SIGNIFICANT DISABILITY

ABOUT THE EDITOR

E. Davis Martin, Jr., Ed.D., CRC, NCC: Professor, Department of Rehabilitation Counseling, School of Allied Health Professions (SAHP), Medical College of Virginia (MCV) of Virginia Commonwealth University (VCU), Richmond. Formerly, Interim Chair, Department of Rehabilitation Counseling, SAHP, MVC/VCU; Professor of Special Education, School of Education, VCU; Acting Dean, School of Community and Public Affairs (SCPA), VCU; Associate Dean and Assistant Dean, SCPA, VCU; Director of Continuing Studies, SAHP, MCV/VCU and various administrative and counseling positions in the state-federal rehabilitation program. Dr. Martin has co-authored/co-edited four major textbooks and has been a frequent contributor to rehabilitation literature. His primary research interests have focused on advocacy, leadership, inclusion, and empowerment for persons with disabilities. He has consulted with local, state, and federal agencies as well as with organizations in the private sector. Dr. Martin has been repeatedly recognized for his outstanding leadership and service by the receipt of many awards and commendations from professional, governmental, and private agencies including appointment to significant Boards and Councils by the past five Governors of the Commonwealth of Virginia. Considered to be a leading forensic disability expert, he has served as a Vocational Expert to the Office of Hearings and Appeals for more than 20 years and has provided Vocational Expert testimony in numerous civil suits involving occupational injury, accidental injury, disability retirement, and issues of product liability involving injury. He is a Licensed Professional Counselor (Virginia), Certified Rehabilitation Counselor, and National Certified Counselor.

SIGNIFICANT DISABILITY

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

Edited By

E. DAVIS MARTIN, JR., ED.D., CRC, NCC

Professor of Rehabilitation Counseling
Virginia Commonwealth University

With a Foreward by

John S. Oehler, Ed.D

Dean, School of Education
Virginia Commonwealth University
Richmond, Virginia

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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
George R. Jarrell, Ph.D., Professor Emeritus
Warren R. Rule, Ph.D., Professor Emeritus
Keith C. Wright, M.A., Professor Emeritus

CONTRIBUTORS

J. Dewey Brown, MS: Adjunct Professor, School of Continuing Studies, University of Richmond. Formerly Biology and Chemistry Teacher, Wheaton High School, Montgomery County Maryland Public Schools. Mr. Brown is an educational consultant with the National Institutes of Health, Office of Science Education, the Howard Hughes Medical Institute, and a faculty consultant for the Advanced Placement Board and the Educational Testing Service. He has been an advocate for inclusive schools and communities and has delivered numerous speeches to legislators, state, national, and international audiences on these topics.

Patricia Johnson Brown, Ed.D: Associate Dean and Director of Community and Professional Education, School of Continuing Studies, University of Richmond. Formerly an Assistant Dean and Associate Professor, School of Community and Public Affairs, Virginia Commonwealth University. She has been a 4-H youth extension agent and international staff associate. Dr. Brown has been an advocate for people with disabilities for more than 30 years. Throughout her career she has worked tirelessly to create inclusive environments for people with disabilities. She is the author of many journal articles and chapters as well as a frequent speaker and consultant on the topic of recreation and disability. Most recently, Dr. Brown was recognized by the University of Richmond with the Story Award for her outstanding contributions on behalf of people with disabilities.

John P. Coates, M.A.: Teacher, The Collegiate School. Formerly taught at St. Catherine's School, Richmond, Virginia and the University of Arizona. Mr. Coates teaches History and English. He was appointed by the Governor of Virginia to the Statewide Rehabilitation Council where he served two terms with distinction. Additionally, he has served on the Chesterfield County Disability Services Board. Mr. Coates has a special interest in the accessibility and availability of assistive technology.

Ann Tucker Durden, MS, CRC: Outreach Counselor, St. Paul's Episcopal Church Prison Ministry. She is a graduate of the Rehabilitation Counseling program at Virginia Commonwealth University where she was the recipient of the prestigious Stalnaker-Wright Award for outstanding academic and community service achievement. Ms. Durden is currently a doctoral student at Virginia Commonwealth University.

