

## CHAPTER 3

# LISTENING TO OUR CHILDREN

### Review

- ▶ What did you learn from talking together as a family? Did everyone in your family participate? If not, why not? How can you encourage everyone to participate this week?

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- ▶ What new observations are you making about yourself as a parent and the ways your family interacts? Was it difficult to share your thoughts and feelings about the photographs or the picture you drew about the family doing something together? Are you comfortable trying new ways to relate to your family?

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Let's reconnect with Laura, the talented runner we met in the last chapter:

When Laura gave birth to her daughter, Sarah, she and her husband were absolutely blissful. Even though Sarah had

arrived a few weeks early and had to spend some time in the neonatal intensive care unit, the doctors reassured Laura and her husband that Sarah was a normal, healthy baby. They examined all the wonderful parts of Sarah and watched her for hours as she ate and slept. A few months later, they began to notice a very disturbing wobble in Sarah's neck when she tried to hold her head up. Then they observed that she couldn't sit up by the time other babies could, and she didn't seem to have any interest in crawling. After several visits to a specialist for tests, Laura and her husband were confronted with a devastating reality: Sarah had cerebral palsy. Not only would she never be a good runner, she might not even walk.

This is our experience, from Jared's point of view:

We had waited a long time to get pregnant. I was finishing my graduate degree and could look forward to stable employment. Alice was ready to do something other than teach. Our relationship was solid enough to imagine having a child. Seven weeks earlier than the due date, Alice started labor. We were surprised but not frightened, for the medical professionals seemed to predict few problems. After a successful delivery and a precautionary trip to the neonatal intensive care unit, we began to call family and friends to give them the good news. Then it happened. An unfamiliar doctor told us that our son had a serious respiratory illness and might not make it through the night. All our dreams crashed. All that we expected to happen was now destroyed. All our plans and expectations meant nothing.

*If you find yourself facing uncomfortable personal memories or are having difficulty implementing new skills, think about contacting a parent coach or family therapist for personal assistance.*

## DISCOVERING THE "REAL CHILD"

In the last chapter, we explored what you expected your experience with your child to be like. You identified your needs and what you wanted to have happen. Now we must face a most difficult truth: Life does not always take us where we want or think we need to go. What do we do then? What do parents do when they had planned to arrive in Italy but find themselves in Holland, or maybe someplace much worse, a place where even survival is at risk?

- ▶ **In the first example, Laura expected Sarah to be a healthy child who could learn and perfect the skills necessary for running competitively. Laura expected to feel proud, excited, and joyful**

as she watched her lovely daughter become a star athlete. But now she knows this will never happen the way she imagined it. What do you think Laura was feeling when she discovered the truth about Sarah's disability and probable future?

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- ▶ In the second example, Alice and Jared thought their first child would fit nicely into their plans for a family. They believed they were ready in every way to become parents. What do you think they were feeling when they were told their son might live only a short time?

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- ▶ How might the way Laura and her husband feel, Alice and Jared feel, affect their attachment to their babies?

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It is our conviction that in order to become conscious parents, we need to admit and experience all of our real feelings and thoughts. We have to accept that we had dreams for ourselves with our children and that things turned out differently. Our dreams and hopes must change. In order not to get stuck in the feelings of disappointment, we must let go of what we wanted. To do that means we must first learn to identify and express the intense feelings raised by not getting what we expected.

Take some time to respond to the following general questions, which will help you explore how these intense feelings might be affecting your parenting.

- ▶ How did you find out about your child's special needs?

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- ▶ How was the diagnosis delivered to you? Who told you? Where? Who was with you? How did you feel about the person who delivered the news?

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- ▶ What did you feel when you first discovered that there was a problem? What did you say or do? Was there anything you wanted to say or do but didn't?

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- ▶ How did your parenting partner react to the information about your child's disability, illness, or delay?

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- ▶ How did your child's diagnosis and condition affect your relationship with your partner?

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- ▶ If you have other children, how did they respond?

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- ▶ How did your parents, other family members, and friends react?

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- ▶ What was the most difficult part of this experience for you?

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Take a moment to compare your feelings and thoughts when you learned about your child's special needs with what you wrote on page 28 about the traveler who just landed in Holland.

