



# Ordinary Families, Special Children

**Third Edition**

**A Systems  
Approach  
to Childhood  
Disability**

**Milton Seligman and Rosalyn Benjamin Darling**

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ORDINARY FAMILIES,  
SPECIAL CHILDREN

*To the memory of my mother, Irma Seligman,  
a woman of great warmth, social intelligence,  
and remarkable culinary aptitude (1910–2004)*

–M. S.

*To my extraordinary grandsons,  
Elijah Wolf Darling and Isaac Olyn Darling*

–R. B. D.

## About the Authors

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**Milton Seligman, PhD**, is Professor Emeritus in the Department of Psychology in Education at the University of Pittsburgh. His chief academic interest is in the area of childhood disability and the family. Other areas of instruction and scholarship include individual and group psychotherapy and clinical supervision. Retired since 2004, Dr. Seligman maintains his private practice, serves on the editorial board for the *Journal for Specialists in Group Work*, and is currently writing a book for parents on childhood disability and the family. He lives in Pittsburgh with his wife.

**Rosalyn Benjamin Darling, PhD**, is Professor of Sociology at Indiana University of Pennsylvania, where she has taught since 1994. Prior to assuming her academic position, she served for 15 years as the executive director of an agency serving young children with disabilities and their families and was the founder and first president of the Early Intervention Providers Association of Pennsylvania. Dr. Darling has authored or coauthored eight books and numerous articles and chapters on disability and human services. She has played an active role in many state- and national-level disability-related organizations and committees and is currently engaged in research on orientations toward disability.

## Preface

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In this third edition of *Ordinary Families, Special Children*, we again want to share some thoughts about the title. Too often people have regarded families of children with disabilities as almost saintly. These parents' quotes from the Preface of the last edition describe this view:

We parents of children with disabilities get a lot of "you are so wonderful as parents taking care of Scott/Heather (you supply the name). I don't see how you do it all . . . working, doing all the stuff for your child, and keeping a home. I know I could never do it."

"You must be special people to get a child like that. . . ." Well, few people ask for a child "like that." You just look at what has to be done and do it. If the other person had a child with a disability, he/she would do what has to be done.

Children with disabilities are born into all sorts of families. Although such a birth is usually an unanticipated event, most families learn to accept, and sometimes even rejoice, in its occurrence. These parents do not begin their familial careers with any special gifts or skills; they simply "do what has to be done." Our title emphasizes this ordinariness in order to suggest the essential similarity of all families.

At the same time, ordinary families are usually poorly prepared to meet the special challenges posed by children with disabilities. They

must confront a lack of specialized knowledge; often negative reactions from other family members, friends, and strangers; the limited accessibility of needed resources; and, often, professionals who provide insufficient or inappropriate assistance. As in the earlier editions of this book, we hope that the present volume will aid professionals in understanding the situation of ordinary families who happen to have children with out-of-the-ordinary needs and in helping these families to meet those needs.

As in the preceding editions, we examine the intertwined child, family, ecological, and sociocultural variables that are thought to contribute to the response of families to childhood disability. We want to illuminate those elements of family and community life that bear on the family's ability to achieve a satisfactory lifestyle. We also want to describe relevant intervention strategies and services for families when such help is being sought. Another task is to update our review of the research and to describe new programs and approaches that have emerged in recent years. We also include pioneering perspectives and approaches that have shed light on childhood disability and the family and that continue to maintain their relevance. In addition to research, we include clinical reports and personal observations from professionals and family members. The expansion of previously written chapters and the inclusion of new chapters reflect developments in the field since the last edition was published in 1997.

This edition is organized a little differently from previous editions. We have grouped the chapters into four sections to highlight our main themes. The first section provides the conceptual framework for the rest of the book and introduces the idea of family systems and social systems. The chapters in the second section use a sociological perspective and view the family over time, beginning in the prenatal period and ending with the child's future adulthood. The third section takes a psychological perspective in examining the impact of childhood disability on various members of the family system. Finally, the fourth section applies the material in previous sections to professional practice.

Since the publication of the second edition, the literature on the "partnership" model in human services has continued to grow. Although that model guided our thinking in the two earlier editions, we specifically discuss its importance in the present volume. Another kind of model that receives increased attention in this edition is the social or sociological model of disability, which has increasingly come to replace the medical or clinical model. Historical trends relating to



the ascendancy of the social model, such as the disability rights movement, are also addressed for the first time in this edition, as are some demographic trends in relation to children with disabilities.