Robin Fischer Hoerber, MS: Customer Service Representative, J. C. Penny. Mrs. Hoerber is a graduate of the Rehabilitation Counseling program at East Carolina University. An active advocate for people with disabilities, she has been appointed by the past two Governors of Virginia to significant councils concerned with issues in independent living. She currently serves as Chair of the Chesterfield County Disability Services Board.

Ruth Mackey Martin, RN, BSN: Psychiatric Nurse, Chesterfield County Community Services Board.. Mrs. Martin has been a tireless advocate on the behalf of children and young people with disabilities focused on inclusive education, supported employment, recreation, and case management. She has volunteered her time and considerable energies in bringing an awareness to the everyday issues faced by persons with significant disabilities.

Michele Martin Murmer, AAS: Mrs. Murmer is presently pursuing a degree in psychology and education for a career in teaching at the elementary level. She has a special interest teaching in inclusive school settings. She is an effective advocate for persons with disabilities and for issues affecting siblings.

John S. Oehler, Ed.D: Professor and Dean, School of Education, Virginia Commonwealth University (VCU). Formerly Director of Continuing Professional Education (VCU) and Director of Continuing Education and Field Services (School of Education). Throughout his career, Dr. Oehler has worked to improve the preparation of teachers. He provided leadership for the development of an extended teacher preparation program at Virginia Commonwealth University. He is an advocate of inclusion, and the School of Education's teacher preparation programs reflect this commitment. Dr. Oehler supported the development of an internationally recognized Rehabilitation Research and Training Center in supported employment and the Virginia Institute for Developmental Disabilities, both affiliates of VCU's School of Education. His interest in high standards for teacher education programs is reflected in current service as a member of the Executive Board of the National Council for Accreditation of Teacher Education and Chair of the Committee on Accreditation of the American Association of Colleges for Teacher Education. He also is a member of the Board of Directors of the Association of Colleges and Schools of Education in Land Grant, State Universities, and Affiliated Private Universities.

Michael D. Payne, MS: Formerly an investment banker for various firms. Mr. Payne is a recent graduate of the Rehabilitation Counseling program at Virginia Commonwealth University. His current research interests are in alternative health and pain management related to persons who have experienced long-term or chronic pain. He is an effective advocate for persons with disabilities and often shares his experience and knowledge regarding Social Security Disability and Long-Term Disability insurance benefits.

James A. Rothrock, MS: President of Rothrock Group, Ltd., Richmond, Virginia, a consulting firm working with business and government on the Americans with Disabilities Act. Formerly, Director of the Department for the Rights of Virginians with Disabilities; Executive Director of Handicaps Unlimited of Virginia; served in positions in both the public and private sector of rehabilitation in Virginia; and was a rehabilitation counselor with the Woodrow Wilson Rehabilitation Center. Mr. Rothrock is quite active in community service, professional organizational activity, and legislative advocacy related to rehabilitation and independent living. He has contributed to the rehabilitation literature. Mr. Rothrock is a Licensed Professional Counselor (Virginia).

Justin S. Rybacki, BGS: Mr. Rybacki recently completed an innovative nontraditional bachelor's degree program at Virginia Commonwealth University in which he designed an academic program in disability studies. He is particularly interested in historical and social treatment of persons with disabilities.

Stanford J. Searl, Ph.D.: Dr. Searl lives in Los Angeles, California and teaches at the Union Institute Graduate College, a self-directed Ph.D. program with emphasis upon interdisciplinary, socially relevant doctoral work. Currently, his research focuses upon the connections between spirituality and social change, with particular references to the practices of contemporary Quakers. In the past, Dr. Searl founded a community-based home health care service, worked as a writer about disability issues at the Center on Human Policy at Syracuse University and taught in the English Department at the State University College at Buffalo.

