

The Impact of Childhood Disability: The Parent's Struggle
by Ken Moses, Ph.D.

I was taught that the way to deal with adversity or pain was to "tough it out." If you could avoid showing the pain, then you had "beaten the rap," and dealt with the problem competently. I am a psychologist who works with people who are grieving over profound losses. Few would argue that facing the devastating and continuing loss of having an impaired child is among the most painful experiences that a person can confront. After working with parents of the impaired for many years, I have come to believe that I was given bad advice. I have come to believe that pain is the solution, not the problem.

Parents, all parents, attach to their children through dreams, fantasies, illusions, and projections into the future. Children are our second chance, our ultimate "life products," the reflection and extension of our very being. To know that a human life exists that grows from our genes, our bodies, that is a result of our existence, brings a measure of spirituality into the most hardened individual. Something basic to our sense of being is stirred when we witness the miracle of the continuity of life. What happens when this core experience is marred irreversibly by disability? How does a parent survive the devastation of a handicap in their child that shatters their heartfelt dream? How do they go on? How can they help their child, then-other children, themselves?

Before I started working in this field, I noted that people who faced adversity basically became better or worse; none stayed the same. What made the difference? Some parents seem to pull their lives together around their child's impairment, others go to pieces. Over fifteen years ago, I ran my first parent group comprised of mothers of children with special needs. These people helped me enormously as I started to answer some of the important questions that relate to coping with childhood impairment. I began the group using tradition group psychotherapy methods, an approach designed to intervene on psychopathology. That approach did not work for a simple reason: Those mothers were not suffering from pathologies, they were reeling from the impact of having disabled children. Gradually, I let go of the old ways of doing things and permitted myself to listen and learn from me. It became evident that these people were manifesting a grieving process. This left me confused. It was clear that they were alternately anxious, angry, denying, guilty, depressed or fearful, but they were not internally "disturbed" people. Conversations focused on through is a presentation of theory, not irrefutable fact. It is meant to help people find their own ways of dealing with the unspeakable. I look at it as a map, not a recipe. A recipe tells people what to do if they desire a particular result. A map, on the other hand, is one person's partial impression of reality that can be used by another to help them get to where they wish to go.

When theories of grieving are used as a recipe to produce acceptance, two false premises are inflicted on parents. The premise that grieving should move through a specific order is flatly inaccurate. A consistent pattern is not evident in people dealing with loss? Worse, when people believe that they are supposed to grieve in a certain way, they often end up thinking they are doing it wrong. Secondly, the concept of acceptance is totally unfounded. In almost twenty years of working with bereaved people, as well as dealing with my own losses, I have never seen anyone achieve

acceptance of loss, only acknowledgment. Belief in the concept of acceptance leads parents into feeling like failures for not being able to attain it. Any use of grieving theory as a recipe is strongly discouraged. Though the feeling states of grieving do not adhere to any strict order, there is a loose pattern that can be detected. Denial is always first, but may re-emerge again and again, as often as the parent needs to experience it. Anxiety generally follows denial, but it can follow other feeling states as well. It is not uncommon for two or more feeling states to be experienced at the same time. Different families are more or less comfortable with showing certain feelings while discouraging others. In short, each person who goes through the grieving process experiences each of the feeling states, but does so in their own unique manner and order.

It is clear that this spontaneous, unlearned grieving process is central to the well-being of the child and parent alike. It is the only way that one can separate from a lost, cherished dream. Many people do not make it. They have their dreams shattered by disability and collapse emotionally under the assault. Resisting the grieving process, they hold feelings in, blame self or others, become embittered, dependent, or even bizarre in their interactions. They can range from the selfless crusader to the deserter, from the alcoholic to the workaholic, from the outrageously high-strung to the person who barely moves or talks. However they manifest their stuckness, these are the people who could not or would not experience the feelings of grieving. Many of them resisted the process because their subculture (their family, neighbors, church, schools, and friends) sent out a consistent message: the feelings of grieving are not acceptable! Others foundered because they were stuck emotionally before they had their educational, and therapy managers, even though they may have minimal knowledge of these areas. That alone should drive home the urgent need for energies to be mobilized and focused by the crucial feeling of anxiety.

Fear

As Anxiety mobilized people to deal with change, fear is a warning that alerts the person to the seriousness of the internal changes that are demanded. One's sense of balance and order are dramatically challenged when one confronts a meaningful loss. The parents experience the terror of knowing that they will be required to change on a fundamental level, against their will, with full understanding that the process of internal change is very difficult.

