



The Journey: A Parent Comes to Terms with Her Daughter's Disability

by Virginia Richardson

When Deborah, my eldest daughter, was diagnosed with epilepsy and intellectual disabilities, I read books and attended meetings and conferences that described parents of children with disabilities as being “in a state of chronic sorrow.”

That bothered me. I felt that if my husband died or if I developed cancer, there would be a period of intense grief and sorrow. My living patterns would be permanently altered, but I would not be forever in a chronic state of grief.

The writers and presenters used words such as “denial,” “guilt,” “anger,” “bargaining,” “sorrow,” and finally “acceptance” to describe “stages of grief” through which I was supposed to pass. They said the pattern was the typical reaction to becoming the parent of a child with a disability. Their language, however, did not fit what I was experiencing. My feelings did not come in distinct phases, nor were they predictable. Rather they seemed entwined, their boundaries blurred.

Instead of framing the experience of having a child with disabilities as chronic sorrow, I believe I managed it as I would any unexpected and life-altering event.

There was:

- Initial reaction
- Extreme feelings
- Refocusing
- Integration of the situation into my life
- Continued reaction and the cycle starts over again

Research tells us that in times of high stress (fire, accident, or storm) 15% of the people can take positive action, 15% are unable to act, and 70% exhibit odd behavior.

My actions encompassed all three categories:

I told my family and friends about my daughter's disability. I sought information about intellectual disabilities and epilepsy. My husband and I talked about it a great deal.

I was unable to act. I went to bed and pulled the covers over my head to shut out the world. I tried to forget. I bargained with God to remove the disability.

I behaved strangely. I could not say the disability words. I didn't want to see anyone. I cried a lot. I did not want to talk to anyone other than family about the subject.

Extreme feelings

I experienced a gamut of emotions:

I was pessimistic, fearful. How could I be a good parent? What if I didn't care for Deborah in the right way?

Did we have enough money to support her? What was the meaning for our entire family? I saw my daughter through a limited lens; I saw only her differences.

I was optimistic. Maybe the experts were mistaken. Surely there would be a cure in a few years.

I was sorry for myself. Why did it happen to me? How could I tell her grandparents? Would she live with me forever?

Looking back, my sorrow was not really about Deborah's birth. Instead my feelings were about myself and my concern about my ability to be the parent of a child with disabilities—a responsibility I did not understand.

Refocusing

As I lived with the reality of Deborah's diagnosis, I began looking at Debbie and the world in a new way. She was a delightful child, happy most of the time and very loving. She learned but in a different way. I had new possibilities, redefined my expectations for her, and found joy again in her accomplishments. I also developed a new perspective of myself: I was a parent who had a better understanding of Deborah's needs and the meaning of disability in her life and a parent who was able to manage the situation most of the time.

Integration, the final state

The notion of having a child with a disability became integrated into the fabric of my life and the life of our family. I still experienced uncertainty and at times I was fearful, but on most days I lived life looking forward, instead of continually glancing back to what might have been.

As I became accustomed to living with Deborah's disability, I found that a quotation from an unknown source described my perspective: "Life is not a problem to be solved, but a mystery to be experienced."

Virginia Richardson, nationally recognized advocate for families of children and young adults with disabilities, is the parent training manager at PACER. She writes: "I would be interested in hearing from parents of children with disabilities on how they came to terms with their child's disability."