

Common Bonds: The Experience of Parenting a Child with Special Health Care Needs

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Because no two children are exactly alike, the experience of parenting is unique for everyone. Even so, most people from the time when they discover they are expecting a new baby will seek out advice from others. Experienced parents usually love to share their hard-earned tips and tricks. It's natural to want to get information and support from other families.

Parenting a child with special health care needs is no different. It's important to remember that first and foremost, our children are children, not their diagnoses. The existence of special needs doesn't make our families less valuable than those in more typical situations. The term "special needs" indicates that some of the supports our families need to thrive are more specialized than those available from traditional sources. One important place to get this more specialized support is from other parents of children with special health care needs who share this common bond.

Some parents of children with special needs describe their way of coming to terms with their children's challenges as moving through the grief process (denial, anger, bargaining, depression, acceptance). Many others respectfully feel this idea only stresses loss and doesn't touch on the positive aspects of having a child with special needs. Certainly, the birth of a child with a disability, the sudden onset of a serious illness in a previously healthy child or an accident are unexpected and life-altering events. But loss or sorrow is only part of what is experienced by families facing these challenges. The following is an exploration of some commonly reported reactions to parenting a child with special needs. The important part of this discussion is not to say that parents will experience these reactions step-by-step but to share a feeling of community among those who have traveled a similar road. When faced with a challenging situation there's nothing quite like being able to say to someone else, "Yes! I felt that too!" That feeling of connection validates the experience and creates a strong, positive bond. Another goal of this discussion is to provide people with an opportunity to be aware of common emotions or reactions that may have been different than their own.

In the beginning...

Most people experience the time in which they first learn that their child has a disability or other health care concern as a highly stressful and difficult one. Reactions can run the gamut from "there must be some mistake, my child is fine" to "My life and my child's life is over, nothing could be worse than this and it will never get better." Many people describe feeling a range of emotions during the time of their initial reactions. Another common reaction is feeling disconnected or "shut down". Communication can be difficult as people find the amount of information thrust at them and the emotional intensity they are experiencing overwhelming. Their decision-making processes may be interrupted or compromised. This difficulty in both expressing and assimilating information can be profoundly upsetting as this is a time when the ability to both think clearly and make appropriate (sometimes life-altering) decisions is crucial. Some of the ways families can be supported through this difficult time include having written information which can be referred to in the future, others having patience in repeating important instructions, active listening and positive, non-judgmental emotional support.

Highs and Lows-The Search for Meaning...

Once a family begins to move away from the initial shock and confusion of the diagnosis or event, other feelings begin to emerge. Many experience anger, guilt, frustration or an intense need to find a cause or answer. They may feel angry at fate or question their faith. They may feel restless or impatient with themselves or others. Some find that ordinary tasks become overwhelming or that the emotions they are experiencing spill over into other parts of their lives; such as being furious with a partner over a minor irritation or crying at work. Some withdraw. Others plunge into constant questioning and searching. Some find hope in optimism or comfort in religious faith or spiritual pursuits. Many people describe themselves as moving back and forth between various emotional states. It's important to remember that there is no one "correct" way of coping with the presence of special health care concerns in a family and that the process of adjusting, although it becomes less dramatic over time, is never-ending. Families may re-visit many of their initial reactions as situations such as developmental or educational milestones are delayed or medical crises occur. All of these reactions are part of the process of finding the meaning of the situation for our families. Why has this happened? What happens now? What does this mean for my child and our family's future? These are all important and deeply felt questions and there is often no easy or uniform answer. Families need help finding their way as they discover their own answers for themselves and their children. Giving people permission to feel and express their emotions, listening to them with an open heart and mind, helping them formulate their questions and directing them toward resources when they are ready are valuable gifts families can give to one another.

Refocusing...

As families move forward in their journey, they realize they're in for the long haul. Some become depressed or find the stress of the situation negatively influencing other areas of their lives, such their work or marriage. Others find their worst fears have not been realized and they can begin to feel more at home in the new world they've been thrust into. Whatever their reaction, with support the joys of parenting and pleasures of life can begin to reemerge or reveal themselves for the first time. A sunny day, a good joke, a developmental milestone (no matter how delayed) can still be enjoyed and celebrated.

Synthesis...

As families begin to adjust and feel more positively about the reality of their situations, they find themselves able to give as well as receive information and support. It is a much more natural and energizing state to be able to achieve a balance between being a giver and a recipient. A person who can do both will feel more in control of his or her life. A person who has been supported and empowered will have the opportunity to look forward with hope rather than back with regret.

As we support one another, the threads of our common bonds weave together to make up the strong and vibrant fabric of our community.