COMMUNITY REHABILITATION SERVICES FOR PEOPLE WITH DISABILITIES

ORV C. KARAN & STEPHEN GREENSPAN

Community Rehabilitation Services for People with Disabilities

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Community Rehabilitation Services for People with Disabilities

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Dedicated to the memory of
Frank J. Menolascino, M.D. (1930–1992),
a valiant leader in the community revolution
in disability services

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Foreword

Frank Menolascino would have been proud of this book. Proud of its tenets and proud of the book's contributors. The chapter authors, like him, have devoted the bulk of their careers to advocating for community services. To the reader this might seem obvious, but this was not the case 25 years ago when Frank helped to establish one of the first community-based programs that emphasized comprehensive rehabilitation services. Frank, like many of this book's contributors, was criticized for his strong position and the delivery of services in natural settings—close to one's family. Although all of us have paid a price for our beliefs, real leaders seem to get the brunt of the criticism. Frank's favorite quote from Thomas Merton directly applies to this book.

> If a writer is so cautious that he never writes anything that cannot be criticized, he will never write anything that can be read. If you want to help other people, you have to make up your mind to write things that some men will condemn.

This book accomplishes two major goals. First, its "heuristic" research advances the positions the authors developed over their lifetime. Second, it serves as a "cutting edge" blueprint in guiding human service personnel in adapting similar services strategies.

The timing of this book is also critical. Never has there been such a need for specific and practical answers for professionals in a variety of disciplines. There are over 100,000 individuals living in large I.C.F.–M.R. facilities who need to be served in the community along with another 100,000 on waiting lists with no services living at home with their family. In addition, the waiting lists are doubling every 3 to 4 years due to the high "graduation" rates of individuals with disabilities.

It is indeed a sad commentary that on the twentieth anniversary of Public Law 94-142 (1975), record numbers of special education students

who have greatly benefited from educational programs are "graduating" at age 21 with no where to go.

What is needed are answers. Specifics on what to do—when, with costs justified and based on sound scientific principles. This book is uniquely qualified to meet this criteria. Hundreds of years of experience in teaching, research, direct services, and public policy efforts are the defining characteristics of this scholarly group of individuals. Seldom has such a gifted group come together to meet this tremendous challenge of the community revolution.

Frank Menolascino worked with many of the authors of this book over the last 25 years. He served as a colleague, friend, and mentor to many of them. He helped to shape their ideas and shared in their devotion. It is fitting that such a book be dedicated to him in that he symbolized the need for community services, for he so clearly identified with the families and understood their need to be with their children. The following quote perhaps best summarizes both what this book and Frank are all about!

> Where there is
> great love
> there are always miracles.
> Miracles rest not so much
> upon faces or voices
> or healing power
> coming to us from afar off
> but on our perceptions
> being made finer,
> so that for a moment
> our eyes can see
> and our ears can hear
> what there is about us
> always.
>
> Willa Cather

The Funeral Liturgy for
Frank Menolascino
Born May 25, 1930
Born to New Life, April 3, 1992

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Preface

This book deals with the community revolution in disability services that has been occurring in the United States over the past two decades. This revolution involves a fundamental change in the way professionals and agencies relate to individuals with disabilities and their families. In the not-too-distant past, service options were limited, with institutionalization or family sacrifice as the two most likely choices. Although many more options have been created for people with disabilities and their families, until very recently the emphasis was still on fitting individuals into existing slots. The community revolution, on the other hand, is grounded in supporting individuals, empowering them to make choices, and redefining the roles of professionals as facilitators rather than decision makers.

Community Rehabilitation Services for People with Disabilities is intended to serve as an introduction to current thinking about the "paradigm shift" in disability services. The book is divided into three parts. In the first part are several chapters that spell out the principles underlying the community revolution in disability services. The next part contains chapters that discuss problems and issues regarding the implementation of these principles. Finally, the third part details how professional and scientific disciplines have modified their practices and value orientations to reflect this still-evolving paradigm shift.