There have been changes in counseling as well as other approaches to help families cope with childhood disability. Cognitive strategies, for example, have proven to be useful in helping families modify their thinking patterns and hone their coping abilities. Interest in group approaches has been an area of focus in helping families gain support, encouragement, and concrete information. Support groups and other types of group interventions are explored, including those for parents and separate ones for fathers, siblings, and grandparents.

Since the publication of the first edition in 1989, promising resources have been developed for families. For example, the Internet has become a wonderful resource. Subscribers to various lists can now get both information and support regarding children's disabilities and family issues. We have included material from such lists to illustrate the family experience and to highlight specific sites for information.

This edition reflects a shift in the language used to refer to persons with disabilities—a shift noted in the second edition. We embrace the perspective of Lyon, Knickelbaum, and Wolf (2005) who wrote:

Disability is secondary to the person; it does not define who she or he is as a human being. The person is not a problem. Instead, attitudes and misconceptions about disability (and people with disabilities) can create barriers to their acceptance and participation as members of the adult community. (p. 831)

Although person-first language is occasionally awkward, this book uses it to acknowledge that a person who happens to have a disability is a person first. However, we want to acknowledge that not all people with disabilities prefer person-first language. Some in the disability rights community, for example, see the shared condition upon which their oppression is based as more salient than their identity as individuals. Members of this group have suggested that person-first language is euphemistic and individualistic. We agree with these arguments but do believe that language shapes thinking and that older constructions may perpetuate undesirable stereotypes about people with disabilities. We also have changed some other terminology to reflect newer preferences. For example, we use the term *intellectual disability* in place of *mental retardation*.

As suggested above, this edition reflects a number of new con-

cepts. Concepts such as “putting the disability in its place,” “family trajectory postdiagnosis,” “disability identity,” “disability pride,” and “typology of adaptation” reflect conceptual lenses that provide fresh perspectives on family and disability. The concept of resilience in children and family members is discussed as well.

Moreover, this edition contains a new chapter that focuses on the “orientations” of adults with disabilities. After all, the desired outcome for children with disability is successful adulthood, however that may be defined by those individuals and their families. The newer orientation of disability pride, which derives from a social or sociological model of disability, is addressed in this new chapter, along with other orientations.

Information on fathers and grandparents occupied a single chapter in previous editions. We believe that separate chapters are warranted as the challenges and contributions of these family members have been brought into clearer focus. Recent conceptions of fathers’ roles and scripts that contribute to major health problems and hinder their full participation in family life serve as a backdrop for a discussion of fathers and childhood disability. Recent research and commentary on grandparents sheds new light on their struggles and contributions.

For siblings, issues pertaining to a fear of contagion in very young children and caretaking in adulthood and in later life are presented along with emerging research and personal reflections of siblings of brothers or sisters with a major emotional or cognitive disability. This is an important topic that has not been given the attention it deserves.

The chapter on family diversity has been updated significantly in light of recent research on the impact of welfare reform and on the intersections between culture and disability. We also include information on single-parent and gay and lesbian families and on some ethnic groups, such as American Muslims, that was not included in earlier editions.

Our final chapter has been updated to include more information about the partnership model in human services and the relevance of that model to services for families of children with disabilities. In addition, we present a detailed discussion of areas to be considered in the identification of family resources, concerns, and priorities. We also address the development of outcomes and service activities, as these are conceptualized in the current evaluation literature.

As in previous editions, we have included the voices of family members themselves to explain and illustrate many of the concepts in the book. In this volume we have retained some older quotes that still

ring true and added some newer ones that reflect more recent experiences.

M. S.:

I want to acknowledge the help and contributions of the following important people in my life:

My wife, Karen, who has considerable knowledge about disability issues from her academic background, her clinical and personal experience, and her point of view as a reader who gobbles up mysteries, biographies, and books written by those challenged by disability. She kept me from a dire fate as I wrestled with the vagaries of the computer world. She is my leaning post.

My daughter Lisa, who rescued me after my retirement from the University of Pittsburgh in September 2004. She graciously volunteered to type handwritten and often unreadable manuscript pages. There would not have been a third edition without her. I am blessed to have this lovely and accomplished lady as my daughter.

