do have.

Neither parents nor schools can wave a wand over a disabled child and make that child's problems disappear. Yet, the parties often treat each other as if this were true.

Parents sometimes have expectations of their schools that reach beyond academics. They want their kids to fit in, love learning, and have predictable, pleasant school experiences. Often, kids with disabilities can do many of these things. Sometimes they simply cannot.

Schools, even the best of schools, can harbor frustrations that impede learning and fitting in. These frustrations should be whittled down until only those hurdles that cannot realistically be removed remain.

Similarly, schools have rhythms that cause unnecessary pain to a disabled child. Simply telling parents "this is how we do things" is an inappropriate attitude. Disabled children may not be penalized for bringing their disabilities to school. Teachers and students must make every reasonable accommodation to welcome them.

### **3. Always provide "face saving" ways out of a dilemma. Have a back-up plan.**

Mediators know that this is the secret of successful mediations. We call it the difference between positional bargaining and principled bargaining.

Assume we have two parties who are arguing over one lemon. Each takes a position and insists on having the whole lemon. No compromises. They go to a judge who uses the rules of basic adversarial procedure to resolve their problem by dividing the lemon in half -to no one's satisfaction.

A mediator will ask each party what they want with the lemon. One party says they want the pulp for lemonade. The other wants to use the rind for zest. The mediator sees a solution the judge missed: peel the lemon and give all of the fruit to one party and all the rind to the other. A win-win solution.

Special needs children benefit greatly from principled negotiations. When parties know what their needs are, they can be more creative in finding solutions to those needs.

Often, parties simply assess their needs in private, and make unilateral decisions as to what they require to satisfy those needs. They then present only these conclusions as their positions in a negotiation: "I need the lemon."

Poker rules dictate that you will "tip your hand" and foul up your chances of winning if your opponents know what your plans are. Keep your cards close to your chest, and bluff it out. In negotiations, especially delicate negotiations, the goal should not be to win (which forces the other side to lose) but to achieve a particular objective.

## Advocacy

Encourage brainstorming among all informed people at team meetings, especially before an IEP. When the collective resources of a group focus on a problem, the solutions that present themselves are amazing.

Have more than one approach to offer. If your initial suggestions cannot be implemented, you should have given some thought to your fallback position.

Sometimes a fallback plan contains a calculated failure. Failures, though unpleasant, are our greatest teachers. If you find yourself at odds with a school administrator's idea, and if this idea will not cause real harm to your child, set a trial period, then let the idea go forward and fail. Just let experience speak for itself.

No one likes to feel like a loser. No one likes to feel humiliated. No one likes to feel stupid, or to worry that if she makes a mistake, this will be held up for everyone to see. No one wants to worry over failing in front of a group. Moreover, everyone will fight tooth and nail to keep these things from happening.

I promise you, if an IEP becomes a contest of who is right and who is wrong, no one will roll over and play dead. Present a position (even a perfectly legal and legitimate one) in unnecessarily demanding terms, and you risk creating an atmosphere where the other side would rather eat steel wool than admit that they are wrong (and they certainly won't capitulate if their opponent is not wholly right on the facts in the first place!)

I am amazed at the number of parents who walk into a meeting and flatly accuse school personnel of professional incompetence - in front of their supervisors - then expect everyone to agree with them!

Sure, wouldn't you, if someone did that to you at your job?

### **4. Build your record.**

What if you are right? What if school personnel are flatly incompetent? Do not say it. Show it!

Be reasonable and calm while you admit that you are concerned about how a situation is developing. Be prepared to show, objectively, how your child is not meeting his goals. Produce reports, articles or test results that will persuade an objective listener (like a due process hearing officer, or a judge) why your suggestions are reasonable.

If you can lay out a "court ready" case at this level, everyone will quickly read the handwriting on the wall. Threats and accusations are unnecessary. The facts speak for themselves. Of course, this assumes that you have some facts on your side.

