

INTRODUCTION

Welcome to *Raising Special Kids!* Congratulations for your courage to embark on this journey with us. You and other parents who share the experience of raising a child or children with special needs are required to do things that other parents do not have to do. Whether this is making frequent appointments with doctors or spending countless days in the hospital, whether it is waiting for yet another psychological report or learning how to use the latest equipment for physical or occupational therapy, you are now involved in a whole new set of activities with your child. Your responses to these events and demands may be familiar, puzzling, or disturbing. Whatever your unique experiences are, they are now part of what it means for you to be a parent.

If your child has or is at risk for a chronic physical, developmental, behavioral, or emotional condition, this *Parent Guidebook* is written for you. Working with this material will, we hope, encourage you to become a *conscious parent*. For some, entering this process may initially be scary, sad, or lonely. We believe, however, that the venture will be worth your time and energy, and we are confident that you will feel less alone and less afraid if you continue with this program. We hope that your choice to participate will enrich your life and help your family become more open and honest with one another. As you engage in this program, we hope you will learn new ways to appreciate all that you are doing to raise not only your child with special needs but all of your children. The challenges are many; the rewards are great.

Two experiences prompted us to write *Raising Special Kids*. The first was the birth of our first child, Caleb, on November 27, 1973. Although he was born seven weeks early, there seemed to be no major problems with his delivery. We soon found out differently. One hour later, a doctor we had never seen before entered our post-delivery room and announced, "We are not sure your son will make it through the night." With those few words, we embarked on a trip of unknown duration and destination. We had no idea how high the climb would be, how low the drop would take us. For five and a half months, until our son died, we lived totally absorbed in the experience with him. We had to learn new skills in order to bathe and feed

him, to suction his lungs, and to provide physical therapy. We had to accept that his home was the hospital. We had to learn how to be his parents in an intensive care unit. We had to find different ways to accept each other and work toward respecting our different styles of relating to our son. We were also challenged to be open to totally new and often scary feelings and thoughts. To this day we can hear the doctor's initial prognosis. To this day we would not wish such a painful experience on anyone, yet, as paradoxical as this may sound, to this day we recognize and appreciate just how much we learned from our time with Caleb.

The second experience concerned our professional work and taught us that parents raising children with special needs deserve to have a parenting program written specifically to address their emotional experiences. In 1994, we offered a traditional six-week parenting program to a group of parents raising children with special needs. Although the curriculum was a good one, the group did not go well. As we presented the material, we noticed that the parents wanted to—even had to—talk about their “out of the ordinary” experiences with their children. Night after night, the room was filled with an emotional charge that could be released only as each parent was given a chance to tell his or her story. We soon realized that we could discuss new ways to discipline children and new ways to communicate within the family only after parents were given the opportunity to tell what it was really like at home. A program for parents raising children without special concerns didn't account for this need, and, as a result, we concluded that an effective program for parents raising children with special needs would need to start from a different place.

Raising Special Kids is the result—a program for parenting a “special child,” as well as a way for us to honor our experiences with Caleb. Building upon the intense emotional worlds in which parents, children, and families reside, it allows parents to tell their stories and learn how to encourage their children and others to tell theirs.

By participating in this program, you are affirming that you are already a very committed parent. Many of you, having read studies, located or even created resources, and applied much advice, are experts in the world of raising a child with special needs. As a result, you may be skeptical of yet another program. Let us assure you that this is not a “how to do it” book. Participating in this program is a major step in the self-care that is so critical for a parent undertaking the very complex task of raising a child with special needs.

Raising Special Kids is designed to explore what works and what doesn't in the unique relationship between you and your child. The real experts are you, your child, and other parents who are living with this experience in a conscious way and who have chosen to share what they've discovered. You are to be congratulated for taking a risk

and choosing to share your energy, frustration, and knowledge. We hope that you find this experience valuable to you and your family. We hope you will send us your feedback and knowledge when you have completed the program.

