The Psychological and Social Impact of Illness and Disability

Sixth Edition
Irmo Marini, PhD, is professor and PhD program director, Department of Rehabilitation in the College of Health Sciences and Human Services at University of Texas Pan-American, Edinburg, Texas. He has national certifications as a rehabilitation counselor and life-care planner. Dr. Marini is on the editorial boards of several rehabilitation counseling journals, editor of the *Journal of Life Care Planning*, and has authored over 70 journal publications, 25 book chapters, and authored and coedited two books, *The Professional Counselor’s Desk Reference* (2009) and *Psychosocial Aspects of Disability: Insider Perspectives in Counseling Strategies* (2012). He is the recipient of four outstanding university faculty awards in scholarship and two in teaching. He also received the Distinguished Career Award in Rehabilitation Education from the National Council on Rehabilitation Education in 2009 and the J. F. Garrett Distinguished Career Award in Rehabilitation Research from the American Rehabilitation Counseling Association in 2010. Dr. Marini is former chair of the Commission on Rehabilitation Counselor Certification, the national certifying body of over 16,000 rehabilitation counselors in the United States and Canada and former president of the American Rehabilitation Counseling Association. Dr. Marini owns and operates Marini & Associates, forensic rehabilitation consultants specializing in vocational assessments and life-care planning in legal cases involving personal injuries, and he is a vocational expert with the Social Security Administration.

Mark A. Stebnicki, PhD, is a Professor in the graduate program in rehabilitation counseling at East Carolina University. He holds a doctorate in rehabilitation counseling and is a licensed professional counselor (LPC) in North Carolina. He has national certifications as a certified rehabilitation counselor (CRC), certified case manager (CCM), and is certified by the Washington, DC–based crisis response team—National Organization for Victim Assistance (NOVA). He is also a Reiki Master level-III practitioner in the Usui Reiki Ryoho tradition. Dr. Stebnicki is an active teacher, researcher, and practitioner who has written five books; most recently *The Professional Counselor’s Desk Reference* (Springer Publishing, 2009), and *Empathy Fatigue: Healing the Mind, Body, and Spirit of Professional Counselors* (Springer Publishing, 2008; Korean translation, 2010). He has over 25 articles in peer-reviewed journals, and has presented statewide and nationally at over 70 conferences, seminars, and workshops on topics that range from youth violence, traumatic stress, empathy fatigue, and the psychosocial aspects of chronic illness and disability.

Dr. Stebnicki has over 20 years experience working with adolescents and adults that have a variety of psychological and chronic health conditions. He served on the crisis response team for the Westside Middle School shootings in Jonesboro, Arkansas (March 24, 1998) and has done many stress debriefings with private companies, schools, and government employees after incidents of workplace violence, hurricanes, tornadoes, and floods. His youth violence program, the Identification, Early Intervention, Prevention, and Preparation (IEPP) program, was awarded national recognition in 2001 by the American Counseling Association (ACA) foundation for its vision and excellence in the area of youth violence prevention. Other accolades include numerous professional service awards and consulting with former President Bill Clinton’s staff on addressing the students of Columbine High School after their critical incident (April 20, 1999).
The Psychological and Social Impact of Illness and Disability

Sixth Edition

IRMARINI, PhD
MARK A. STEBNICKI, PhD
Editors

SPRINGER PUBLISHING COMPANY
NEW YORK
To my sisters, Connie, Carole, and Darlene, and my nine nieces—thank you for supporting me and never doubting I could do all this. I think my parents and sister, Diane, would have been equally proud. To my wife’s family, whose ongoing love and support has inspired us—thank you. To my colleagues and friends, who continue to nourish rather than drain my life force—thank you for always being there. Finally, to my wife, Darlene, who has always selflessly been quietly behind the curtain, but whose shoulders from which I have always gazed further than most, I think you have earned your wings.

—Irmo

Words cannot express my gratitude for Irmo’s deep friendship, collegial relationship, and awakening my mind, body, and spirit to the true meaning of resiliency and psychosocial response to disability. I would also like to thank all my mentors at the Rehabilitation Institute, Southern Illinois University, Carbondale, where it all began for me with its creator, Dr. Guy Renzaglia (1913–2005) and my closest mentor throughout my master’s and doctoral program, Dr. Harry Allen (1941–2009).