Do not shy away from the damning evidence. Develop a strategy to deal with it. A good lawyer knows all the strengths and weaknesses of her case. We know where we expect to have trouble and prepare for this as best as we can. Again, objective data from non-school district personnel is the best place to start.

Independent medical, developmental and psychologist's evaluations and private therapists' reports and evaluations are crucial to setting up the facts. So are third party advocates or therapists who come to the school and observe your child in his school environment. You have to listen to what these reports and third parties tell you.

## Advocacy

### *Parents must be willing to face the reality of their child's abilities!*

If your child has tantrums when frustrated, do not demand that his day be frustration-free. Provide and document solutions how the frustrations and tantrums should be handled.

You are not being disloyal to your child by admitting his problem areas. You are being disloyal to your child if you do not prepare for them. Get the facts in writing. Do not rely on your own opinions and feelings.

This is not to say that parental opinions and feelings are bad. In fact, they are wonderful! In addition to what we may think or feel in our guts, we need to understand of what we can reasonably expect for our child in the classroom environment in a given timeframe.

Our best hopes and dreams come true one step at a time. Parental feelings are the most powerful thing on earth. Our insights are invaluable in setting goals, therapies, and just getting things done. They are not evidence!

We will fall flat on our faces if we indulge in the belief that our opinions, by themselves, will persuade an objective hearing officer or judge that we are right in any contested issue. Courts sympathize with parents but do not defer to parents.

As parents, we are expected to be many things for our children but "objective" is not one of these things. We are, by Nature's design, the least objective persons in the room. Cull and collect objective evidence to buttress any argument you have. If you get caught off-guard on an issue in an IEP and believe you need written back-up for your position, adjourn the meeting and reconvene when you have a chance to have your child assessed by a qualified professional. IDEA does not require the parents to be rushed into anything.

### **5. Walk a mile in the other side's moccasins.**

It will not hurt to indulge your thoughts about how things are for the other side. In fact, experimenting with perspective is necessary to brainstorm solutions or to decide the order in which you will play your cards.

Spend sustained time at the school. Volunteer in your child's classroom and other classrooms. Watch the kids on the playground and in the lunchroom. What really goes on inside school? How tired are you at the end of a school day? How tired must the teachers, the aid, the principal, and your child be?

On the other side, encourage teachers and other school persons to visit you at home in different circumstances, so they know what your life is like, too.

Do not forget to sell your solutions. When we want interventions for our children that are designed to maximize potential, do not forget that IDEA will not support us. Find a way to make your proposal appealing for the school district.

When Amanda was in Early Childhood, the teacher (a wonderful woman) used her tried and true methods for disciplining Amanda. While these methods may work well with other kids, they were not appropriate for Amanda. Instead of objecting to this procedure, we offered a suggestion that we said would make things easier for the teacher. Framing our suggestions this way made it easier to implement.

## Advocacy

Well-reasoned but abstract ideas about how things should be have little application unless you can offer practical advice about how they can be. It is not enough to know how you think things should be done, although this is an excellent place to start. To make workable suggestions, you need to understand how the people involved can do this job within the context of their day, training and budget.

Learn what they have to do and how they do it. Use that knowledge to advocate. Offer practical ideas about how to address problem areas.

It is harder to ignore the problem-finder if he or she is also the solution-giver. Conversely, it is easy to ignore people who do not know what they are talking about. Parents of special needs kids know this better than anyone else. We are constantly told how to do things by people who have no idea about the realities of living with our children. We rightfully ignore those people. School personnel will ignore you unless you understand the realities of what they do.

### **6. Listen actively, especially to the things you do not want to hear.**

No one is all knowing. Really. As much as I know about my child, and I know an awful lot about her, I still have things to learn. To my knowledge, no one has yet descended from the sky.

Often the solutions we seek are stranded on the barren land of "What We Do Not Want to Hear", and are calling out to us.