Significant losses produce a profound sense of abandonment and vulnerability. We have a number of sayings to cope with this level of fear, e.g., "It is far better to have loved and lost, than to have never loved at all." Each person must find their own words to confront the sense of abandonment and vulnerability generated by a significant loss. Most parents experience the fear of vulnerability about having more children after they have had an impaired child, or about "over-protectionism," the gut-wrenching fear of permitting their impaired child to do anything that feels risky. Given the ways that this part of grieving is manifest, it should not be difficult to see that fear is the medium that encourages the struggle to reattach, to love again in the face of a loss.

Guilt

Parents of impaired children manifest guilt through the normal course of grieving and are often criticized for doing so. Guilt is a feeling state that

has become so identified with being neurotic that people feel guilty about feeling guilty. Since sharing such feelings often evokes negative judgments, it can be difficult for a sophisticated parent to talk about guilt freely. On the surface, guilt-ridden people may appear not only neurotic, but superstitious, ignorant and primitive. They are often viewed as unpleasant, uncomfortable people to be with and therefore are dismissed or treated harshly by friends, family, and professionals. Generally, parents of impaired children express guilt in one of three ways. One way is by telling a story that explains how they are responsible for their child's handicap. Their story is often accurate and, on the whole, persuasive. The current emphasis on the prevention of birth defects has brought many parents to feel that they caused their child's impairment. or offered distractions. Such responses are inappropriate, for depression is part of normal, necessary, and growthful grieving. It attends to another aspect of a basic human struggle that loss stirs.

As we mature, we develop and modify our definitions of the following words: competence, capability, value, and potency. They are words of profound personal significance. They are the criteria that people use to decide if they are OK or not. What criteria does a person have to meet to feel like a competent parent, a capable worker, a valued friend, or a strong person? Each person determines these standards privately, even secretly. When parents are confronted with an impaired child, whatever definitions they held for competency, capability, value, and potency usually no longer apply. How does a mother feel competent when she has a retarded daughter? She can't use the measures of her peers, like having a daughter graduate from college, or become homecoming queen. What is the worth of a father who cannot "fix" what is broken in his impaired son? Out of this struggle of defining one's worth come the frightening feelings of helplessness, hopelessness, and haplessness. Faced with loss, a parent feels unable to act effectively (helpless), unable to imagine that things will ever get better (hopeless), and unable to believe that their lives are touched by good luck (hapless).

Such feelings are terrifying for both the parents and those around them. For that reason, it is hard to see that depression is a normal and necessary part of the grieving process. Depression is the medium that helps parents come to new definitions of what it takes to be a competent, capable, valuable and strong people, even though their child has impairments that they cannot cure.

Anger

Anger, for many people, is the most disconcerting of the feeling states. It too is natural and necessary part of the grieving process. Parents feel anger at the harm done to their child and the shattering of their dreams. When one encounters a significant loss, it is likely that one's internal sense of justice is severely challenged. To continue to trust in the world, one must have a sense of justice that confirms an orderliness and fairness to the way the world works.

A parent can righteously demand to know why he or she has an impaired child: "Why me, why not you!" Implicit in the question is the notion that there must be a good reason that such a thing happens to one parent and not to another. A parent's concept of justice, like value and worth, is another one's sense of justice, the outrage must be expressed. Those expressions help to redefine one's concepts of fairness and justice.

Conclusion

The parent of an impaired child separates from dreams that were shattered by impairment through grieving. Denial, anxiety, fear, depression, guilt, and anger all emerge. If they are shared with other people, these feelings help parents grow and benefit from what might be the worst tragedy of their lives. Grief must be shared deeply and fully until the underlying issues are revealed. The reopening of these issues changes the parent's world view. New perceptions of themselves and their world serve as a solid foundation for coping with the disability and for personal growth. Yielding to the grieving process helps parents find the inner strength and external support needed to face profound loss; to mobilize and focus the energies needed to change their lives; to reattach to new dreams and loves in spite of feeling abandoned and vulnerable; to redefine their criteria for competence, capability, value, and potency; to reassess their sense of significance, responsibility, and impact upon the world around them; and to develop new beliefs about the universal justice system that makes the world a tolerable place to live, even though anxiety, fear, depression, guilt, and anger may be used in surprisingly positive ways when the feelings are fully shared.

Perhaps you can now see why I think that experiencing and sharing the pain is the solution, not the problem. Through my life I have experienced many losses. For many years I dealt with these losses by stifling feelings, workaholicism, toughing-it-out, and innumerable other ways that kept me from experiencing what had happened to me. I became one of the "walking wounded" that I was committed to helping. Ironically, it was not until I myself had a child with impairments that I began to take the advice that I had so freely given to other parents. I started to yield to the natural and necessary process of grieving. Like everyone else, I discovered that only now am I growing with the impact of the loss. I will continue to grieve and to grow as my child and I develop and experience new losses and new strengths.

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