- ▶ **Are the feelings similar? Would you imagine that yours are more intense? Explain why or why not.**

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## **WHAT IS YOUR CHILD EXPERIENCING?**

To complicate matters for some parents, your child may also be struggling to understand his or her experience of being “special.” Let’s take a moment to understand what this might mean for Jason and his mother:

Jason was a five-year-old born with congenital disability that resulted in one arm’s being deformed. Other children often walked up to him and asked what happened to his arm. His mother was near tears at what she felt was rude and disrespectful questioning. But when Jason was alone on the playground, he would sometimes respond to the other children’s inquiries by throwing a ball in the air and hitting it with his deformed arm to demonstrate what tricks he could do with his body. Sometimes Jason liked the special attention others showed him, but, often, when he was around his mother, he became shy and hung back because he knew how much the stares and questions upset her.

- ▶ **What do you imagine Jason is thinking and feeling about his arm when he is with his peers?**

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- ▶ **How would you characterize Jason’s mother’s response to his disability when she is in public? What might she be feeling?**

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- ▶ **Why do you think that Jason’s behavior changes when he is with his mother?**

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Many parents encounter problems separating their own feelings from those of their children when they imagine that their child feels the way they do. We see this in Jason's mother. We also observe that Jason is aware of what his mother is feeling and adjusts his behavior accordingly. This interchangeability, or mirroring, of feelings between parent and child begins at a very early age. A depressed parent, for example, may not be able to smile and laugh with a toddler, and it soon appears that the toddler is depressed. More likely, the toddler is mirroring the parent's emotional state. This may be true with anger or fear as well, and it is certainly a factor when the child is in pain. If the child hurts, the parent hurts as well.

As understandable as mirroring is, it is central to conscious parenting to recognize that children may not be feeling the same way the parent is and, conversely, the parent may not be feeling the same way as the child. Parents unaware of this interplay of emotions constantly find themselves *reacting* to their children rather than *responding* to them as separate human beings with experiences quite different from their own. Significant discipline difficulties can emerge when this happens. For example, in the last chapter, we witnessed Miguel reacting to José when José did not take care of the soccer equipment. Miguel was not aware that José's experience is completely different from his own because José has never had to make do with poor equipment. He may also not even enjoy playing soccer.

## WHAT AM I EXPERIENCING?

To break the ineffective cycle that results when they assume that they know how their child feels, parents must listen to their own feelings and thoughts and become more attuned to the true feelings of their child. This new kind of listening can be very challenging: It requires practice to be present with oneself and one's child. We will expand on these listening skills in chapter 5.

- ▶ **How would you assess your current ability to separate your feelings from your child's feelings?**

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- ▶ **If your child is old enough to talk, what feelings has he or she disclosed about having a special need?**

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- ▶ If your child is nonverbal, what have you observed about the way he or she responds to other people's reactions? What do you observe about his or her body language with other people present? Does he or she behave differently when you are not present?

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You are beginning to explore the differences between your child's experiences and your own experiences. Chapter 5 will have more to say about this issue.

## Chapter Summary

- ▶ Parents have dreams for their children. This is natural and inevitable.
- ▶ It is essential that parents raising children with special needs recognize that the child they expected is different from the real child in their life.
- ▶ In order to accept the realities of parenting children with special needs, we must identify and then express to a significant other adult what changed in our life after the diagnosis and how we feel about these changes.
- ▶ Along with our awareness of the impact having a child with special needs has on our life, we must increase our ability to observe how this affects our child, his or her siblings, and other family members.
- ▶ Parents are challenged to separate their thoughts and feelings from their child's in order to help the child reach maximum independence. This begins when parents ask: What am *I* feeling?

## Interactive Family Activities

1. Draw a picture of how you felt when you first heard your child's diagnosis. Share this with other adult family members and encourage them to draw their own pictures.
2. During the coming week, observe your child in an interaction with another person who doesn't know your child. Notice your own feelings as you watch their interplay. Do not intervene. See if you can identify what your child might be feeling. Notice whether your child seems to feel the same way you do about his or her special

qualities. Observe whether the other child or adult is more curious, critical, or accepting of your child than you imagined. Notice how your child handles the reactions of others. Is this the same as or different from the way you would react?

3. If you have other children at home, notice how their interaction with your child who has special needs is the same as or different from that of other individuals. Does the sibling's behavior change when you are present?
4. Find a time when you and your parenting partner are free to have an extended conversation. Explore what each of you feels and thinks about the social interaction your child is having with others. Do you see it in the same way? Do you imagine that your conclusions will change over time? Are there changes you need to make in order to imagine a more favorable future?
5. Contact another family raising a child with special needs. What do these parents say about their child's social skills? Are they interacting with their child in ways that you admire?