

# Families, Professionals, and Exceptionality: A Special Partnership

Second Edition



Ann P. Turnbull  
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SECOND EDITION



**FAMILIES,  
PROFESSIONALS,  
AND EXCEPTIONALITY**  
A Special Partnership

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Merrill Publishing Company  
Columbus • Toronto • London • Melbourne

Cover: The interweaving arrows of the logo represent the dynamic and constant reciprocity that exists between people with disability, their families, their friends, professionals, and society. The heart-shaped form represents feelings—the warmth, caring, commitment, embracing, recharging energy that comes from the reciprocity and that, in turn, fuels it.

This book was set in Italia.

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Library of Congress Catalog Card Number: 89-63525  
International Standard Book Number: 0-675-21207-3  
Printed in the United States of America

3 4 5 6 7 8 9—94 93 92 91

C9136

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**To Jay, Amy, and Kate—**

Each exceptional, each our family, and each our teacher, making positive contributions.

**To Mary Boone Patterson and Ruth W. Turnbull—**

Who gave inherent strength to their families and who, though gone, are everlasting.

**To Elizabeth M. Boggs—**

Family advocate and our mentor, who taught us about choices by telling us about shoes.

**To Richard L. Schiefelbusch—**

Whose pithy aphorisms reveal great expectations and teach that every problem is an opportunity.

**To Marianna and Ross Beach—**

Whose compassion, competence, and commitment have created relationships for people with disabilities not just in Kansas but throughout the hemisphere.

**To James MacDonald Fowler, "Jamie"—**

Deserving of full citizenship but denied it, not because of his disability, but because of society's—a denial that this book seeks to overcome.

# P R E F A C E

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*Families, Professionals, and Exceptionality: A Special Partnership* concerns families, people who are exceptional, professionals, and ways they can work together more effectively. Although this topic is not original, the focus of this book is unique and the book itself is different from previous works in important ways.

This edition is explicitly value-based. We identify and operationalize six values that guide our research, training, and dissemination efforts at the Beach Center on Families and Disability at The University of Kansas. These values enable us to see families in a different light and then help them better. The values are:

- *Positive contributions*—Persons with disabilities contribute positively to their families. They enrich not only their families, but also their communities and society.
- *Great expectations*—Visions can become realities. Families need new perspectives of what life can be as well as support to fulfill these dreams.
- *Choices*—Families can direct their own lives. Enabling families to act on their preferences allows them to build on their strengths.
- *Relationships*—Connections are crucial to family unity. Family members need to be connected to each other and to friends in the community.
- *Full citizenship*—"Less able" does not mean "less worthy." People with disabilities and their families are entitled to full participation in American life.
- *Inherent strengths*—Families have many natural capacities. Nevertheless, they may need support to affirm positive contributions,

achieve great expectations, obtain full citizenship, act on their choices, and enjoy relationships.

Throughout the book, we point out ways to incorporate these values into professional practice.

This second edition also places greater emphasis on *applying* family-systems theory in professional practice. Much has been learned in the last three years about family-systems theory and about how it can be applied. This text teaches you what our research and practice have taught us about applying theoretical concepts in everyday interactions with families. It addresses the needs of a much wider range of families, with particular attention and sensitivity to their cultural, racial, and socio-economic differences. Certainly, respecting family diversity is one of the major responsibilities of educators.

The first and second editions also have many elements in common. We deal with exceptionality in broad terms, addressing all types of disability (mental, cognitive, emotional, physical, language, and sensory) and characteristics of those who are gifted. We regard people with exceptionality as having many similar characteristics with respect to how they affect and are affected by their families and professionals. Accordingly, when we refer to individuals with exceptionalities, we include people who have disabilities as well as people who are gifted. But we recognize that there are distinctions that make a difference. People are different because of the type and extent of their exceptionality. We address their differences as well as their similarities.

We do not confine our discussion to a particular age range. We address the needs of families and people with exceptionalities throughout their life cycles, from infancy through childhood and school years and into adulthood. Although the subject matter requires that some aspects of the book have a deliberate school-years focus, for the most part, we deal with families at different life stages.

We take into account the enormous variety and diversity in families and guide professionals through a systematic and scholarly analysis of families. We apply the family-systems approach in the context of exceptionality across the life cycle. In doing so, we present state-of-art knowledge and reality-tested practice in family-professional relationships. We combine theory and application, not just in the four chapters that specifically address the family-systems concept but throughout the book, showing in many chapters how professionals may work with families within that framework.

We address the family in all its diversity: size, cultural background, geographic location, values, interaction styles, met and unmet needs, and the changing characteristics of a given family over time. By addressing the family as a system, we are not bounded by a focus on one family member, typically the person with an exceptionality. Indeed, we seek to show the complex interrelatedness of all members in a family

and the importance of adopting a comprehensive view of professional interventions. We stress that each family must maintain its own critical balance, its unique center of gravity in order to allow any professional intervention to be beneficial to a family member or to the entire family. We encourage professional support of families.

In using a broad approach to exceptionality and families, our aim is to make this book useful to a wide range of professionals—to people working in special education, social welfare, psychology, counseling, health, and in related professions such as ministry and gerontology. Our orientation is interdisciplinary, relying on the most recent research in education, social work, counseling, law, and ethics, and providing relevant illustrations, suggestions, and resources.

We draw heavily on the published and unpublished stories of families. Accordingly, we have seasoned the book with a compelling real-life flavor. We undergird its theories and concepts with the reality of the living laboratory, the reality of family life. Our own experience has added to this combination of theory and reality—our three children are all exceptional, each in a different way. Our son Jay, who has mental retardation, and our daughters, Amy and Kate, have been our catalysts for personal insights into the ways in which disability impacts family relationships.

