The Process of Discovery: Finding Out Why Your Child is Struggling

By: Karen J. Foli (2002)

Karen J. Foli has been a parent for the past ten years. She is also a writer and holds a doctorate in communications research. Her memoir, Like Sound Through Water: A Mother's Journey Through Auditory Processing Disorder, describes her three-year process of discovery. During these years, she searched for the answers to her son's severe delays in speech and comprehension. For additional information or to contact the author, see Karen's web site at www.karenfoli.com.

A few years ago, a parent described her feelings to me. She said that at her daughter's birth, she believed her child was healthy and normal. But as the years passed, she discovered her child's delays, difficulties, and struggles. She confessed that it would have been easier to know there was something wrong when the child was born. Somewhere along the line, she felt that fate had played a trick on her.

She conveyed so many of the emotions that parents of struggling children feel. Bewilderment and confusion as you try to make sense of what is happening. Fear of the unknown. Guilt that something you did or didn't do caused the difficulty. Sadness at what the child has to experience. Gratitude that this child can teach you so much and offer you real joy. Perhaps a little denial mixed with fragile hope. Anger at the impact on your life and the system's inefficiencies. And finally, exhaustion.

The intensity and range of feelings that parents of struggling children experience creates a wide spectrum of emotions. One of these emotions, grief, looks a little different now. For what exactly is the parent grieving? Society tells us that our children should talk between these ages, be able to learn to read at certain times, and accomplish X, Y, and Z by first grade. Society describes for us the child who will play sports and pass the standardized tests without special assistance. It shows us pictures of boys who learn to read in kindergarten. And tells us of the girl who learns to speak by the time she's two.

The realization that your child hasn't accomplished those feats—and may not—creates a loss of what I call the "dream child," that notion of what we wanted or assumed our child to be. What we want all children to be. When a child's difficulties become apparent in the early years, the parent is hit with a sudden, usually unexplainable sense of loss. But when a child's mind is struggling, the difficulties may not be clear-cut. And the harsh reality is that it may take months or years to really understand what is the underlying cause of the difficulties.

But no matter how hidden or overt the struggles, the child we hug, the child who sits next to us at the kitchen table hasn't changed from what he or she always was. The difficulty was there, we just didn't know about it. What we have is the real child, the child who is loved and needs help. The child who overwhelms us, pushes us to the limits of endurance, and challenges our definition of love. For me, it was a child who taught me what mattered in life—but that realization only came with time.

The emotions parents go through are also complicated by the unknown factors that they are facing. Will my child learn to speak normally? Will she succeed in school? Will he get along with peers? Tolerate noisy situations? Write notes during a lecture? Pass the test he needs to in order to receive a high school diploma?

Parents are typically faced with what I call "multi-faceted struggles," problems in more than one area. And just when one problem seems to be under control, another one surfaces to take the stage. The process of discovery, the search for understanding a child's struggles, is confusing and frightening, and often long-term.

During this process of discovery, parents must appreciate their critical role. Time is precious, and society allows these children less and less of it. And while this parental responsibility is overwhelming at times, parents should also feel empowered by their love.

Here are some strategies that may help during this process of discovery:
Talk about your feelings, even ones that society may not approve of, such as anger, embarrassment, and exhaustion.

Select someone—a spouse, a friend, a clergyman, a sister, and a brother—who will listen without passing judgment. The Internet has become a place for people to connect. While care should be given in disclosing personal information, just reading the posts of others can be very reassuring. It can decrease the feeling that you are alone.

Acknowledge that parenting this child can be very challenging at times.

The drain on finances, time, and energy can overwhelm us. The minority status that we feel as parents of struggling children doesn’t provide ready support. The focus is on helping the child, not how the parent is doing. By acknowledging that what you are doing is hard, you may feel a relief or a sense of acceptance of your own feelings.

Educate yourself as best you can about the behaviors you’re seeing in your child.

Finding information isn’t easy, especially when you aren’t sure what is going on with your child, and specialized professionals may be difficult to find. Again the Internet can be a great resource, when used with care and good judgment. Use it like a reporter who verifies his information with more than one source.

But parents can’t be knowledgeable in all the areas that affect their child and certainly, not to the degree of a professional. But they can ask efficient questions. For example, when a label or diagnosis is presented, the parent should feel free to ask: What behaviors, signs, and symptoms does my child have that support this label? And just as importantly: What signs, symptoms, and behaviors DO NOT fit this label?

Celebrate your child’s gifts.

My son will always be marked by his early years of struggle. He is hard working, sensitive, and aware of being measured by others. Yet he is also empathetic, kind, and tenacious, skills that will serve him well in life. Every child has special qualities, gifts that can be used to help the child adapt to his or her world.

Feel hope, if you can.

Things will get better. There are terrific tools available today and with the proper guidance these tools can make incredible differences in your child. The combination of hope, finding skilled and caring professionals, and trusting your own knowledge of your child’s world can make a real difference.

During an interview recently, I was asked to name the most important intervention that made the critical difference in my son. The interviewer insisted that I cite only one thing. Without hesitation, I answered, “We never gave up.” And so it is with the process of discovery. It is essential that we never give up until we have found the answers to our questions. In the final analysis, our child’s quality of life depends upon these answers.

© 2002 - Mother’s Journey Through Auditory Processing Disorder


© 2008 WETA. All Rights Reserved.