As with all revolutions, the community revolution in disability services has generated considerable confusion and controversy. Some disciplines have been quicker to adapt to this revolution than others, and within each discipline are practitioners who differ in their willingness to change their values and practices. Financial realities limit the implementation of flexible practices aimed at increasing the quality of life of individuals with disabilities. Nevertheless, the community revolution has brought about—in a comparatively short time—some fundamental

changes in the way people with disabilities are viewed and served. It is hoped that this book will help to further this revolution by giving future practitioners an understanding of where the disability field has come from and where it appears to be heading.

Orv Karan

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Community Rehabilitation Services for People with Disabilities

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PART I

The New Paradigm: Conceptual, Legislative, and Ethical Foundations

The first part of this book provides a conceptual framework and both a historical and ethical perspective on the shifting paradigms, where they came from, the controversies that surround them, the laws that have been shaped by the thinking of the contemporary paradigms, and the ethical implications derived from considerations of the daily decisions and challenges inherent in services built around individual preferences, values, and choices. In Chapter 1 Bradley and Knoll examine the process of change and develop a rationale for the emergence of a new paradigm, identifying its essential characteristics and highlighting the implications for professionals in the field. As they note, the keystones of the emerging paradigm are commitment to community, human relationships, functional teaching, individualization, and flexibility. To these authors, such emerging values are potentially more revolutionary than the values that originally took us as a field out of institutions and into the community. Such changes that have been driven by the new paradigm may cause significant dislocation in existing service structures and complicate the lives of those comfortable with the status quo. However, these shifts will move real services closer to the ultimate goals of normalization and the fulfillment of the dreams of people with disabilities and their families.

In Chapter 2 Leake, James, and Stodden place the concepts of the paradigm shift in historical perspective. They then discuss how commitment to different sets of principles leads to discord within the field over correct policy and practice for services. A primary divide currently appears

to be between those guided by empirically supported theories and those guided by philosophical principles. For these authors, the support paradigm is a practical rather than just an ideological response to a crisis that now exists in the service field. The new paradigm from their perspective is capable of bridging differences within the field. In fact, to these authors the support paradigm is the only paradigm that can be used to guide current services into a new era simply because existing paradigms have such serious shortcomings that can be addressed only in terms of more money, more research, and more training of professionals. However, not enough more will be forthcoming from government or private sources.

In Chapter 3 Fifield and Fifield analyze past legislation to identify specific themes that set precedents for current legislation. From these themes they have tried to forecast some of the trends of the future. It is their position that society's attitudes and values and thus its paradigms are codified in the language and provisions of laws and the rules and procedures we follow in meeting the needs of persons with disabilities. They believe it is possible to better understand the legislative provisions through a historical perspective by analyzing legislative trends and thereby anticipating legislation of the future. This second function, forecasting legislative provisions, is particularly important if we are to do more today than fix the problems of yesterday. Their review of the laws impacting on disabilities stretches from those of the seventeenth and eighteenth centuries to the current provisions of the Americans with Disabilities Act.

The final two chapters in this part, both by Greenspan and Love, deal with the ethical challenges involved in supporting people with disabilities and the development of a code of everyday ethics for services. In Chapter 4, Greenspan and Love argue that implicit in the evolving service models is a set of moral judgments about the rightness of making human services more respectful of the individual's preferences, dignity, and personhood. They note that the literature on ethics and disability emphasizes medical issues, and that much less attention has been paid to the ethical aspects of everyday life and services for persons with disabilities. In their first chapter they emphasize the role of ethical theory in guiding the everyday treatment of persons with disabilities. They review the normalization principle because of its central role in providing an ethical framework for changing the way in which people with disabilities are allowed to live their everyday lives. They discuss the new paradigm and note that in spite of its emphasis on individual rights, choice making, and self-expression, there is still the potential for new areas of abuse based on the continuing power differential between consumers and professionals.

In Chapter 5 Greenspan and Love articulate a universal code of conduct to which agencies, professionals, and other workers may subscribe, a code