Personally Speaking:

***Personally Speaking** provides a forum for readers to describe important issues or events in their lives and the role, if any, counseling has played. Guidelines for submitting manuscripts may be obtained from Stephen G. Weinrach, 303 Falvey Hall, Villanova University, Villanova, PA 19085-1699.*

It's been 10 years now since my only son and my oldest child, Tariq, was a seemingly normal happy toddler. At 18 months he was just beginning to speak and had developed a small but useful vocabulary. I still recall vividly the look of apprehension and then the thrill of achievement expressed with a smile as he took his first awkward steps. I was so proud. What an amazing accomplishment. I was cheering him on every halting step. He had been meeting all of the developmental milestones, and I imagined that before long he would be playing Little League baseball. In my mind's eye, I would beam with pride as he fielded the ball or swiftly ran the bases. Further down the road, I imagined having philosophical discussions with him as a young man.

Unfortunately, none of my dreams was ever to happen, for at 18 months, Tariq was treated for an ear infection and was never the same after that. He became frustrated and withdrawn. He cried a lot and didn't sleep well at night. I worried, especially at night, when I was awake with him. At first, the pediatrician thought it could be an emotional response to no longer being an only child since my daughter, Antoinette, had recently arrived on the scene. I hoped that the doctor was right, but I was scared of what it would mean if he was wrong.

Soon Tariq stopped talking and stopped playing with the toys he had received for his birthday. He began playing with a transparent rattle with brightly colored beads inside. He seemed fascinated and played with this toy for days and weeks on end. He ignored virtually everything else around him including his baby sister. I was tense and anxious, and wondered if I or his mother had done something to cause his condition.

It was like not having a toddler anymore. He became very agitated and upset if the rattle was taken away. His life, which had been a great joy to me, became a worry. I was glad to see him when I got home from work, but the fun of playing with him was gone. He still liked being touched and cuddled, so I clung desperately to the hope that Tariq would be normal once again. When he was 2 years old, I spent the whole summer with him. I worked to get his attention—to establish eye contact and a connection again. I would put him on the swing in the backyard and stand in front as I pushed him. All the while I tried to catch his gaze for a fraction of a second. He was a master at avoiding me. It was frustrating, especially because I was skilled at helping children, but all my efforts with my own son had no results.

As his third birthday approached, it was clear that he could not attend regular preschool. Now the trips to numerous specialists and special schools began. There were many sleepless nights waiting for various test results. There were no answers, or no one was brave enough or sure enough to break the bad news. One psychologist thought he might be hearing impaired. A specialist found fluid in his ears, which blocked his hearing, and he was treated for this condition with medication. My hopes rose as tests of his brain stem indicated that his ears worked. The fluid cleared up, but there were only grunts and babbling and crying—no words. Still, I dreamed at night that the babbling would turn into words because that's what babbling leads to for the average child.

Tariq was in an early intervention program by now, and he was the most difficult child in the school to manage. He required one-to-one attention all the time. He couldn't or wouldn't stay in his seat for more than a few seconds if left unattended. Whenever I wasn't teaching myself, I spent the day with him in school, helping the teachers.

Eventually my son was diagnosed as being afflicted by a "pervasive developmental delay," a nice term for autism. The team of professionals that evaluated him at the hospital where he was born used the words "autistic like" and "retarded." I went numb and was livid with rage at them. They seemed to have no hope for my son. How could they give him such a diagnosis? How could I give up on Tariq? "You should understand by now that your son is retarded," the social worker said. My head throbbed; my eyes filled with tears, but I held them back with my rage at the professionals who were telling me the news.

