

About Grief

Kathie Snow in her book *Disability Is Natural* (BraveHeart Press, Woodland Park, Colorado), 2001, writes about the grief experienced by parents when their child is diagnosed with a disability. She explains that we as parents need to get over it. I agree. We need to relax, research and rejoice. Although often in many ways it is harder (i.e. more patience, time, money may be needed) to raise a child with a disability, it can be just as rewarding as raising a “typically” developing child, if not more. In her book Kathie explains that we grieve the loss of the “ideal” child when we get the diagnosis, and that the diagnosis is merely a medical diagnosis and a “sociopolitical passport to services.” We must learn to separate the label from the child and keep in mind the real truth, namely that we have a child who has one or more parts of her body that work differently and that the disability is merely a condition that may require accommodations, assistive technology and other tools and techniques that enable her to succeed. For instance, my child needs a wheelchair for mobility, a voice output device for speaking more clearly, glasses to see better, and more time and direct instruction for learning. She won’t be doing everything just like most of her peers, but she’s more like them than not. In fact, she likes music, nail polish, malls, “Judge Judy-type shows” and trash TV.

Kathie Snow further explains that grief revisits some of us at various times for various reasons—at birthdays, graduations

etc., usually when we are reminded that our child is not the “perfect”—typical child. But whose child is? For me, grief revisits when the going gets tough—like when my daughter had major reconstructive hip surgery at age 13 or when she has a seriously bad, bad hair day. But remember, no one died, except for the notion of the “ideal” child. We can’t let others (society) define the success of our child as a person or the joy and happiness our child brings to us. Our children have different abilities, not problems. Problems arise when someone blocks a curb cut and a wheelchair can’t get through, or when others don’t gently teach their children that it’s not OK to point, stare or laugh at someone who looks, sounds or acts differently.

When my twins were born twenty-some years ago, they were premature and all I could focus on was for them to live. They did and they are doing very well. I took it one step at a time. I remember seeing an old friend who asked me about my children and how I was doing. I told him that I was doing better because I realized that I had stopped crying on a daily basis, as I had done for the first six months of their lives. He was shocked. I was, too. Now, I’m not sure what the genesis of my crying was, but I think it was linked more to the hard work involved with two premie babies at home and lack of sleep, rather than their still unlabeled disabilities. However, I did worry about their future, too. I remember sharing my feelings with a friend who taught children with disabilities. She said, “Don’t worry. They

might not go to Harvard, but they will make it.” That stopped me in my tracks, because I thought, hey that’s not so bad, I didn’t make it to Harvard either and look at me, I’m fine (somewhat). Years later, I think about that conversation a lot and look at problems other people have had with their children that don’t have disabilities—drugs, alienation, gangster-behavior and more—and remind myself how lucky I am.

Here are some tips for nurturing and enjoying your child with a disability:

- **Relax**

1. Let go of your grief. Or, if you’re like me where things get you down once in a while, keep it in perspective. I like to tell anyone who will listen to me that I believe in worrying or feeling sorry for yourself for only a finite period of time, if at all. Ten minutes, maybe—then force yourself to do something. Clean out a closet, volunteer, call a friend, write an essay, listen to music, do your bills. It’s amazing how curative it is to focus on something else that takes your mind off of yourself.
2. Join a parent support group, or find a parent buddy and talk to other parents. I am in a group that meets, eats, shares stories, and focuses on our business at hand (at least for a little while). It’s a non-threatening, non-judgmental group where it’s not a problem if you miss a meeting because you have something else to do, or your child is ill or is having a bad day. For instance, years ago, I was worried about the logistics of my daughter’s menstruation. Another parent in the group had a daughter a few years older than mine, so I decided to ask her how she handled it. She said that her daughter used diapers during her period, and that little, somewhat easy bit of information relieved my anxiety.

3. Discover and use relaxation techniques that work for you. Long hot bubble baths. Mystery novels work.
4. Laugh. A lot. One of my friends has a 10 year old son who has autism. He likes the sound of breaking glass. One day she realized things were too quiet and suddenly heard the sound of breaking glass, only to discover most of her dinner plates broken on a sidewalk outside her kitchen door. Although she was initially upset by this, she now laughs and shakes her head in amazement that he was so astute with pulling this caper off. She now uses plastic plates.

- **Research**

Learn as much as you can about what your child need to succeed. Speak to professionals from an informed vantage point. Be assertive about what you know and think. Use the internet, books, observations and opinions of other parents and any other source that will inform you. Get to know other people with disabilities, especially adults and learn their secrets to success. Years ago, I used to take my daughter to work with me on occasion, and one of my co-workers who also uses a wheelchair would talk with my daughter. One day, my co-worker told me that my daughter really asked her a lot of pointed questions, about issues that another person who uses a wheelchair could best address, and that that was really good. She said she wished her mother had done that for her. Although everyone may not have the opportunity to know a “mentor” we should all try, and certainly pay attention to the many people with disabilities who are successful. I don’t just mean successful in high-achieving professions either.

- **Rejoice**

Celebrate your child. Include him in your family life. Enjoy his antics. Laugh with him. Teach him. Watch TV with him. I once ran into my same friend from my parent group at a free Saturday concert at the Kennedy Center with her daughter. Her daughter didn't talk or walk and maybe didn't understand most things, but she enjoyed the live musical concert and her mother enjoyed taking her. I like to take my daughter out to lunch on occasion, just the two of us, for a girls' day out. I see others in the restaurant looking surreptitiously at us as we talk, but I won't let others define our fun.

Certainly having a child with a disability has its challenges. It's sometimes more expensive and time consuming and can be a lot more work. However, the rewards are infinitesimal, especially when your heart soars because your child has an accomplishment or says kind words to someone else in pain. What can be better than that?

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