The Duh Factor!

THE "SET-UP" FOR GRIEF

Revolutionary Common Sense by Kathie Snow

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Grief is considered, by many, a "normal" reaction to the birth of a child with a disability. But should it be?

At one time, grief was thought to be limited to the death of a loved one. But as our society has become increasingly influenced by the medical profession (including mental health disciplines), grief is now seen as an *expected*—almost routine—response to all types of naturally-occurring, ordinary human situations which are seen as "losses:" the loss of a job, a marriage, one's youth, and so on and so on. This article won't attempt to address these larger issues of "loss" and the accompanying "victim" status, but it *will* speak to the so-called grief as it relates to parents of children with disabilities.

"What do you want: a boy or a girl," is a routine question directed to mothers- and fathers-to-be. A typical response—whether from a movie star or the neighbor next door—is something like, "It doesn't matter, as long as the baby is healthy." Translation: as long as the baby doesn't have a disability. Further translation: babies with disabilities are not considered "healthy" or "normal," thus, they are not wanted.

> **Grief is the agony of an instant; the *indulgence* of grief the blunder of a life.**
>
> *Benjamin Disraeli*

This sentiment is parallel with (and perhaps derived from) the medical model of disability: the presence of a disability is an undesirable, unfortunate problem that needs to be fixed/cured/treated by medical professionals. And witness the response when parents tell others about a child's disability diagnosis: "Oh, I'm *so sorry."*

Is it any wonder that many parents grieve when their babies are diagnosed with disabilities? *Duh!* We're *programmed* to grieve by a society that worships perfection and abhors differences.

Counselors, medical personnel, parent groups, speakers at conferences, family members, and others attempt to address the grief that's become part and parcel of a disability diagnosis. At the same time, the cradle-to-grave programs for people with disabilities and their families thoroughly and pervasively reinforce the notion that a disability is such a serious problem that it requires not only the attention of parents, but also the *intervention of state and federal governments!* (In my most skeptical moments, the services mandated for people with disabilities seem to be a theoretical form of "compensation" for a "loss," instead of the assistance they're purported to be.)

This combination of factors (societal beliefs about disability and services offered to help the "problem") can validate the "need to grieve" which, in turn, leads many parents down the rocky road of "cures" or treatments to make the child "normal" or "better." Many parents go willingly. Others are made to feel obligated, and some are virtually coerced, to embrace every recommendation of physicians, service providers, and even other family members, regardless of how the recommended treatments affect the child, personally, or the family, as a whole.

Parents' feelings—shame or embarrassment about a child's differences, fears about the future, pressure from others, and more—have a profound influence on the child's life. We'll come back to this in a moment. But first, what "loss" have parents "suffered" that demands grief? Is the child dead? No! He or she is *alive!* The grief is over the "loss" of the *image* of a "perfect child"—the *image* every parent is trained to expect in our perfection-driven society.

Can we recognize that the "perfect child" *is* just an illusion? It's a picture we've created in our collective minds. If our minds had the power to *create* that image, our minds also have the power to create another image: the image of a successful, wonderful, desirable child who has, among his many other characteristics, one characteristic our society calls a disability.

The very notion that parents should feel the need—or be expected—to grieve is horrific. Having said that, I'll share that I went through a very brief period of feeling sad when my then infant son was diagnosed with cerebral palsy. Like others, I succumbed to societal attitudes and the prognoses of professionals. But as my baby son grew, the joy his life brought our family and our positive attitude about his future erased these feelings. And this was an incredibly freeing experience!

In addition, when my son was three, I had the good fortune to meet adults with developmental disabilities during my participation in the Partners in Policymaking leadership development program. These adults helped shape my attitudes and faith in my son's future. They also helped me learn the devastating effects of parental grief: it can hurt children deeply, in ways that may never be undone.

Many of these adults wistfully and sadly said, "I wish I could have made my parents happy..." and "I wish my parents could have loved me just the way I am..." All the interventions and therapies provided to them by their loving parents made them feel worthless as children. Some continued to feel worthless as adults; others have been able to move beyond these painful experiences. (There are many more natural ways we can help our children reach their potential without "therapizing" their lives and making them feel like they're "not okay," which I discuss in other articles and in my *Disability is Natural* book.)

While we may never *speak* of grief, sadness, or fear in front of our children, our actions, beliefs, and feelings *cannot be hidden from them.* Children are very intuitive. They may not be able to discern our exact feelings or decipher the reasons for our actions, but they know when we believe something is "wrong." In turn, this can lead to our children feeling unloved, unworthy, unsure of themselves, and worse.

Some of our actions, however, *are* easily translated by our children. When we turn our sons and daughters into perpetual "patients" via years of therapies and special services, they figure out, sooner or later, that *we believe* they're "not okay" just the way they are. That's a devastating blow—as I learned first-hand from adults with developmental disabilities.

When our children with disabilities are treated differently than their brothers and sisters or other children they know, they begin to "see" themselves as "different" and "not as good as" other children. This is a common occurrence when children with disabilities are segregated with other children with disabilities in "special," segregated programs at school, church, or in the community.

Children see themselves through our eyes, at least until they're older and can begin to define themselves. They need and deserve the ability to believe in themselves and their futures. If they don't receive this gift of hope from their parents, where *will* they get it? Grief robs us of the ability to give that precious gift.

If grief still lives in your heart, throw it out with the rest of today's garbage. If you can't get rid of all of it at once, throw some away every day; soon it will all be gone. Remember that our children will live up or down to our expectations. And remember that when we provide our children with the assistive technology devices, supports, and accommodations they need, anything is possible!

Replace grief with a positive new image of your child and fresh hope. In the process, you'll create new lives for yourself, others in your family, and most importantly, your child.