

FROM EMOTIONS TO ADVOCACY: THE PARENTS' JOURNEY

by

**Pamela Darr Wright, MA, MSW
Deltaville, Virginia**

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**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:

"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? 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.

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, and 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 a "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 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:

"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:

“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. In addition, 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.

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.

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.

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.

It is essential that you join the major disabilities groups, including the Learning Disabilities Association of America (LDAA), The International (Orton) Dyslexia Society (IDS), and Children and Adults with Attention Deficit Disorder (ChADD). If your child's disabling condition is in another area (i.e. autism, mental retardation), then you also need to join the advocacy organization that represents this group. Parent memberships in the three organizations listed above will cost about \$100.00 annually. Many parents ask why we require them to take this action (and incur this expense). The answer is a simple one.

Each of these three groups represents a rich source of information and support that is invaluable to parents, regardless of the child's handicapping condition. Although your child may not have been diagnosed with dyslexia, the International Orton Dyslexia Society is a pioneer in areas related to neurological research and educational methodology. At least seventy-five percent of its members are professionals involved in the field of remediating language/ learning disorders. The information that you will obtain from IDS will be enormously helpful if your child has any type of learning or attention deficit problem.

The Learning Disabilities Association of America is a national organization devoted to defining and finding solutions for the broad spectrum of learning problems. And ChADD, a relative newcomer in the field, is the leading organization serving people with ADD/ADHD. Each of these groups publishes newsletters with information that will put you on the "cutting edge" of what is known in the field.

Hours before an Eligibility meeting, a young mother wrote us the following 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.

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."

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, as of his last report card, he was 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."

Remember—your emotions will 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!