—Mark
Contents

Contributors xi
Foreword Arthur E. Dell Orto xv
Preface xix
Acknowledgments xx

PART I HISTORICAL PERSPECTIVES ON ILLNESS AND DISABILITY

1. History of Treatment Toward Persons With Disabilities in America 3
   Danielle D. Fox and Irmo Marini
2. On the Origins of Negative Attitudes Toward People With Disabilities 13
   Hanoch Livneh
3. History of Treatment Toward Persons With Psychiatric Disabilities 27
   Kim Nguyen-Finn
   Richard L. Beaulaurier and Samuel H. Taylor
5. Models of Disability: Implications for the Counseling Profession 61
   Julie F. Smart and David W. Smart
6. Changes in Attitudes Toward People With Handicaps 79
   Beatrice A. Wright
   Personal Perspective: Coping With a Journey Toward Recovery: From the Inside Out 85
   Dale Walsh

PART II THE PERSONAL IMPACT OF DISABILITY

7. Psychological Adaptation to Chronic Illness and Disability: A Primer for Counselors 95
   Hanoch Livneh and Richard F. Antonak
   Andrew A. Phemister and Nancy M. Crewe
9. Psychosocial Disparities Faced by Women With Physical Disabilities 117
   Margaret A. Nosek
10. Sexuality and Spinal Cord Injury Counseling Implications 135
    Eva Miller and Irmo Marini
## Contents

11. Cross-Cultural Counseling Issues of Males Who Sustain a Disability  
   **Irmo Marini**  
   151

12. Psychiatric and Psychological Issues in Survivors of Major Disasters  
   **Carol S. North and Alina M. Surís**  
   165

13. Quality of Life and Psychosocial Adaptation to Chronic Illness and Acquired Disability: A Conceptual and Theoretical Synthesis  
   **Malachy Bishop**  
   179
   **Personal Perspective:** Using Rational Emotive Behavioral Therapy Techniques to Cope With Disability  
   **Albert Ellis**  
   193

### PART III FAMILY ISSUES IN ILLNESS AND DISABILITY

14. My Child is Not My Carer: Mothers With Physical Disabilities and the Well-Being of Children  
   **Ora Prilleltensky**  
   207

15. Parenting a Child With a Chronic Medical Condition  
   **Jane Case-Smith**  
   219

16. In the Midst of a Hurricane: A Case Study of a Couple Living With AIDS  
   **Lydia P. Buki, Patti Uman, Lori Kogan, and Bethanne Keen**  
   233

17. Parental Illness, Family Functioning, and Adolescent Well-Being: A Family Ecology Framework to Guide Research  
   **Sara Pedersen and Tracey A. Revenson**  
   249

18. My Life With Muscular Dystrophy: Lessons and Opportunities  
   **Robert P. Winske**  
   273
   **Personal Perspective:** Dealing With Spina Bifida: A Mother's Perspective  
   **Janet Lingerman**  
   280

### PART IV INTERVENTIONS AND RESOURCES

19. Substance Use and Substance Use Disorders  
   **Chuck Reid and Maria Barrera**  
   291

20. Working With Trauma-Related Mental Health Problems Among Combat Veterans of the Afghanistan and Iraq Conflicts  
   **Jamylah Jackson, Lisa Tboman, Alina M. Surís, and Carol S. North**  
   307

21. Users of Assistive Technology: The Human Component  
   **Martin G. Brodwin, Francis W. Sui, and Elizabeth Cardoso**  
   331

22. Dance of Disability and Spirituality  
   **Boni Boswell, Michael Hamer, Sharon Knight, Mary Glacoff, and Jon McCbesney**  
   341

23. Rehabilitation Professionals and Abuse of Women Consumers  
   **Martin G. Brodwin and Frances W. Sui**  
   353
   **Personal Perspective:** Recovery and the Rehabilitation Process: A Personal Journey  
   **James T. Herbert**  
   364
PART V NEW DIRECTIONS: ISSUES AND PERSPECTIVES

24. Positive Psychology, Wellness, and Post-Traumatic Growth Implications for Rehabilitation Counselor Education 377
   Irmo Marini and Mitka Chacon

25. Successful Aging: A Disability Perspective 395
   Meredith Minkler and Pamela Fadem

26. An International Conceptualization of Disability: The International Classification of Functioning, Disability, and Health 405
   David B. Peterson

27. Psychosocial Impact of Empathy Fatigue on Professional Helpers 423
   Mark A. Stebnicki

28. Obesity as a Disability: Medical, Psychosocial, and Vocational Implications 435
   Maria G. Romero and Irmo Marini

   Steve Zanskas and Wendy Coduti

30. Mental Health Preparedness for Terrorist Incidents 461
   Alina M. Suris and Carol S. North

31. Key Concepts and Techniques for an Aging Workforce 479
   Susanne M. Bruyère, Debra A. Harley, Charlene M. Kampfe, and John S. Wadsworth

32. Reflections and Considerations 485
   Irmo Marini and Mark A. Stebnicki
   Part A: Reflections on the View From Here 485
   Part B: Reflections 490

   Personal Perspective: Life’s Lessons Taught to Me by My Disability 497
   Alfred H. DeGraff

APPENDIX A: PERSPECTIVE EXERCISES

Perspective Exercise 1 503
   Common Pain, Mutual Support 503

Perspective Exercise 2 504
   Who Needs This Kind of Help? 504

Perspective Exercise 3 504
   Is the Person With a Disability More Important Than the Family? 504

