SOMETHING'S WRONG
WITH MY CHILD!

ABOUT THE AUTHOR

Harriet Wallace Rose brings over 30 years of experience to the subject of childhood disabilities. She and her husband, Tom are the parents of four children. Their youngest daughter, Nancy, has multiple disabilities.

Although her primary interests have always revolved around her family, Mrs. Rose has done occasional freelance writing and has worked as editor of marketing publications for a financial services firm.

In 1990, the Joseph P. Kennedy, Jr. Foundation, named the Roses the "First Family of Achievement" for the State of Kansas. Since 1982, they have been actively involved in Families Together, Inc., a statewide parent training and information center headquartered in Wichita, Kansas. Families Together is a member of the National Parent Network on Disabilities in Washington, D.C.

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SOMETHING'S WRONG WITH MY CHILD!

A Valuable Resource in Helping
Parents and Professionals to Better Understand
Themselves in Dealing with the
Emotionally Charged Subject of
Children with Disabilities

By

HARRIET WALLACE ROSE

With a Foreword by

Ann P. Turnball

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This book is lovingly dedicated to my children
Bill, Judi, Jim and Nancy
who have also been
my teachers and my friends.

With special thanks to Tom
for sharing with me
his talent for living
and giving.

FOREWORD

Having just completed reading this manuscript, I want to share with you my reactions from both a parental and professional perspective. My first parental reaction is one of affirmation–affirmation of my own feelings and experiences of being a mother with a son with a disability, affirmation of the "normality" of my own family situation, and affirmation of the humanness of all who share similar experiences with disability. I felt affirmed when I read statements such as the following:

> If you find yourself feeling inadequate as a parent of a child with disabilities or sense that this feeling is being imposed upon you by others, remember: the art of parenting has been around longer than any other specialized field. Your child is, first and foremost, a child. His or her disability is a secondary factor. There is no specialist in the world that will have as much impact on your child's life as you.

The second major parental reaction that I had was a wonderful reminder of the importance of **balance** in the lives of families. Harriet's description of her family and how they attended to Nancy's special needs and yet lived in very ordinary and natural ways is a critical key for all parents to keep in mind. I also welcome her emphasis on the balance of attention to all family members. I particularly like this description that she shared:

> All of our children grew up with the ever-present knowledge that they represented one-fourth of the total minority population of our family. Did we play favorites? You bet we did! Whichever child needed us the most at any given moment, in any day, in any year–that child took precedence over the other three for however long the need was there. There were many times when Nancy was Number One. But there were frequent periods of time when she played second or third fiddle to her sister and brothers.

A third feature which was very important to me was Harriet's emphasis on positiveness and constructiveness. Having known Harriet now for several years, I can attest to the fact that her written words and her actions are consistent. She lives what she writes, and writes what she lives. Her realistic, but also constructive, response to grief is an important example of her positiveness:

> Why me? Why not! You are not singled out to undergo grief. To savor joy you must taste sadness and those who limit themselves to skimming over the emotions of life, forfeit its purpose and meaning.

At a later point in the book she so aptly states:

> Attitudes are hereditary; your feelings about your child and his handicap

> will determine his attitude about himself. . . Attitudes are also contagious. Your child's feeling of personal worth will influence how other people react to her. If she learns to have an open, honest, matter-of-fact attitude about herself, other people will feel comfortable with her and will find it easy to accept her disabilities.

One other feeling that struck me very much as a parent was reading about experiences that Harriet has had with her family that are similar to ones that I have already experienced. I felt a sense of bonding in knowing that others have had feelings and reactions similar to my own. But it was also a special part of the book to read about experiences that we have not yet had as a family and to have glimpses of insight into how those experiences might play out in our lives. An example is Harriet's description of Nancy's high school graduation. Realizing that my son will graduate from high school next year is a somewhat frightening experience in thinking about what his life will be when he no longer has the opportunity for a public education and also wondering about what my emotions will be at the actual event of his graduation. I was enthralled by Harriet's description of Nancy's graduation and could not keep the tears of poignancy from welling in my eyes as I read this very powerful part of her family's story.