Hear them. Listen to everything with a whole heart and a whole head. If you find yourself getting angry or defensive because you disagree with what someone is telling you, or because the person is talking to you in an offensive way, pay attention to your reaction. When we feel defensive, we stop listening. We begin to think about a rebuttal. Our thoughts are no longer on the issue, but how we will respond to it.

If you find your temperature rising, disengage your ego from what is happening. Breathe deep. Calmly restate what you heard like this: "I want to understand your position, Ms. Jones. Are you saying \_\_\_\_\_?" Then restate what you thought she said, not what you thought she meant.

She will confirm or deny your recollection. Keep at this until you are sure you understand her position. Only then can you calmly state your position. Often, what we think we hear, we did not hear. Or the other party innocently misspoke.

These oversights can be remedied easily. If not, then everyone at the table fully understands what the disagreement is about, and can try to deal with it. In addition, hearing all points repeatedly allows even the most uncomfortable of them to sink in enough to be objectively evaluated.

### **7. Encourage everyone to love your child, then let them!**

Pediatricians and child psychologists have a term of art called "gate-keeping". Gate keeping occurs when people set themselves up like watchdogs over a child, guarding the gate against intruders. Sometimes nurses and doctors will gate-keep a particularly sick child. They become convinced that they are the only ones who can really act in the child's best interest and actively discourage others from helping.

## Advocacy

However, no one can gate-keep over a sick or disabled child the way parents can. We are stunning in this ability. Nature has blessed us with innumerable instincts for just this task. When is gate-keeping appropriate? When it protects your child from a real harm. When is it not appropriate? When it gets in the way of loving or talented people who can help.

Parents must strive to maintain their sense of judgment. They must be able to tell the difference between real harm and potential or imagined harm. If we treat every person who disagrees with us as an enemy, we will dull our instincts so we will not be able to detect the real enemies in our presence.

A school speech therapist told the mother of a nonverbal autistic boy that there was no hope for him because she could not reach him. She told the boy's mother: "You know, these autistic kids just don't get it!" This statement demonstrated her dangerous ignorance about autism. She may as well have said, "You know those deaf kids? You talk to them, but they don't hear you!" This woman was a real threat to that boy. She would not help him. In fact, she caused him to regress. Gate keeping was a wonderful skill for his mother as she strove to get another therapist for her son.

However, if a knowledgeable educator has a different approach or opinion from ours, this does not make her the enemy. Do not gate-keep around those people - they are invaluable, untapped resources.

Let them close to your child to see the wonders and beauty you do. When they learn to love your child from their heart, they will be motivated to do what they can to help and will listen to what you have to say. If you push them away, they will never get a chance to find out what they and your child are capable of doing. Everyone loses that way.

I am convinced that children can never be loved too much or by too many people. Love will move mountains. Let it in.

### **8. Have a little faith.**

As a lawyer, I have remarkable faith in the human spirit. I believe that most people are good at heart and will do their best if they are given an opportunity.

In the field of education, it makes sense to be optimistic. Think about it. No one becomes a teacher, an aid, an administrator or a facilitator because of the money, the hours or the Nike endorsements. They do this because they want to make a difference to children.

Of course, intelligent people will disagree about the proper way to make that difference. Those persons closest to the children will have a different perspective than administrators.

Very few, if any, of the people you will meet in your child's school is out to hurt anyone. Be alert for the occasional bad apple.

Generally, give your child's team some credit for acting in good faith. If they need education, supply it. If you disagree, try to work it out without getting personal. Do not demonize well-intentioned people. Utilize them. Even if they have priorities that you cannot share, they can turn out to be of great help to your child.

## Advocacy

### Summing Up

Your child's IEP should never be a gamble. IEP meetings should not turn into a game of nerves with everyone trying to guess who is bluffing, betting or folding on the strength of their guess. An IEP should be a strategic meeting where a talented advocate need not lie about his or her hand, but can play any facts to the child's advantage.

Keep the game fair and in good spirits, when possible. Know what your goals are and work them. Many roads lead to the same place. Many different cards can win the game.