Perspective Exercise 4 505
   Enough is Enough 505

Perspective Exercise 5 505
   Fragile: Handle With Care 505

Perspective Exercise 6 506
   I Am in Love With a Stranger 506

APPENDIX B: PERSONAL PERSPECTIVES

Chris and His Mother: Hope and Home 507
   Chris Moy
Contents

Karen—My Daughter Forever  512
  Linda Stacey
Living in Spite of Multiple Sclerosis  514
  Tosca Appel
Surviving Amyotrophic Lateral Sclerosis: A Daughter's Perspective  517
  Judy Teplow
My Life With a Disability: Continued Opportunities  521
  Paul Egan
For Better or for Worse  524
  David Collins
Experiencing Sexuality as an Adolescent With Rheumatoid Arthritis  527
  Robert J. Neumann

Index  533
Contributors

Richard F. Antonak, PhD
University of Massachusetts
Boston, Massachusetts

Tosca Appel, MS
Newton, Massachusetts

Maria Barrera, BS
Research Assistant
Department of Rehabilitation
The University of Texas-Pan American
Edinburg, Texas

Richard L. Beaulaurier, PhD, MSW
Florida International University School of Social Work
Miami, Florida

Malachy Bishop, PhD, CRC
University of Kentucky
Lexington, Kentucky

Boni Boswell, PhD
East Carolina University
Greenville, North Carolina

Martin G. Brodwin, PhD, CRC
California State University
Los Angeles, California

Susanne M. Bruyère, PhD, CRC
Director of the Employment and Disability Institute
Cornell University
Ithaca, New York

Lydia P. Buki, PhD
University of Illinois
Champaign, Illinois

Elizabath Cardoso
Hunter College
New York, New York

Jane Case-Smith, EdD
Ohio State University
Columbus, Ohio

Mitka Chacon, MS, LPCI
San Benito, Texas

Wendy Coduti, MA, PhD
Michigan State University
East Lansing, Michigan

David Collins, MED
Montgomery College
Rochville, Maryland

Nancy M. Crewe, PhD
Michigan State University
East Lansing, Michigan

Alfred H. DeGraf, EdD
Fort Collins, Colorado

Paul Egan, MS
Dracut, Massachusetts

Albert Ellis, PhD
Albert Ellis Institute
New York, New York
Contributors

Pamela Fadem, MPH
University of California
Berkeley, California

Danielle D. Fox, PhD
Department of Rehabilitation
The University of Texas-Pan American
Edinburg, Texas

Mary Glacoff, PhD
East Carolina University
Greenville, North Carolina

Michael Hamer, PhD
East Carolina University
Greenville, North Carolina

Debra A. Harley, PhD, CRC, LPC
Department of Special Education and Rehabilitation Counseling
University of Kentucky
Lexington, Kentucky

James T. Herbert, PhD, CRC
The Pennsylvania State University
University Park, Pennsylvania

Jamylah Jackson, PhD, ABPP
Staff Psychologist and Assistant Professor
VA North Texas Health Care System
The University of Texas Southwestern Medical Center
Dallas, Texas

Charlene M. Kampfe, PhD, CRC
University of Arizona
Tucson, Arizona

Bethanne Keen, MD
Arizona Department of Corrections
Phoenix, Arizona

Sharon Knight, PhD
East Carolina University
Greenville, North Carolina

Lori Kogan, PhD
Colorado State University
Fort Collins, Colorado

Hanoch Livneh, PhD, CRC
Portland State University
Portland, Oregon

Jon McChesney, PhD
Western Kentucky University
Bowling Green, Kentucky

Eva Miller, PhD, CRC
Department of Rehabilitation
The University of Texas-Pan American
Edinburg, Texas

Meredith Minkler, DPH
University of California
Berkeley, California

Chris Moy, MS
Scranton, Pennsylvania

Robert J. Neumann
Chicago, Illinois

Kim Nguyen-Finn, MA, LPC-S
The University of Texas-Pan American
Edinburg, Texas

Carol S. North, MD, MPE
The Nancy and Ray Hunt Professor of Crisis Psychiatry
VA North Texas Health Care System
UT Southwestern Medical Center
Dallas, Texas

Margaret A. Nosek, PhD
Center for Research on Women With Disabilities
Department of Physical Medicine and Rehabilitation
Baylor College of Medicine
Houston, Texas

Sara Pedersen, PhD
University of Montreal
Montreal, Quebec
Canada

David B. Peterson, PhD, CRC
California State University
Los Angeles, California

Andrew A. Phemister, PhD
Minnesota State University
Mankato, Minnesota

Ora Prilleltensky, PhD
Vanderbilt University
Nashville, Tennessee
Chuck Reid, PhD, CRC  
The University of Texas-Pan American  
Edinburg, Texas

Tracey A. Revenson, PhD  
Vanderbilt University  
Nashville, Tennessee

Maria G. Romero, PhD, CRC  
Department of Psychology  
Texas A&M International University  
Laredo, Texas

Francis W. Siu, PhD, CRC  
California State University  
Los Angeles, California

David W. Smart, PhD  
Brigham Young University  
Provo, Utah

Julie F. Smart, PhD, CRC  
Department of Special Education and Rehabilitation  
Utah State University  
Logan, Utah

