Children with Special Needs: Helping Parents Through Grief

By Rebecca Oekerman

Tom and Mary Anderson have come to enroll their child in your program. William, age two, has Down syndrome. They carefully explain the ways in which William's development is not typical and the extra services necessary for his everyday existence. They seem OK with the child's situation, and William appears to be happy. But in the parent's eyes you see a profound sadness. You sense a sorrow that is impossible to fully conceal. You want to help but are not sure what to do.

Many teachers who care for children with special needs have encountered this dilemma. What is happening with the parents? What is your role as the teacher or the program director? How can you support the family?

Understanding the sadness

When a family finds out they are expecting a child, it is usually a time of celebration and planning for the future. Even before the child is born, the parents and extended family talk about what the child will look like, what he or she will grow up to be, and the activities that the whole family will do together. William's father, for example, may dream about playing baseball with the child.

However, when the child is born and parents learn their baby has a disability, these expectations undergo a radical change. It could even be said that something dies. That something is the dream the family had built up around their child. And the reaction, like that when someone dear dies, is grief.

Parents who have experienced the birth of a child with special needs go through a grief process. And just as the term implies, grieving is a process, one that takes time to work through. Families differ in the way the process occurs, but it still occurs.

Stages of grieving

Elizabeth Kubler-Ross, in her book *On Death and Dying*, identifies the series of emotions that people usually experience when a loved one dies. Mental health professionals believe this series of emotions may occur whenever a person confronts a loss or crisis.

The typical stages of grief appear below. They do not necessarily occur in this order, and it is not unusual for people to move back and forth between the stages.

Denial: *"Oh, no. Not me. Not our family. There must be some mistake."*

Anger: *"How dare you say something like that!" "Why me?"*

Bargaining: *"If we see the right doctors and pay enough money, they can make things OK."*

Acceptance: *"Ginny has a disability. Things have not turned out as I expected."*

From Elizabeth Kubler-Ross. *On Death and Dying*. New York: Simon & Schuster, 1997.

Stages of grieving

The first stage in the process is usually one of shock during which the parents may be unable to focus on what the doctors say about their child. This may be followed quickly by disbelief and denial as the parents begin to understand that something unexpected has occurred. They do not want to accept the diagnosis or the fact that their lives will be changed forever.

At this point parents' emotions come into play as they begin to think about what they have been told about their child. They may feel guilty as they look for a reason for their child's condition. They may question their own part in what has occurred: *"What did I do to make this happen?"* Next, they may feel angry and resentful, lashing out at those around them. They want to know *"Why me?"*

As parents fully confront the fact of their child's disability, a great sadness or depression may settle over them. They begin to think of the future and may worry about how they will care for the child. They may worry what will happen when they can no longer provide for the child themselves.

Finally, though, comes a sense of acceptance. Tom and Mary accept William for what he is rather than what they had hoped he would be. Then, hope may begin to grow as parents enjoy the strides the child makes and take pride and satisfaction in the child's accomplishments.

What can teachers do?

Knowing about the process that parents go through can help teachers and program directors know what to do. Some suggestions:

- **Accept** that the grief process is natural and good. We all need to grieve when loss occurs. This helps us make sense of what has happened.
- **Acknowledge** that not all parents go through the same grieving process. The stages mentioned here and the order in which they are outlined serve only a guideline for what may happen. Some parents may not experience all these emotions, and the intensity of their emotions will vary. But no matter the order or strength of the emotions expressed by the parents, the emotions need to be accepted.
- **Understand** that grief may reoccur. Even when parents have reached the acceptance stage, events may occur that cause them to revisit previous stages. For example, they may become angry or sad when they see all the other babies in the program begin to walk and their child cannot. They may feel sad when their friends' five-year-old joins a T-ball team and their child cannot. Be ready and supportive in these circumstances.
- **Be prepared** with information the parents may need, or know where to find the information. Help parents by compiling a list of service providers, knowing who to talk to in the public school system, or having a list of clergy and other counselors available.
- **Help parents** celebrate the successes of their child. Although the child may not be able to do what other children the same age are doing, look for and acknowledge what the child can do.
- **Be an advocate** for children with special needs. Read and learn more about how to assist these children and their parents. Arrange for a speaker to come to your program or ask the program director to do so. Attend workshops and conferences on the subject. Join professional organizations whose missions are to inform and advocate.

By becoming sensitive to the possibility that parents of children with disabilities are grieving, you are in a better position to offer support. You can help them view their child, not as one with special needs, but as you do every child, simply special.

Resources for parents and caregivers

Chandler, Phyllis A. *A Place for Me*. Washington, D.C.: National Association for the Education of Young Children, 1994. Gerber, Magda. Your Self-Confident Baby. New York: John Wiley, 1998.

Gilgen, Martha. *And Miles to Go: A Guidebook for Parents of Infants and Toddlers Needing Early Intervention Services*. Bosie, Idaho: Idaho Parents Unlimited, 1998.

Greenspan, Stanley. *The Child With Special Needs*. New York: Addison-Wesley, 1998.

Lerner, Vlaire. *Learning and Growing Together: Understanding and Supporting Your Child's Development*. Washington, D.C.: Zero to Three, 2000.

Thurman, S.K. and A.H. Widerstrom. *Infants and Young Children With Special Needs*. Baltimore: Paul H. Brooks, 1990.

About the author

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