- See more at: <http://www.wrightslaw.com/advoc/articles/iep.bollero.hearts.htm#sthash.fDNUfESf.dpuf>



## Advocacy

### National Resources

#### **Wrightslaw**

Website: [www.wrightslaw.com/](http://www.wrightslaw.com/)

#### **Understood**

Website: [www.understood.org/](http://www.understood.org/)

#### **Center for Parent Information and Resources**

c/o Statewide Parent Advocacy Network

35 Halsey St., Fourth Floor

Newark, NJ 07102

Website: [www.parentcenterhub.org/](http://www.parentcenterhub.org/)

#### **Council of Parent Attorneys and Advocates, Inc.**

P. O. Box 6767

Towson, Maryland 21285

Phone: 844-426-7224

Website: [www.copaa.org](http://www.copaa.org)

#### **US Department of Education**

Phone: 1-800-USA-LEARN (1-800-872-5327)

Website: <http://www2.ed.gov>

## Advocacy

### State Resources

#### **Maine Department of Education Special Services**

23 State House Station

Augusta, ME 04333-0023

Voice: (207) 624-6600

Website: [www.maine.gov/doe/specialed/index.html](http://www.maine.gov/doe/specialed/index.html)

#### **Child Development Services**

Phone: 877-770-8883

Website: [www.maine.gov/doe/cds/index.html](http://www.maine.gov/doe/cds/index.html)

#### **Disability Rights Maine**

24 Stone Street, Ste. 204

Augusta, Maine 04330

Phone: 800.452.1948 (V/TTY) 207.626.2774 (V/TTY)

Website: <http://drme.org/>

#### **Kids Legal**

P.O. Box 547,

Portland ME 04112

Phone: (207) 774-8246 | Toll Free: 1-866-624-7787

Website: [www.kidslegal.org/](http://www.kidslegal.org/)

## Advocacy

### Maine Parent Federation Lending Library

#### Library Procedures

The MPF Library is a valuable resource to families and professionals in Maine. The success of the library is greatly determined by the quality and availability of the materials we offer. To help us maintain our library, we ask that you follow these guidelines.

#### How to Request Materials

Call:	1-800-870-7746 or 207-588-1933	E-mail:	dnewcombe@mpf.org
		Fax:	207-588-1938
Write:	MPF Library P O Box 2067 Augusta, Maine 04338	Visit:	484 Maine Avenue, Suite 2D Farmingdale, Maine 04344 Hours: 8:30 - 4:30 Mon. – Fri.

#### Library Policy

The complete library list is available in print or online at [www.startingpointsforme.org](http://www.startingpointsforme.org).

You may borrow two materials at a time. You are responsible for the cost of return postage.

Materials will be mailed out on the day you request them if they are available.

Materials are loaned for a three week period. If you need materials longer and call to check with us, we may be able to extend the due date if no one is waiting for them.

If materials are more than one week late we will ask you for a \$5 late fee donation payable to the MPF Library for every week the material is overdue. A reminder card will be mailed during the first week that materials are overdue.

We keep a waiting list for materials that are already on loan when you request them. You can ask that your name be added to the waiting list and materials will be mailed to you when they become available.

#### About the Library List

The library list is arranged by topic then listed alphabetically by title. Materials are not cross-referenced, so each title appears only once and you may have to check other sections.

**\* Please remember - we are always adding new materials and updating the library list.**

## **Advocacy**

The following materials on **Advocacy/Self Advocacy** are available from our library:

**From Emotions to Advocacy – The Special Education Survival Guide** by Pete Wright & Pam Wright (Book)

This book will teach you how to plan, prepare, organize, and get quality special education services.

**Teenagers Preparing for the Real World** by Chad Foster (Book) –Learn how to get the skills needed to help you succeed in life.

**Teaching Self-Determination to Students with Disabilities** by Wehmeyer, Agran, & Hughes (Book) – Versatile instructional methods for teaching basic self-determination skills to students with disabilities.

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