Linda Stacey  
Framingham, Massachusetts

Alina M. Surís, PhD, ABPP  
Professor of Psychiatry  
Director, Division of Trauma and Disaster  
VA North Texas Health Care System  
The University of Texas  
Southwestern Medical Center  
Dallas, Texas

Samuel H. Taylor, DSW  
University of Southern California  
Los Angeles, California

Judy Teplow, MSW  
Canton, Massachusetts

Lisa Thoman, PhD  
Staff Psychologist and Assistant Professor  
VA North Texas Health Care System  
The University of Texas Southwestern Medical Center  
Dallas, Texas

Patti Uman, BS  
Colorado State University  
Fort Collins, Colorado

John S. Wadsworth, PhD  
Department of Counseling, Rehabilitation, and Student Development  
University of Iowa  
Iowa City, Iowa

Dale Walsh, ScD  
Cambridge, Massachusetts

Robert P. Winske, MS  
Boston, Massachusetts

Beatrice Wright, PhD  
University of Kansas  
Lawrence, Kansas

Steve Zanskas, MS, PhD  
Michigan State University  
East Lansing, Michigan
In preparation for the prior five editions—1977, 1984, 1991, 1999 and 2007—the goal was to recognize the importance of the past literature, put it in a current context, introduce new and emerging themes, and address current as well as future needs of the consumers and providers of health care and rehabilitation services. From my review of the sixth edition of *The Psychological and Social Impact of Illness and Disability*, it is clear that this tradition has continued and has been expanded.

It is important to note, however, that while significant and substantial gains have been made—some of which we did not even consider or anticipate—there is more to be accomplished. We have realized that the journey does not have a final destination but rather the more that is accomplished often results in other emerging horizons, more challenging landscapes, and major climate change with all the anticipated and unanticipated fall out.

These points are put forward by Gunnar Dybwad, Irving Kenneth Zola, Harlan Hahn, and Bob Marinelli who in earlier forewords made the following statements:


Irving Kenneth Zola: 1984, second edition: “By the time the next edition of this book comes out we shall see how the Independent Living Movement has fared. I am sure that we will need another decade of dedicated effort … the line between the able-bodied and the disabled is a thin and often temporary one” (ix).


Harlan Hahn: 1999, fourth edition: “Both personal and social improvements can be achieved by embracing rather than overcoming the valuable contributions of a life with a disability” (xvii).

Bob Marinelli: 2007, fifth edition: “Disability is increasingly viewed as an enabling experience. This has allowed for the development of personal growth in life domains and contributions to the lives of others that were previously unavailable” (xxii).

One of the most complex tasks in preparation of the prior and current edition was not to be comfortable in presenting some of the most prominent and significant literature, as reflected in the classic articles. The difficult task was to try to learn from the vision of scholars who had the ability to address futuristic needs and emerging issues that would be world-changing and have a lasting impact on the evolutions of policy, services, and the lives of those who are or will be impacted by a new reality. Talk about a climate change and the melting of some beliefs that have been frozen for years!
Reflection on the previous editions results in the conclusion that these scholars were successful in some areas but not so in others. It was not anticipated that with landmark legislation there would be complex issues that would surface. Also, that the dramatic impact of technology would create a gap between what was available to some would not be affordable or accessible to many others. That with great wealth and accumulation, there would be, for some, the most desperate poverty and what once was a hope, has become an uncertainty (e.g., jobs, health benefits, home ownership, and universal access).

Also, when the first edition was printed in 1977, domains that are an embedded part of our landscapes were not apparent or not even on the horizon for many (e.g., traumatic brain injury, mental illness, global financial concerns, AIDS, and natural disasters). All of these changes have a direct and indirect impact on The Psychological and Social Impact of Illness and Disability, as it is now and as it is evolving. This sixth edition has been successful in channeling the confluence of historic themes, current issues, and futuristic concerns.

This is accomplished in a most readable and cogent style and format. For the reader, the classic articles present some of the foundation constructs and principles in a meaningful context and the new material addresses issues and themes that are meaningful, timely, and most relevant. The personal statements validate the experience and perspectives of consumers and those who serve and advocate for them. The discussion questions stimulate thought and discussion on issues and topics that warrant consideration as well as action and resolution. For many of us, and our significant others, the journey of life and living are not exactly what we had hoped or planned for.

No surprise here, even though there is great value on planning for the future and trying to control and contain the realities of life that often become our tsunami. This point was made by Dr. Zola in the foreword of the second edition when he stated: “For then as we age and change, both in body and mind, we shall not see this time as one of impending doom and decline but rather as a time when we will grow and manage our resources differently” (x).