Just as parents will find powerful messages in this book, so, too, will professionals. In fact, I believe that this is a book that *all* professionals would benefit from reading. They will benefit for many of the same reasons that parents benefit–because of the incredible insight and powerful description of life as experienced by families. With remarkable accuracy, Harriet compares the attitudes of professionals toward what life is like as experienced by families with the actual attitudes of parents. She correctly raises the issue that the vast majority of research studies have focused on the negative and burdensome impact of a child with a disability on families; and, therefore, many professionals read this research and anticipate that family life is far more negative than it actually is. She comments:

> The attitude of the professionals is more likely to be based on the conclusions of previous researchers, while parents' opinions were formed through personal experience. . . For example, much of the research done in the 1970s suggested that the presence of a "handicapped child" has negative psychological effects upon the parents and creates maladjustment among siblings. Professional people in the 1980s, basing their opinions on previous research and feeling well informed and well intentioned, have told parents that they should "be realistic" and expect to have problems. It's very difficult for parents to totally ignore the opinions of well-educated professionals, so many of them expect to have problems and end up fulfilling their own expectations.

The major contribution of the Rose family's experience is that professionals will have an opportunity to gain insights into a family who have benefited positively and constructively from the presence of a member with a disability, and they will learn coping strategies that they can pass along to other families on how to transform disability into a positive family experience.

In this regard, I am reminded of a saying that my father shared with me on innumerable occasions while I was growing up. The saying is, "It takes an awful lot of knowledge to make a little bit of wisdom." *Something's Wrong With My Child!* is not only brimming over with knowledge but also inordinate wisdom. It is for this reason that this book is for everyone. It is an incredible gift from Harriet to the rest of us–it is her many years of experience that has filtered through layers of knowledge and found its strata undergirded by roots of wisdom. And what is even more appealing is that the book is so easy to read. It is well-written in an almost melodic way. It has style!

I urge you to treat yourself to a wonderful experience. Set aside time to read this book, mull over Harriet's experiences and insight, and grow with her into your future, knowing that *her attitude is contagious. You too, can catch it!*

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Our good friend Ben Anderson of BreakThrough, Inc., for demonstrating to us–and to many others–that the misconceptions and prejudices of society are often more burdensome to people with disabilities than the actual disabilities.

My sister, Virginia McHenry, for helping me to clarify my concepts, organize my thoughts, and rearrange my sentences, and for patiently revising and retyping my manuscripts.

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H.W.R.

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SOMETHING'S WRONG WITH MY CHILD!

PROLOGUE

You've just learned that something is wrong–very wrong–with your child. It doesn't matter how you learned it. It doesn't matter who was the first to know. It doesn't matter if you figured it out all by yourself, or if the doctor figured it out, or your mother, or your Aunt Mary, or the kid next door, or the checker at WalMart. All that matters is that something is wrong with your child–and all of a sudden–at this moment–you know.

A split second ago you were safe and sound in your familiar little world. Not perfect, perhaps, but familiar. A split second ago tomorrow was Tuesday and Christmas was coming in December and spring was going to follow winter and the arrow on the compass always pointed north. But now you're on a strange planet where nobody knows anything about tomorrow and Christmas is just another day and flowers couldn't possibly bloom in the spring and you can't find any directions because your compass won't work.

You can't stay here or something terrible will happen. You'll cease to be you–you won't exist anymore. There's only one thing to do. Run. Back to safety. Back to the real world. Back to before that split second ever happened. Maybe, if you go back, you can keep it from happening.

There. You're safe. You never want to go "there" again. But wait–something's wrong. Everyone here is acting like the split second did happen. They're talking to you as if you know that something's wrong with your child. If you listen to them, you'll be forced back to that other planet again. Obviously, you have to find a place to hide. Get away from everyone. In the meantime, you have no choice but to pretend that everything is fine. Humor them. Pretend that tomorrow is Tuesday and Christmas is coming and flowers bloom in the spring. But keep looking for your hiding place. You've been there before, haven't you? Remember that other time the world painted you into a corner and you found your way out? Remember? Keep looking. You'll find it. You'll be safe there; you won't have to think. You can make time stop for awhile.

When you find it, relax–breathe easy, rest a little. But when you're ready to start thinking again, will you do me a favor? I know you need to be alone now but eventually, will you let me join you? Just for a little while? You see, I've been to that other planet and it's not as frightening as it appears. But you must understand–your old compass will never work there. I've got one that will. I built it myself. It's a little different, but I'll teach you how to use it.

I'm ready whenever you are. But please–don't wait too long to let me in. You see, tomorrow really is Tuesday. And outside your hiding place–there's still something wrong with your child.

