

*Module:* **Family-Centered Practices  
for Infants and Toddlers With Visual Impairments**

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**Session 1: Building Reliable Alliances**

**Handout F**

**Parenting a Child With Special Needs: The Emotional Reactions and Adjustment of Parents and the Support That Caregivers Can Offer**

Maroney, D., & Davis, D.L. (October 30, 2001). Parenting a child with special needs: The emotional reactions and adjustment of parents and the support that caregivers can offer. *Mental Health Issues for Infants and Toddlers with Special Health Needs*. Retrieved September 16, 2002, from [http://www.jfkpartners.org/Emotional\\_Responses.pdf](http://www.jfkpartners.org/Emotional_Responses.pdf)

**Dianne Maroney, R.N., and Deborah L. Davis, Ph.D.**

As we talk about “**special needs**,” we are referring to a broad category that includes anything that

- is beyond what is considered typical in child development or health,
- requires significant therapeutic intervention and
- requires a significant adjustment of parenting skills and expectations.

Special needs can include:

- Chronic or life-threatening physical impairment or disease (e.g., diabetes, heart disease, CP, lung disease, cancer, HIV, blindness);
- Feeding and growth challenges (e.g., failure-to-thrive, oral aversions, allergies, food sensitivities);
- Birth defects and genetic anomalies (e.g., cleft lip/palate, Down syndrome, heart defects);
- Behavioral/emotional imbalances or developmental delays (ADHD, autism, Asperger’s, learning disabilities, chronically inflexible/ low tolerance for frustration);
- Unidentified problems, where the parents know that something is different and problematic, but we don’t have an understanding of or diagnostic category for it yet;
- Complications of prematurity, which can involve a constellation of any of the above, that is unique for each child.

Special needs occur along a continuum, where some are more challenging or life-threatening than others, some require more intensive intervention than others, some require more adjustment of parenting skills and expectations than others. But different special needs mean different things to different parents, and it’s important to respect the variety of reactions you may see among parents. In other words, what is supremely challenging for one family may be taken in stride by another family. Accept that different families will have different reactions, and that they are all doing the best they can with what they bring to the table and with the challenges they encounter. Each family is on its own unique journey, and one key to offering support to parents is *respecting that journey*.

## **Emotional Reactions and Adjustment**

Even though every parent is unique, all parents share a common ground: their reaction and adjustment to having a child with special needs is a **grieving process**, which starts with mourning the loss of what might have been, and leads toward coming to terms with and accepting what is and will be. Indeed, grieving is what enables parents to come to terms with the losses associated with parenting a child with special needs.

Because grief is so painful to endure, some people believe that grieving is something bad to be avoided or something to be gotten over as quickly as possible. But grief isn't a problem to be solved—it's a process that unfolds. Indeed, *grieving is what enables parents to adjust*. Grief is also complicated, more than just sorrow, and more than just a set of simple stages that parents march through. At any time after crisis hits, parents can experience a mixture of painful, sometimes bewildering feelings. It can be so helpful to parents to hear that grief is a fluid experience of

sadness, anger, guilt, regrets, and failure,  
longing, fear, disbelief, numbness and emptiness,  
preoccupation, confusion, anxiety, irritability,  
hopelessness, depression, powerlessness, and agony.

They may also experience physical symptoms, such as

fatigue, sleeplessness, sighing, poor appetite, crying spells,  
shortness of breath, tightness in the throat or stomach,  
clenched jaw, heart palpitations or  
other manifestations of anxiety or depression.

A parent may feel some or all of these emotions and symptoms. And there are no timetables. Instead, tell parents to throw deadlines out the window, and to recognize that their painful feelings will ebb and flow, and indeed, as their initial shock wears off after the diagnosis (or after each new diagnosis), they will probably feel worse rather than better. While this can be disheartening, gradually the ups will become more frequent, and the downs more gentle and few.

Also tell parents to expect to be affected by triggers. For example, birthdays, developmental milestones, visits to the hospital, seeing other children of the same age who are progressing normally, looking at baby pictures, becoming pregnant again--any sights, smells, or experiences that trigger painful memories or grief. When parents can acknowledge and identify these triggers, their emotional turmoil can make more sense to them. Encourage them to take advantage of these triggers as opportunities to release more layers of feelings, advancing their journey of adjustment. Reassure parents that even though they are revisiting similar emotions, they are not in the same place they were the last time. Remind parents as they grieve, they are also adjusting.

There is so much more to the grieving process than can be displayed on a piece of paper--it is complicated by the baggage parents bring to the situation, by the pulls of various responsibilities and relationships that are so difficult to balance, by the realization that bad

things can happen to their precious child even when they least expect it, and by the grip, at times, of overwhelming and agonizing emotional pain.

## **How can caregivers support parents?**

### **Listen**

To help parents work through their grief, sit with them and LISTEN. Ask them how they are really doing, or empathize about how hard this must be for them. And then listen. If they cry, don't try to wipe away their tears. It's not your job to fix them, it's your job to be their companion through the process. If they cry or vent, know that they are on the right track, and walk with them through their grief.