This point, in the context of persons who are temporarily able-bodied, had emerged as connecting construct, more limited in the earlier editions but much more prominent in the more recent fifth and the current sixth editions. It was not always this way. In the past, our understanding of the psychological and social impact of illness and disability was based on the world as it was known with an element of what could and should be. When I was a student in 1966 during my first graduate internship at a state vocational rehabilitation office, I met a young man who was living with, and in spite of, a C-4 spinal cord injury. When we were discussing potential services, I was told by my supervisor that the agency did not provide services for people with catastrophic injuries. I was amazed because this was a young man, very independent—he had modified his van—who was just looking for some basic services. While this occurred 46 years ago, it still has an impact on me because while there have been major changes in the philosophy and principles of health care and rehabilitation, there are still emerging needs and issues that must be addressed. This sixth edition puts these in a meaningful historical, current, and futuristic perspective.

A bedrock concept of this sixth edition as well as the previous editions is that there is an emerging, evolving, and challenging body of knowledge that attempts of grasp and understand the complexity of life and living in the context of transient health, illness, disability, loss, change, and human resilience. A simple but profound saying is “One must appreciate where one has been in order to better understand where one is going, how to get there, and be prepared to make the requisite adjustments along the way.” This is not unlike the rehabilitation process, which
demands many life changes, challenges, losses, and rewards. For me, this has been quite a journey that began in early childhood when I bore witness to friends and family members who had major health issues but who maintained their bearings in life and became role models for many even though the resources and supports were limited or nonexistent—apart from family and friends. In some ways, some things have not changed.

As a graduate student, I had the privilege of attending a lecture by Dr. Howard Rusk. His message, focusing on the theme of “A World to Care For,” is more meaningful today than it was then. My personal introduction to the psychological and social aspects of disability began as a student in the 1960s but began in reality when I was a child and in a class with a boy who had a deformed hand. This was not an issue for me since we had a great time together, but I was told by others not to play with him. Childhood can be most understanding or very brutal.

The beginning of this book, which clearly began in 1971, happened when my colleague, Dr. Robert Marinelli stopped by my office and asked me to review some new material he was developing for his course on the psychosocial aspects of disability. He told me that the field was rapidly developing and he wanted to keep the course current and wanted my input on what he had selected. This was most timely because we had an upcoming meeting with Dr. Tamara Dembo at Clark University. At this meeting, we had the opportunity to listen to her historical and futuristic perspectives, her work with Dr. Beatrice Wright, and the content of a lecture she would be giving at Boston University. When we left the meeting, Bob and I looked at each other and realized that we had a lot to learn. When the lecture date arrived, we had expected 40 or 50 people attending at the most. We were surprised and most pleased when there was well over 100 present. It was not only the number that pleased us but also who was in attendance to hear Dr. Dembo: famed international scholar, Gunnar Dybwad who wrote the foreword to the first edition in 1977, Irving Kenneth Zola who did the forewords to the second and third editions as well as many other consumers and rehabilitation leaders. These were giants in the field. People of great vision, passion, and sensitivities. They would not accept what was, and challenged all of us to address what should and could be. This was a very significant experience because it put the topic at hand in a much larger context than we had understood it to be. Also emphasized was the impact on the consumer of services, and not just the world needs and perspectives of the provider. In 1973, Bob and I had the opportunity to attend a national conference with Dr. Dembo. What was special about this journey was that we would have many hours in airports and on the plane with Dr. Dembo. Those who knew her would understand the content of the ongoing discussion with this master scholar and most special human being.

At the end of the return flight, Bob and I realized how much information and perspective we had gained, and with the encouragement of Dr. Dembo the idea for a book emerged, and it became reality with the first edition in 1977. The point of this is that we had the benefit and support of many mentors and role models who advised, encouraged, and challenged us to pursue the topic and address the current and emerging needs of the consumers whose lives are most directly impacted by the quality and relevance of services and the visions of policymakers and commitment of providers.

In all of the previous editions, we have attempted to have theory balanced by reality and validated by the testimony and perspectives of those living the treatment and rehabilitation process. Key to negotiation of the life and living process is the fusion of the ongoing life lessons and learning that demand ongoing adjustments to the grinding conflicts between what we want, what we need, what we expect, and what we have. The personal statements in the book address these issues and provide the reader with personalized messages from those consumers who have a unique and meaningful perspective on the issues related to
The Psychological and Social Impact of Illness and Disability. Consequent to this effort we have formed ongoing life-long relationships with many consumers who have shared their life stories.

This tradition of personal statements has continued in the sixth edition. This is not by default; in fact, the current editor, Dr. Irmo Marini, was an ongoing content specialist, advisor, and contributor to several prior editions. With his experience as a scholar, consumer, and researcher, he and Dr. Mark Stebnicki have been able to address emerging trends in the field and include some of the most timely content while retaining selected classics. I am most pleased that the sixth edition has continued this tradition.

When Bob Marinelli decided to retire, and not do a fifth edition, we discussed who we wanted to replace him. We wanted a person who could bring an expanded perspective to the book, and we were most pleased that Dr. Paul Power accepted our invitation and the content of the fifth edition is most reflective of his input and vision.