My daughter Lori, who provides me with many insights into what disability means to family life. Although she is challenged by disability, she forges ahead to be her own person, gaining independence, friends, and confidence—and winning a 2004 Jefferson Award in Pittsburgh, an award given to an individual who makes a difference in her community. I am proud of her and doubly blessed.

R. B. D.:

We both owe a great debt to several graduate assistants at Indiana University of Pennsylvania who made important contributions to this volume. Michelle Stagmer transferred all of the references from the last edition to EndNote format, and Patricia Heiple added many new references to the file. Debra Mason compiled information for an appendix, which we chose not to include because of limits on length. Debra and Julie Grant provided teaching support that allowed me time to work on this book. I am also indebted to Indiana University of Pennsylvania for providing me with a sabbatical semester, during which I completed most of my share of the writing.

As always, I want to thank my husband, Jon, for his unwavering support in all that I do. I am fortunate to have him as a partner.

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# CONCEPTUAL FRAMEWORK

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# 1

## Introduction and Conceptual Framework I

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### Social and Cultural Systems

To put the magnitude of extant disability in the U.S. population into perspective, the year 2000 disability status report from the U.S. Bureau of the Census counted 49.7 million people with a chronic illness or disability. This figure accounted for 19.3% of the U.S. noninstitutionalized population ages 5 and older—or nearly one person in five (U.S. Bureau of the Census, 2003a). These figures do not include infants and children from birth to 5 years of age. Among the population from 5 to 15, about 2.6 million, or 5.8%, had disabilities, with boys representing a larger proportion of the total than girls. Overall, 5.2 million children and teenagers—one out of every 12—have a physical or mental disability. These numbers represent an increase over those in data collected previously. In addition, in this population, disabilities are more common among Native Americans and African Americans than among European and Asian Americans. According to Schonberg and Tifft (2002) and Batshaw (2002), 3–5% of births result in a congenital disability or genetic disorder.

Childhood disabilities range from high-incidence impairments to those that are less frequent in the population. High-incidence impair-



ments in persons 6–21 make up 92% of impairments overall, including specific learning disabilities, speech or language impairments, intellectual disability, and serious emotional disturbance (U.S. Department of Education, 1996; Hunt & Marshall, 1999). Lower-incidence impairments, which for each condition constitute less than 2%, include multiple disabilities, hearing impairments, orthopedic impairments, other health impairments, visual impairments, autism, deafness–blindness, and traumatic brain injury. Furthermore, more than 6.3 million children and youth, ages 3–21, received special education services during the school year (U.S. Department of Education, 2002).

We suspect that these statistics provide a meaningful yet incomplete picture of the portion of the U.S. population that has a disability. In accumulating data from various sources, one should be mindful that there are differences in definitions of what constitutes a disability, differences in how data on multiple conditions are determined and counted, sampling method differences, and decisions that are made about when certain age groups are included/excluded (Olkin, 1999; Shapiro, 1994). This concern does not diminish the validity of the reported figures, but it does suggest that there may be even more people with disabilities than the figures indicate. These numbers indicate that persons with disabilities constitute the largest minority group in the United States (Olkin, 1999), and one that anyone can join at any time as a consequence of illness or accident. • Actually, less than 15% of people with disabilities were born with their disability (Shapiro, 1994).

- Dramatic improvements in medicine have benefited the existing population of infants, children, youth, and adults with disabilities.
- Enhanced methods of assessment and diagnosis, along with a greater awareness of symptoms by informed family members have increased the early identification and remediation of disabling conditions. By keeping people alive, and by keeping them alive longer, medicine has contributed to a disability population explosion (Shapiro, 1994). Such medical discoveries as chemotherapy for cancer, insulin for diabetes, and the methods to sustain low-birth-weight infants have kept people with impairments alive and functioning, yet often with disabilities.

- Social change has not kept pace with clinical progress. People with disabilities remain at a disadvantage in relation to those without them in virtually every area of life. These individuals are much more likely to be unemployed, to live in poverty, and to remain at home rather than attending social functions. In addition, only 34% of those with disabilities say they are very satisfied with their lives, compared with 61% of those without disabilities (*National Organization on*