Some parents will be easier to walk with than others. Know the strengths and weakness that you bring to your work and remember that you will have a better fit with some parents than with others. Collaborate with your colleagues, so that you can support each other with ideas and insights, and sometimes share the load.

### **Educate**

Earlier, we touched on educating parents about the grief process, which helps them have realistic expectations and facilitates coping skills. In addition, parents need to understand their child's condition, prognosis, treatment options and etiology. Having this information helps them regain a sense of control, which was diminished when they discovered their child's condition or disabilities. In addition, sharing information enlists parents as integral members of their child's medical/therapeutic team, which benefits parents and child alike. Information also helps parents figure out what questions to ask and empowers them to advocate for and make decisions in their child's best interests.

Education can also enhance adjustment, because with information comes mastery. Plus, being able to get a handle on the situation greatly enhances their abilities to cope. Without information, parents feel lost, without a compass or guide. Even when information is painful or overwhelming, lacking information is even more painful and overwhelming.

Because information can be overwhelming for parents at times, it is important to stay with them as they process it. Remember that they are entitled to their feelings about it, and that your supportive, listening presence can be a comforting container for them. Also honor each parent's unique pace. For some, it may be a while before they are ready to delve into details, while others may want details right away. Encourage parents to stay aware of their questions, even the ones they're afraid to ask. Their questions can be a guide as to how much and what kinds of information they need and want.

Even when parents want information now, it can take time for them to form the questions they have or to absorb what they're given. Offer them written materials and encourage them to ask permission to audiotape important meetings with doctors and therapists. Having access to notes, pamphlets, articles and audiotapes will give them more time and opportunity to absorb and reflect on the information they're being told.

### **Respect**

Earlier, we talked about respecting each parent's journey. Respect also means not pathologizing what the parents are going through. Even when parents are having a lot of

difficulty coping, it's not necessarily that something is wrong with them--it is the situation that is so extraordinarily difficult to cope with. Reassure parents that their reactions are normal and natural responses to the challenges. Even when parents need therapy or medication to boost their coping skills, know that their needs are not a mark of failure or inadequacy, but of imbalance that comes from the stress of feeling with a sick or challenging child. Encourage parents to seek counseling as a matter of course. Reassure them that the need for additional emotional support is normal and will help them be better parents. Point out that by nurturing themselves, this will in turn enable them to nurture their child.

### **Empower**

Besides empowering parents with information, also empower them by honoring their protective urges. Protectiveness is a normal and natural response to having a child with special needs. Protectiveness comes from parents listening to their intuitions about the problems their child faces and the interventions that are worth a try. These parental intuitions can be valuable sources of insight, and honoring them can be central to empowering the parents of children with special needs.

What about overprotectiveness? This too can be a normal part of a parent's adjustment to meeting their child's special needs. Even as the child stabilizes, goes into remission or recovers, parents may continue to hover as they deal with the emotional fallout. It is normal to start out this way, but also important to move beyond it.

To help parents move beyond overprotectiveness,

- Model seeing and treating the youngster as a whole child, not a medical specimen (“How is your little one enjoying this summer weather?”)
- Point out the child's areas of strength and robustness (“Your child has wonderful balance.” “Your child's lungs and heart sound perfect, as usual.”)
- Let parents know when their child's vulnerability to complications has passed (“Your child is getting stronger every day, and though you might still feel worried, you can start learning to trust that when your child looks like she's doing well, it's because she is doing well.”)
- Teach parents to separate imagination from reality-to check whether their protectiveness is arising from what they imagine might be going on or from what they are actually observing-and to disregard the former so that they can focus on tending to the latter.
- Wean the child (and parents) from intensive care and medical support (for instance, think about the message we give parents when we wait until the moment of discharge to remove monitor leads from their little one.)
- Help parents deal with anxiety by encouraging them to voice their fears. By pinpointing their fears, parents can get a handle on what's bothering them, instead of letting their anxiety fester and generalize to other aspects of the child's condition or development, thus fueling overprotective urges. Sometimes, it can take a while for a parent's fears to surface, or they may need more time to put into words whatever is bothering them. Keep the lines of communication open, so that they are free to talk about worries when the time is right for them.
- Encourage parents to forgive themselves for whatever they feel they have failed at, so that guilt doesn't add fuel to overprotective urges. If they feel any guilt for causing their child's condition, help them to recognize that they had very little control over the

circumstances. Even if they are convinced that they are to blame, they can be encouraged to move toward forgiving themselves for not knowing then what they know now. In addition, the balancing act required for parenting a child with special needs is tremendously draining. Parents who have perfectionist tendencies may feel a keen sense of failure around feeling stretched beyond their limits. Remind parents to slow down and not expect themselves to do it all or be everything to everyone. Help them to identify their priorities and to give themselves permission to let go of certain standards or unimportant responsibilities.

Dianne Maroney is a former NICU nurse, the parent of a preemie, and the coauthor of *Your Premature Baby and Child* (1999). Debbie Davis is a developmental psychologist, the author of several books for bereaved parents, most notably *Empty Cradle, Broken Heart* (1996), and coauthor with Mara Tesler Stein of *The Emotional Journey of Parenting Your Premature Baby* (2002).