Steven J. Taylor, Ph.D.: Professor of Cultural Foundations of Education, Coordinator of Disability Studies, and Director of the Center on Human Policy, a disability research and policy institute, at Syracuse University. He currently serves as Editor of the journal *Mental Retardation*, which is published by the American Association on Mental Retardation (AAMR), and was the recipient of the AAMR's Research Award in 1997. He is the author of numerous articles and books, including *Introduction to Qualitative Research Methods: A Guidebook and Resource; The Social Meaning of Mental Retardation: Two Life Stories; The Variety of Community Experience: Qualitative Studies of Family and Community Life; and Life in the Community: Case Studies of Organizations Supporting People with Disabilities.* He is also Co-Editor with Stephen Blatt of *The Collected Paper of Burton Blatt.*

Charles C. Wakefield, Jr., M.Ed.: Exceptional Education Teacher, Prince George County Public Schools, Virginia. Formerly, a Learning Disabilities Teacher, Richmond Public Schools, Virginia. Mr. Wakefield was a Dental Technician for 15 years prior to his subsequent educational pursuits. He is currently completing a second graduate degree in special education with the long-term goal of completing doctoral work advancing further in the field of advocacy.

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.
Dean, School of Education
Virginia Commonwealth University
Richmond, Virginia

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 called, collected data on six areas:

1. *Demographics*: Information relating to race, marital status, gender, education, living situation, and affiliation with advocacy groups.
2. *Eligibility*: Information regarding disability status vis-a-vis the definition of developmental disability regarding the seven areas of major life activity: self-care, receptive and expressive language, learning, mobility, self-direction, economic self-sufficiency, and the need for lifelong services.
3. *Independence*: Information regarding ability to function independently.
4. *Integration*: Information regarding ability to function in community activities and settings and interaction with persons without disabilities.
5. *Productivity*: Information regarding employment (income, fringe benefits, transportation, unpaid work in the home and community).
6. *Services and Satisfaction*: Information regarding availability of services, satisfaction with services received, and need for additional services.

The analysis of the data for each state could be undertaken in slightly different ways. In Virginia, we chose to relate findings to two major themes: (1) *Targets for Improving Services* and (2) *Targets for Improving Quality of Life*. This paralleled changes at the national level in terms of a move from categorical definitions of disability to a more functional definition of disability. This change related primarily to the seven areas of major life activity (as noted in PL 100-146) and toward a philosophically driven movement that inclusion in the work and play of a community promotes a higher quality of life for people with significant disabilities and conversely for all people. Additionally the issues of employment, housing, education, transportation, healthcare, and community living in the context of major life roles (e.g., child/youth, student, leisure and social person, worker, citizen, spouse, parent, homemaker, retiree) guided the analysis of data. Findings of the Virginia Consumer Satisfaction Survey revealed (Goalder, Martin, Heck, Gandy, & Jarrell, 1990, pp. v–xii):

Targets for Improving Services

1. Consumers with developmental disabilities were dissatisfied with sitting on the sidelines of life. They wanted services and supports that would allow them to be active and integrated members of their communities.

   Consumers gave high satisfaction ratings to all services aimed at increasing community participation. They indicated a high level of need for services and supports such as community living assistance or training, self-help or support groups, and community support services. This finding was not surprising since our data indicated limited social community integration among members of our sample despite the fact that more than 80% of adults rated community integration as important to their lives.
2. Services and supports related to financial welfare dominated perceptions of satisfaction and need.

   The most consistent perceptions of satisfaction and need were related to financial welfare. Thus, high levels of need were indicated for income assistance, food assistance, financial management assistance, private health insurance, payment for medication, and payment or provision of medical equipment. Why was this area of assistance of such importance? Because having adequate income allows independence, community integration and productivity, values strongly endorsed by consumers.
3. While satisfaction with Virginia's direct services was generally high, satisfaction with supports (that were often needed to use services effectively) was much lower.

   Assistance to Virginia's consumers comes in two forms: services (e.g., sheltered employment) that were provided to mitigate the effects of a consumer's disability and secondly, supports (e.g., job coach) that were provided to increase the effectiveness of the service and/or to contribute to the quality of life of the consumer. A decade ago, Virginia's service system offered virtually all persons in a category of disability the same service mix regardless of a consumer's uniqueness. Today, there is a gradual trend toward designing a unique set of services and supports around the specific needs of the consumer.