When the sixth edition request was made, Paul and I had decided also to retire. We did not want the book to end, and we called Bob to discuss our options. We were all in agreement that the person we wanted to turn over the helm to was Dr. Irmo Marini who was part of the book for many years. Along with his coeditor, Dr. Mark Stebnicki (this sixth edition has built on the content of past editions), he has expanded the scope of the book, addressed the topics of 2012, and also set the stage for future issues, concerns, and challenges.

I am most honored to have been asked to write this foreword. I also want to acknowledge the support and guidance of our role models and mentors whose spirit is reflected in this work as well as in prior editions. In particular, I like to acknowledge Gunnar and Rosemary Dybwad, Irving Kenneth Zola, Tamara Dembo, Bernard Kutner, Nancy Crew, Hanoch Livneh, Paul Corcoran, Al De Graff, Elmer Bartels, Bill Anthony, Harlan Hahn, and Irmo Marini. These are just a few. The rest, you know who you are. Thank you!

To the editors, Dr. Irmo Marini and Dr. Mark Stebnicki, congratulations on a most meaningful and relevant book. I hope that the seventh edition will note how some of the most challenging issues have been addressed and that the new realities are clearer in focus and within the reach, hopes, and aspirations of those whose lives will be impacted, enhanced, or limited by what has been accomplished by those who have the power, wisdom, and ability not only to make a difference but to do what is right.

Arthur E. Dell Orto, PhD, CRC
Professor Emeritus, Sargent College of Health and Rehabilitation Sciences
Boston University
Preface

It was indeed an honor, albeit somewhat intimidating, to receive a call from Art Dell Orto in 2010, indicating that he was not only retiring after an outstanding career at Boston University but also retiring from his many other professional projects as well. Art and I have been friends and colleagues for over a decade, and I was flattered and honored to learn that he and Paul Power had selected three of my previous publications for the 5th edition of this best-selling and historic textbook, which dates back to 1977, with Bob Marinelli who had coedited with Art on the first four editions. However, to receive the call from Art indicating that he had recommended me to Springer Publishing to carry on the torch for the sixth edition of this text was a flattering and humbling moment for which I could not decline.

The perplexing part for me, however, was that I was in the middle of coauthoring with colleagues Noreen Glover-Graf and Michael Millington my second book ironically dealing with the same topic. So the juggling act of course became one of recognition that, although there inevitably had to be some overlap between the two, they still had to be uniquely and distinctly different. As I write this preface and look at the table of contents for both books, I am confident to conclude that they are definitely different in many ways. This text, first and foremost, had to continue with the best-selling formula that Bob and Art, and finally Art and Paul, had originally conceptualized.

My first thought when accepting the project was realizing that I needed help. Unhesitatingly, I turned to my good friend and coeditor on our first book, Mark Stebnicki. Mark and I first met when I hired him straight out of Southern Illinois University at Carbondale back in 1995, and we have worked and played since that time. He is an outstanding clinician and writer, having shaped his career in a number of fascinating ways as you will read in his biography. I am blessed to be surrounded by such good friends and colleagues and get to write about the topics of which we all share a passion.

This brings us to the sixth edition where almost two-thirds of the chapters are new and/or updated. We wanted to maintain the quality of information from the previous editions while choosing special topics and issues that relate to the profession today. As such, we are confident that we have successfully balanced this objective. Specifically, we retained 11 of the 36 chapters in the fifth edition due to their importance and ongoing significance. Second, we went back to eight of the authors from the fifth edition and received significant updated revisions of their chapters. Third, we reread the classic articles from the first four editions, and reinserted two of those chapters which continue to be benchmarks some 35 years later. Finally, we found and/or solicited 11 new chapters, two of which were gleaned from the literature, and nine newly written chapters from some prolific writers in the field.

So, knowing that this sixth edition has been significantly reconstructed while maintaining the integrity of its predecessors, I ask exactly how is it different? Well, the
landscape concerning the psychosocial issues of persons with disabilities has shifted somewhat in America and abroad. As the United States continues to struggle with its investment in two arguable wars battling terrorism, the implications to our citizens, military, and their families are numerous both to their physical and mental health. As such, we have updated the chapter concerning the psychological issues of survivors of major disasters as well as add a new chapter dealing with mental health preparedness for terrorist incidents and the persistent threat and stress of terrorism on Americans. In addition, working specifically with the mental health issues of trauma-related combat veterans and their families the Afghan and Iraqi conflicts are addressed.

The psychosocial issues of women with disabilities are also discussed, both in an updated chapter regarding their psychosocial issues and in a new chapter dealing with physical and sexual abuse. The epidemiology of obesity and its epidemic increase with related physical, psychosocial, vocational, and health-related implications are also addressed. Although the above topics represent just some of the contemporary issues facing persons with disabilities and rehabilitation professionals in the 21st century, we also explore some of our history. In two newly written chapters, we explore the history of treatment of persons with disabilities, and specifically psychiatric disabilities in the United States. As rehabilitation counselors and researchers continue to reframe disability as a socially constructed concept and the critical interrelationship between an individual and his or her environment, knowing where we have been to derive at where we are today requires this exploratory and often unpleasant sociological perspective.