We have synthesized wide-ranging subjects in the 14 chapters of this book. First, we emphasize the history of parental roles in exceptionalities (Chapter 1), then family-systems concepts (Chapters 2–5). After tying those concepts to family-professional communication skills and strategies (Chapters 6–7), we present the dominant legal framework within which families and professionals must work (Chapters 8–11), concluding with a discussion of family support strategies (Chapters 12–13) and an analysis of moral issues in family and professional relationships (Chapter 14).

To accompany this edition we have compiled an Instructor's Manual that is available from Merrill Publishing Company. This manual provides ideas for how to teach the content of each chapter of the book and is especially helpful by providing family vignettes, small-group problem solving, and role plays that can enliven the didactic content. One of the special features of the Instructor's Manual is that it provides suggestions for how best to use *Parents Speak Out: Then and Now* (Merrill Publishing Company) and pair the two into a comprehensive instructional sequence. (*Parents Speak Out: Then and Now* is a collection of essays written by family members. It provides candid accounts of issues associated with disability. The experiential content of *Parents Speak Out* is highly complementary to the instructional content of this textbook.)

Descriptions and results of research and training projects at the Beach Center on Families and Disability at The University of Kansas, which we co-direct, are incorporated throughout the chapters. The Beach Center is involved in over a dozen research projects related to the six values stated at the beginning of this preface.

Finally, throughout the book we convey optimism, hopefulness, and enthusiasm about families, people with exceptionalities, and family-professional relationships. In this respect, we emphasize the positive contributions that individuals with exceptionalities, their families, and professionals make to each other, rejecting the focus of so much other literature in this field on pathologies and negative stereotypes related to exceptionality.

Our goal has been to organize knowledge so that it is value-based, scholarly, understandable, holistic, relevant, and inspiring. Above all else, our hope is that the information we present makes a positive difference in your life and in the lives of the professionals and families with whom you interact.

We invite you to communicate with us about ways by which we can enhance the relevance of the content of this book in future editions.

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## Acknowledgments

Because it represents the contributions of colleagues and friends, this book symbolizes the collegial atmosphere at the Beach Center on Families and Disability, the Bureau of Child Research, and the Department of Special Education at The University of Kansas. We want to acknowledge many of those individuals and to state that countless others have also influenced our thinking and provided catalysts for the directions we have taken.

Substantial contributions have been made to the first and second editions by graduate students who are emphasizing family and policy issues in their graduate studies in the Department of Special Education at The University of Kansas. The book has grown out of our interactions with students, and we hope that these interactions will continue for many years. We truly believe that they are part of our collegial family as well as our textbook family.

Since this second edition includes a significant portion of the original work, we would be remiss if we did not acknowledge the helpful assistance we received with the first edition of this book. In the first edition, we were greatly aided by the collaboration and contributions of our colleagues and friends, Jean Ann Summers (Chapters 2, 5, and 13), Mary Jane Brotherson (Chapters 3 and 4), and Holly Benson (Chapters 6 and 7). At that time, they were doctoral students working with us, now they are professional colleagues. We also acknowledge the cheerful and conscientious efforts of a number of people in preparing the first edition manuscript, including Mary Beth Johnston, Dorothy Johanning, Marilyn Fischer, Connie Roeder-Gordon, Harriet Shaffer, Thelma Dillon, Lori Llewellyn, Joni Randel, Barbara Bartz, Lisa Wilshire, Jon Gaines, and Kiesa Harris. Further, we are indebted to the following for their construc-

tive criticism: Cindy Bernheimer, University of California at Los Angeles; Pam Winton, University of North Carolina at Chapel Hill; Joan Safran, Youngstown State University; George Sugai, University of Oregon; and Jane Morse, Lawrence, Kansas.

Invaluable contributions have also been made to the second edition by a number of authors. These include Julie Sergeant (Chapters 1 and 12 and Appendix A), Betsy Santelli (Chapters 6 and 7), Marilyn Shank (Chapters 5 and 10), Chriss Walther-Thomas (Chapters 3 and 4), Lori Unruh (Chapter 9 and Appendix B), Chuck Rhodes (Chapter 13), Laurie Ford (Chapter 2), and Gloria Graves (Chapter 11). We underscore the contributions of Julie Sergeant in helping us coordinate the entire revision process. Her competence and conscientiousness made a critical difference in our ability to make substantial revisions. Manuscript preparation was superbly handled by Mary Beth Johnston and Opal Folks. We acknowledge with gratitude the photographic expertise of Karen Sorenson. In addition, we thank Liliano Mayo, Nancy Richards, and the staff of Families Together, Inc. (Topeka, Kansas) and the Special Education Early Childhood Intervention Program at The University of Kansas for assisting with photographs. Others who helped with the numerous revision tasks include Dorothy Johanning and Susan Shaffer.

We are convinced that we are surrounded by the most supportive and stimulating colleagues anybody could wish for. We salute and thank our colleagues at the Beach Center on Families and Disability, the Bureau of Child Research, and the Department of Special Education. Likewise, the quality of our work is continually enhanced by the problem solving and networking of our superbly qualified Project Officer, Naomi Karp, at the National Institute for Disability and Rehabilitation Research. We also value the opportunity to have worked with our previous administrative editor at Merrill Publishing, Vicki Knight, and our current editor, Ann Castel. We appreciate the competent and cheerful assistance of all the staff at Merrill, in particular editorial assistant Brenda Rock. Finally, we express gratitude to the reviewers who helped shape and improve the second edition: George Sugai, University of Oregon; Sandra W. Gautt, University of Missouri, Columbia; Diane Klein, California State University—Los Angeles; Raymond Dembinski, Northern Illinois University; Annette Tessier, California State University—Los Angeles; and Kent Gerlach, Pacific Lutheran University—Tacoma.

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