I withdrew inside myself as I learned about the disorder. It was painful to read that autism was a severely incapacitating and lifelong disability. It was hard to comprehend that my child's brain could not process what he hears, sees, or otherwise senses. The information that he takes in is distorted or fragmented, making it incomplete or confusing. I was told that communication with others or the world outside him would be extremely difficult. In the daytime now I walked around numb, and at night I cried and cried. There was no comfort. Professionals, relatives, and friends rarely seemed to know what to say or how to say it. Like many parents in similar situations, no expense was spared in the quest to find a cure for Tariq. Speech and movement therapies and even vitamins and a special diet were tried. The burden of the debts from these treatments was in itself for years a constant reminder of my hope for a cure. My dreams died slowly as I ran out of treatments to try.

Lost Dreams, New Hopes

ROBERT NASEEF

Unfortunately, I got no help from within my marriage. The strain tested my marriage and added to the other stresses that led to our divorce. As a single parent, I faced a life that had changed permanently and profoundly—something I had not planned on nor allowed myself to imagine. But now the reality was setting in.

Every minute of every waking hour was affected. The list of Tariq's special needs seemed endless, and the amount of care required was overwhelming. Because he rarely slept through the night, I was constantly exhausted. The entire house had to be child-proofed lest there be danger to my child or to my possessions. As a child who knew no danger, my son was a constant threat to run into traffic. The only part of my original dream that came true was that Tariq became a fast runner. Unfortunately, this made for few relaxing moments.

I couldn't reconcile the counseling I was receiving with the reality I was experiencing. I was stuck at a certain point that had to do with my family of origin, my failed marriage, and my own psychodynamics. Therapy helped me to express my feelings, but I could make no sense of them, and I was not being helped with this. The constant emphasis on doing more for Tariq was not helping me with my guilt.

At that point over 6 years ago, a colleague and close friend showed me an article in the *Journal of Counseling and Development* about the grief experienced by the parents of the handicapped. As I read, I came to a deeper awareness of myself. Suddenly, many disconnected feelings and thoughts began to make sense. When I completed the article, I leaned back in my desk chair, breathed a sigh of relief and said, "So that is what Tariq is all about; I am a bereaved parent. I have lost the dream of a normal child."

From that day on, my life changed for the better. My new self-knowledge helped me in the process of learning to cope with the many problems associated with having a handicapped child. It took time and help from others. I understood my thoughts and feelings better. As I look back, I believe that the failure of my counseling in this regard was partially a failure of my therapist and partially a general lack of understanding in the field about the grief experienced by parents of children with disabilities.

I still struggled through some horribly dark moments, but I began to reclaim my life. Cindy, the friend who showed me that article, helped me and eventually became my lover and by the end of this story, we married. Life did indeed go on with new dreams.

I had entered a doctoral program before knowing for sure that my son was handicapped. Because I was doing everything possible for Tariq, I concluded that delaying my own development would serve no purpose. It was trying at times, but my professors and my boss at work were very supportive. There were things to look forward to once again—both personally and professionally.

For my dissertation, I researched the qualities of the families who coped successfully with having a child with a disability. I hoped to help bridge the gap of understanding that frequently exists between the families of exceptional children and those professionals whose job it is to help them in some way. This dream came true as I spoke to countless groups of parents and professionals in various settings. As I became more effective at helping people to connect across the parent-professional chasm, I was asked to help develop a training package to foster parent-professional collaboration. The activities that I contributed were an important part of the final project that is now being implemented throughout New Jersey.

My son's disability has helped me to develop more ability than I thought I had. The knowledge and wisdom that I learned through losing my dream of a normal child are helping me to be all that I can. Tariq's disability was so severe that he needed a residential program by the time he was 8 years old. As much as it has hurt and continues to hurt, Tariq has brought me an awareness of the value of life. He is so innocent and generally happy. He is smilely and cuddly. He has always been a favorite of the staff wherever he has been in school, and these thoughts make me smile. When my daughter, Antoinette, learned to read, I was very, very thankful. By this time I understood normal human development as the miracle it really is.

I am experiencing more fulfillment than I ever knew existed. I feel whole and loved and loving. I can help others understand their thoughts and feelings, find humor at times in their situations, and go on to cope with their problems.. . I only wish I could tell Tariq about it.

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