Finally, a psychosocial text concerning disability would not be complete without the perspectives of persons with disabilities who have lived the experience. As such, Mark and I have retained the majority of these poignant personal accounts written by persons with disabilities and/or their loved ones who care for them. Each section of the book contains classroom discussion talking points and exercises regarding the topical areas as well as personal stories found after some of the chapters. These insights will continue to give students and practicing counselors a different perspective of life with a disability in the United States.

ACKNOWLEDGMENTS

We would like to most humbly and appreciably thank several key people who made this book possible. Editor extraordinaire Sheri W. Sussman, who now having guided and supported us through two Springer Publishing books, has made this experience stress-free, mostly fun, and flawlessly compiled. Thanks also to Kathryn Corasaniti for keeping us organized with old chapters, new chapters, and revised chapters. A special thank you to a most respected colleague Arthur Dell Orto, who after 35 years, entrusted us to carry on with his, Bob Marinelli, and Paul Power’s best-selling textbook. Dr. Dell Orto’s numerous book contributions to the field spanning his career has elevated thousands of educators and counselors alike in various disciplines. This sixth edition maintains at least a third of these scholar’s previous ideas from the fifth and earlier editions. We also would like to acknowledge Darlene Marini, who once again took on the tedious task of inputting the reference lists for certain chapters. Finally and most importantly, we acknowledge the select group of authors who have contributed to this sixth edition. Their expertise and field research elevates the social consciousness on disability studies. Similarly, we would like to thank the authors for their personal stories regarding the lived experience of having a disability or sharing a life with someone who is disabled. The six editions of this textbook would not have been as successful without these personal perspectives.

Irmo and Mark
Historical Perspectives on Illness and Disability: Introduction

The first part of this book addresses disability more from a sociological or social psychological perspective, focusing on exploring disability from the outside looking inward. A major premise for contemporary scholars in the field has been to explore the impact the environment can have on the individual with a disability and his or her family. Somatopsychology and ecological and minority models of disability emphasize the positive and all too often negative psychosocial implications societal attitudes, physical barriers, and so on can have on persons with disabilities. As such, we feel it is best to first explore where we have been in these matters before we can proceed to discuss why and how persons with disabilities and/or their families respond, react, adjust, or adapt to their situations. The empirical literature over the past 25 years has documented a fairly consistent set of conclusions on this matter. Perceived negative societal attitudes and physical barriers in many, but not all, cases do negatively impact the self-concept and mental health of persons with disabilities. Conversely, positive societal attitudes and minimal barriers in many, but not all, cases lead to better adaptation for persons with disabilities.

Chapter 1 is new and reviews an embarrassing and mostly closeted history of how primarily Americans with disabilities and “different others” were viewed, treated, and mistreated over the past century. Fox and Marini explore the stark contrast between Emma Lazarus’s Statue of Liberty engravings that note: “Give me your tired, your poor, your huddled masses yearning to breathe free, the wretched refuse of your teeming shore. Send these, the homeless, tempest-tost to me, I lift my lamp beside the golden door!” In many instances, U.S. immigration laws and various state laws enacted quite the opposite by excluding, detaining, and sterilizing thousands of persons deemed unfit to become Americans.

Chapter 2 revives a second edition original by Livneh, in his chapter, “On the Origins of Negative Attitudes Toward Disability,” and explores why “typically developing” others or those without disabilities perceive persons with disabilities the way they do. What are the reasons why some people are anxious or afraid of people with disabilities? What are these misperceptions and how do they originate? Livneh explores both conscious and often subconscious human psyche mechanisms at work as to what the root causes of some of these societal perceptions entail.

Chapter 3 is new and deservedly receives its own discussion by Nguyen-Finn, separately exploring the historical treatment of persons with psychiatric disabilities in America. Perhaps more so than any other diagnosed disability, persons with psychiatric disabilities or mental illness have arguably been perceived and treated more harshly. From early beliefs of demonic possession, involuntary confinement in subhumane “institutions,” prefrontal lobotomies and what can be today defined as torture, to current-day homelessness.
Historical Perspectives on Illness and Disability

and prison incarceration undoubtedly places psychiatric disability in a category by itself. Nguyen-Finn chronicles this history and what happens to individuals when they are perceived as less than human.

Chapter 4 by Beaulaurier and Taylor provides a brief synopsis of some of the atrocities and mistreatment of people with disabilities historically, but spends much of the time regarding the civil rights pushback of this population in social work practice. Specifically, the authors explore the disability rights movement, traditional approaches to disability in health care settings, and the need for advocacy and self-empowerment of this population concerning lack of accommodations, as well as negative societal attitudes. The authors stress the need for rehabilitation professionals to philosophically operate from a disability rights perspective and the need to assist by self-empowering them as opposed to helping but facilitating learning helplessness.

