

SIGNIFICANT DISABILITY

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SIGNIFICANT DISABILITY

Issues Affecting People with Significant Disabilities from a Historical, Policy, Leadership, and Systems Perspective

Edited By

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With a Foreward by

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For

*My Beloved Son, Richard David Martin, who has taught me much
about disability and hope;*

and

My Mentors, Colleagues, and Good Friends

Gerald L. Gandy, Ph.D., Professor Emeritus

Richard E. Hardy, Ed.D., Professor and Chair Emeritus

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FOREWORD

The concept of inclusion is a singularly American ideal. To exclude or separate persons on the basis of an attribute is antithetical to the American way of life. But, as a society, that is exactly what we have done from a historical perspective. At various times in our history we have excluded groups of persons because of an attribute that differed from the majority. The great hope of American society however is our capacity to do the right thing—to undertake a course of action that brings us together. And, in the end, a recognition that our diversity is our enduring strength.

Professor Martin provides the reader with a unique perspective of significant disability and what it means to have a disability. From the horrors of institutionalization to the contemporary stories of the text's contributors, several recommendations spring forth that we must heed:

1. We must insist and require that teachers, counselors, and other health service professionals receive the appropriate pre-service education and training that results in certification, licensure, or endorsement of their particular skill or area of expertness. While certification does not guarantee competency, it does assure a greater probability that services delivered by teachers, counselors, and others are consistent and effective and support schools and organizations in doing the right thing.
2. Our schools must continue to develop inclusive models that afford the best possible opportunities for children and youth to become a part of American society. Separation and stereotypical thinking as noted by Professor Martin, leads to a parallel existence of shadow within the larger community after exiting a school experience of separation.
3. "We must listen." Professor Martin concludes the text with these words. Indeed, we must listen, not only to the words of

the present but we must heed the lessons of the past.

This is a well-written and researched text. The inclusion of individuals' and families' life stories adds a dimension which enriches the education of teachers, counselors, and other health professionals.

JOHN S. OEHLER, ED.D.
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PREFACE

This text will provide the reader with a comprehensive overview of the issues that affect people with significant disabilities from a historical, policy, leadership, and systems perspective. The text will be particularly useful in either graduate or advanced undergraduate courses for prospective rehabilitation counselors, teachers, community mental health professionals, social workers, psychologists, case managers, or allied health professionals. A major goal of the text is to transmit the ideal of living, working, and playing in the community; an ideal that has often been denied to persons who have significant disabilities. The issues that parallel the typical progression of life such as education, employment, transportation, housing, health care, and leisure are often impeded in important ways for persons with significant disabilities. Some persons who, perhaps, were institutionalized for a part of their life, or were educated in segregated or self-contained classrooms, or were isolated from their peers—other people—as a result face a life of shadow when compared to the general population. An understanding of these issues hopefully will motivate us—persons with disabilities, parents, siblings, loved ones, and professionals—to become effective advocates for an inclusive society that allows all of its members to access the meaning and reality of the “American Dream.” Additionally, the book should prove to be a useful and current source for the rehabilitation or community mental health practitioner or the educational professional.

An outstanding group of contributors was selected. They have achieved an excellent balance between their personal and professional experience, and service to the community of persons with disabilities. Considerable thought was put into the organization of this book to assure a consistent and integrated frame of reference as reflected in the following description of each section.

In Part 1 of the text, “Historical, Philosophical, and Public Policy Perspectives,” issues relating to community living—education, employment, housing, transportation, health care, and leisure—are explored from a historical perspective that begins with the identification of issues affecting persons with significant disabilities that have impeded independence, productivity, and inclusion within the larger community. Professors Taylor and Searl overview the various social contexts and connections between social and economic forces—urbanization, industrialization, and immigration—that fostered the development of institutions as a means of dealing with the poor, deviant, and those with disabilities. Drs. Taylor and Searl chronicle the history of institutionalization as well as the key legal and constitutional challenges to segregation and exclusion of persons with disabilities. Much of the material they present, when judged by contemporary standards of care, reveal some particularly inhumane and depressing facts. Nonetheless, if we are to learn from the past, as the philosopher George Santayana has warned us, we must be aware of that past. This section of the text concludes with an analysis of the legislative response as well as implications for future trends.

In Part 2, “Portraits of Leadership,” the perspectives of persons with significant disabilities, parents, and siblings focus on the issues of everyday life from the vantage point of life roles. Topics ranging from funding, inclusion, IEPs, related services, assistive technology, employment, stigma, spirituality, advocacy, case management, medication policies, education and training for human service professionals, and adaptation among others are presented in a passionate, personal, insightful, and meaningful manner. Sincere appreciation and warm thanks are extended to each person who shared their experiences, thoughts, and recommendations: Pat and Dewey Brown, Christopher Brown, John Coates, Ann Durden, Robin Hoerber, Ruth Martin, Michele Murmer, Michael Payne, Jim Rothrock, Justin Rybacki, and Charles Wakefield. Their insights will challenge the reader to truly understand the meaning and implications embedded in the values of independence, productivity, and inclusion.

The final part of the text concludes with an assessment and analysis of current policies and advocates that our educational and human service systems develop an infrastructure or foundation which allows for positive change and encourages inclusion. Specific recommendations of the text’s contributors complete this section.

Special thanks and appreciation is extended to my graduate Rehabilitation Counseling Fall 2000 Semester class who read and discussed the final manuscript and provided me with many substantive suggestions: Linda Albrecht, Charles T. Blaine, Debra A. DeLorey, Kendra DelBalzo, Jessica Dotson, Karla Helbert, Elaine Platt, V. J. Petillo, Mimi Stoner, and Shona Whitfield-Sykes.

Finally, grateful appreciation is extended to Michele Martin Murmer, my much beloved daughter, who typed, contributed, and assisted me in editing this text. She is a person of keen intelligence, warmth, and humor. She has added much to my life and to that of her family.

E. DAVIS MARTIN, JR.

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SIGNIFICANT DISABILITY

Part 1

**HISTORICAL, PHILOSOPHICAL, AND
PUBLIC POLICY ISSUES**

Chapter 1

SIGNIFICANT DISABILITY: AN OVERVIEW OF THE ISSUES

E. DAVIS MARTIN, JR.

THE 1987 AMENDMENTS to the Developmental Disabilities Assistance and Bill of Rights Act signaled a major change in the perspective and attitudes held toward persons with developmental disabilities and similarly enhanced the concept of habilitation/rehabilitation by introducing into legislation the values of independence, productivity, and integration. The stated purpose of this legislation was to “. . . assure that all persons. . . receive the services and other assistance and opportunities necessary to enable such persons to achieve their potential through increased independence, productivity, and integration into the community.” This legislation required the solicitation of consumer input into the planning process:

Each State Planning Council shall conduct a review and analysis of the effectiveness of, and consumer satisfaction with. . . services. . . to all persons with developmental disabilities in the State. Such review and analysis shall be based upon a survey of a representative sample of persons with developmental disabilities receiving services and their families, if appropriate.

Each state planning council was mandated by this legislation to collect data, hold public forums, and develop a comprehensive report to be submitted to the Governor and State Legislature. Data from each state and territory was to be aggregated and forwarded to the Secretary of Health and Human Services and then to the Congress of the United States of America. The Consumer Satisfaction Survey, as it was to be