Part 1

CRISIS

From the moment of birth, we are faced with the process of learning to deal with our emotions. In varying degrees and in increasingly complex situations we react to circumstances which arouse feelings of fear and contentment, love and hate, grief and joy, anger and happiness. Our personal experiences with each emotion give us a point of reference to use in coping with the same feeling the next time it confronts us.

There are times in our lives, however, when the impact of a circumstance strikes us with such force that we are assaulted by a wide range of conflicting emotions. This attack on our inner selves creates a falling apart of our equilibrium, a feeling of utter helplessness–a crisis.

Learning that something is seriously wrong with your child creates just such a crisis. Fear, love, anger, guilt, frustration, grief, self-pity–all these emotions engulf you. Where do you begin? Everyone may not experience them in the same succession, but you will need to face them all eventually–and the only way you can handle them is one at a time.

Chapter 1

FEAR

(God's Special People Myth)

Sometimes, when I'm really frightened, I find myself wishing I were a child again. Children instinctively know what to do when they're afraid or hurt. They run away. They hide. They cry.

When I was young, my favorite hiding place was a tree in my parents' backyard where the spreading branches were worn smooth from generations of small climbers. It became my refuge as a teenager. The crises that I struggled with in those days are laughable to me now, but they were crucial at the time. How could I get even with my sister for borrowing my best sweater without asking, and how could I get that cute boy in algebra class to notice me, and would I ever, ever stop getting taller and start looking like a cheerleader instead of a candidate for the basketball team!

As I grew older, I learned that it's not acceptable for adults to run away and hide or for grown women to climb trees. But when I first learned that something was wrong with my child I ached for the comfort and security of that sprawling oak and longed for the simplicity of my childhood problems. I knew that eventually I would have to find a time and place to be alone. Alone to sort out my thoughts and to face the fears that were assaulting me.

It's almost impossible to think rationally at the time because, initially, the only thing you know for sure is that you can't handle being the parent of a child with disabilities. You just can't! All parents want their children to be able-bodied and "normal"; the thought that your child might be "different" is too frightening to consider. It's a basic instinct of human nature, a built-in defense mechanism, to reject anything which threatens to shatter the very core of your existence. No one is capable of jumping to immediate acceptance of a major life change.

At this point, there's no harm in considering the possibility that your child's disability might not be as bad as it appears. Everyone makes an occasional error in judgment–even doctors. Early problems sometimes vanish or eventually correct themselves and no one ever understands why. Although you may comfort yourself with these possibilities, it's still practical to listen to that small voice that keeps asking, "What will I do if it's true? What will I do if there really is something seriously wrong with my child?" You may stay wrapped in your cocoon of fear for hours or days but, ultimately, the only answer to that voice is, "I don't have a choice. I can't spend the rest of my life hiding. If it's true, then I'll have to learn how to handle it."

Accepting

The best formula for dealing with fear is to ask yourself, "What is the worst thing that could happen?" If you can prepare yourself to accept that, if necessary, you will be able to handle every eventuality. Accepting the worst, though, does not mean you forfeit the right to hope. On the contrary, it frees you from the nagging fear that you might not be able to cope. As the Chinese philosopher Lin Yutang has written, "True peace of mind comes from accepting the worst. Psychologically, it means a release of energy." Once you can do this, you have nothing more to lose, and everything to gain.

So–what is the worst thing that could happen? Your fears could be confirmed. Your child's disability could be as severe as you had feared. There's so much that you don't yet know or understand. How can you accept what has happened if you don't know anything about it? Chances are that you, like most people, have a limited, secondhand knowledge of the world of children with disabilities and their parents. Your information may be based on a vague collection of concepts gained from old-wives' tales, hearsay, fiction, and the media. Right now, you probably remember every terrible thing you've ever heard, or seen, or thought, or read about people with disabilities. What's the worst thing that could happen? You don't know! And that's the most frightening thing of all!

Unfortunately, our society does not paint a realistic picture of children with disabilities and their families. What's worse, most of the input we are given is so negative that we are unconsciously discouraged from even thinking about it except as something that happens to "other people." Many years ago, I became one of those "other people." Now, I'd like to help you to see that the worst thing that can happen is not as unacceptable as you may think. It's not as frightening as you believe it to be. Of course you don't want to be the parent of a child who has disabilities. Nevertheless, once you have learned something about your new role, you might find that it's not so very different from your old one.

Role-Playing

As a child, you probably experimented with many different roles in the process of growing up. Using that marvelous, mysterious, exclusively human