Before we begin, we want to offer you a preview of where we will be going together. We do so by telling this story, written in 1987 by child advocate Emily Perl Kingsley about the experience of living with her son Jason, born with Down syndrome. The story struck a chord with parents and has been translated into numerous languages and published on scores of Web sites.

WELCOME TO HOLLAND

I am often asked to describe the experience of raising a child with a disability—to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this . . .

When you're going to have a baby, it's like planning a fabulous vacation trip—to Italy. You buy a bunch of guide books and make your wonderful plans. The Coliseum. Michelangelo's *David*. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland."

"Holland?!?" you say. "What do you mean, Holland? I signed up for Italy! I'm supposed to be in Italy. All my life, I've dreamed of going to Italy."

But there's been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is that you haven't landed in a horrible, disgusting, filthy place full of pestilence, famine, and disease. It's just a different place. So you must go out and buy new guide books. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

It's just a different place. It's slower paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around . . . and you begin to notice that Holland has windmills . . . Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy . . . and they're all bragging about what a wonderful time

they had there. And for the rest of your life, you will say, “Yes, that’s where I was supposed to go. That’s what I had planned.”

And the pain of that will never, ever, ever go away . . . because the loss of that dream is a very, very significant loss.

But if you spend your life mourning the fact that you didn’t get to Italy, you may never be free to enjoy the very special, the very lovely things . . . about Holland.

This story captures what it is like to be a parent of a child with special needs. You plan for an expected experience but find yourself having a totally unfamiliar and, at first, undesirable one. The demands of being this kind of parent are not at all what you prepared for. They’re probably dramatically different—so different, in fact, that you need to begin talking not about where you are but rather about where you thought you were going.

This unusual journey is the subject of the first part of *Raising Special Kids*. It includes an exploration of what we expected our trip to Italy would be like and a discussion of what it is like to be somewhere else. We need to face the fact that we are in Holland with skills we learned for our expected arrival in Italy! In chapters 1 through 4, we will look at your dreams—what you thought your world would look like with the birth of your child. We will slow down the preparation and landing process of your anticipated trip to Italy. Much of your time in the first four chapters will be spent on your feelings and thoughts: where and how you learned about parenting, what you expected your child would be like, and how you have handled other painful experiences in your life. This will require an honest revisiting of your own experiences as a child and an exploration of what many parents simply take for granted about their own lives. By responding to open-ended questions, you will be invited to think about and record these feelings and thoughts.

The second part of the program, chapters 5 through 8, will offer you a chance to raise and examine more specific issues about your life with your child. Discussion will focus on particular challenges you face as a parent. New listening skills will be offered. Developmental information will be provided to assist you in working with these challenges. You will be given an opportunity to practice new ways of seeing your child separate from the emotional intensity of your own experience

Each chapter presents a central theme that weaves together your own needs and the needs of your child. We use imaginary family situations and occasionally refer to our own experience. We ask that you take time to respond to the many different kinds of exercises that are offered in order to make this experience as beneficial to you as possible. One of our primary goals is to recognize and strengthen

each family so that all individuals in the family are able to develop to their optimal level.

We have discovered that the best way to participate in this program is for you to work in the guidebook on a regular basis. Our suggestion is that you take a week for each chapter so that you will have a chance to think about the issues raised. To do so will also give you and your family the opportunity to practice some of the skills suggested. The more engaged you become in the process, the more likely you will be to benefit from this program. If you have a parenting partner, set aside time to discuss what you are learning. Parents who are on the same team offer their children a safe and secure home in which to develop.

In *Raising Special Kids*, we recognize that no matter what our specific challenges are as parents, we are all involved in a continuous process of growth and understanding. We suggest that a true celebration of our children includes the ongoing acceptance of both what we have lost and what we have gained. By spending time exploring what you expected in Italy, then what you now have in Holland, we hope you complete the program with fresh vision, hope, and inspiration. Holland is, after all, a worthwhile place to be!