Chapter 5 by Smart and Smart explore the four primary models of disability: the biomedical model, the functional model, the environmental model, and the sociopolitical model. Depending on one’s frame of reference regarding disability, each model presents a philosophical and treatment approach to working with persons with disabilities that not only impacts rehabilitation professionals’ attitudes but also their emphasis on how they go about counseling and/or treating their patients/clients. This framework often lays the foundation for how persons with disabilities interrelate with professionals as well.

Chapter 6, Beatrice Wright’s classic article regarding changes in attitudes toward people with disabilities, aptly concludes Part I by noting the affirmation of human rights, and a synthesis of seven of her original 18 value-laden beliefs and principles regarding working with this population. The essence of these values and beliefs are guidelines for rehabilitation professionals that largely take into consideration treating others with dignity and respect, advocacy for the removal of environmental barriers, fundamental civil rights for all persons, and the importance of self-help organizations. Wright’s 40-plus years as a leader in the field regarding the psychosocial aspects of disability provides tangible examples of assisting persons with disabilities in practice.
Despite the common ideal that the United States is the land of opportunity, the early history of the United States was not necessarily a welcoming one for everyone. The fear of diluting the American bloodlines had a huge impact on public and governmental beliefs and attitudes. This fear, combined with the eugenics movement in the early 19th century, led American lawmakers to pass laws that specifically restricted certain people or groups from entering the United States and, within some city ordinances, even kept them out of public view. Early American lawmakers believed that by doing this, they were protecting the welfare of the country and Americans as a whole. The purpose of this chapter is to review the history of treatment toward people with disabilities (PWDs) in the United States.

“Give me your tired, your poor, your huddled masses yearning to breathe free, the wretched refuse of your teeming shore. Send these, the homeless, tempest-tossed to me …” (Lazarus, 1883). This is a section of the 14-line sonnet that is engraved on the Statue of Liberty in New York City. The statue was completed in 1886 and the verse actually inscribed on her in 1945. These words symbolized an American ideal against oppression to all immigrants who entered the United States during the early 20th century. In reality, however, American immigration legislation and practice during this time was in direct opposition to the Statue of Liberty engraving’s intended message.

EARLY IMMIGRATION LEGISLATION

“It is often said, and with truth, that each of the different alien peoples coming to America has something to contribute to American civilization. But what America needs is desirable additions to, and not inferior substitutions for, what it already possesses” (Ward, 1924, p. 103). Early immigration literature and the apparent attitudes and treatment toward PWDs, as well as certain other immigrant populations, were blatantly prejudiced and discriminatory. Antidisability sentiment became more evident with immigration restriction, which began as early as the development of the first North American settlements. It was after 1838, when a large influx of immigrants came to the United States, that the issue of disability became more pressing to the early American settlers (Treadway, 1925).

Antidisability legislation began in 1882 and continued through 1924, with some of the original laws in effect until the 1980s. The concept behind early immigration legislation was to prevent the immigration of people who were considered undesirable. Early Americans believed that preventing people considered “undesirable” to enter the United States was
Historical Perspectives on Illness and Disability

a means of protecting not only the people of the United States but also the welfare of the country as a whole (Ward, 1907). Baynton (2005) states, "disability was a crucial factor in deciding whether or not an immigrant would be allowed to enter the United States" (p. 34). The term "undesirable" was used to describe people from any race, ethnicity, or religion, and/or with a disability, that are believed to be more likely to pass on less-than-desirable traits to their offspring. The purpose of early immigration legislation was to protect the American bloodlines, and according to early lawmakers, this meant excluding people based on any trait that could be considered as undesirable. Baynton (2005) states,

One of the driving forces behind early federal immigration law, beginning with the first major Immigration Act in 1882, was the exclusion of people with mental and physical defects (as well as those considered criminal or immoral, problems seen at the time as closely related to mental defect). (p. 32)

This marked the beginning of the exclusion of PWDs in America.

In the years after 1882, early American lawmakers became more and more concerned about the bloodlines of immigrants seeking entrance into the United States and their possible effect on the bloodlines that were already present. With the 1891 revised Immigration Act, a key wording change made restrictions even more discretionary regarding excluding PWDs. Baynton (2005, p. 33) notes that the original 1882 law wording was "any lunatic, idiot, or any person unable to take care of himself or herself without becoming a public charge," changing the phrase in the 1891 law from "unable" to "likely to become a public charge." In 1894, the Immigration Restriction League (IRL) was established in Boston. The primary focus of the IRL was to "carry on a general educational campaign for more effective restriction and selection" (Ward, 1924, p. 102). According to Ward of the IRL, the league’s fears were that the United States was becoming an “asylum for the poor and the oppressed of every land” (p. 100). Ward went on to explain:

Americans began to realize that the ideal of furnishing an asylum for all the world’s oppressed was coming into conflict with changed economic and social conditions. The cold facts were that the supply of public land was practically exhausted; that acute labor problems, aggravated by the influx of ignorant and unskilled aliens, had arisen; that the large cities were becoming congested with foreigners; that large numbers of mentally and physically unfit, and of the economically undesirable, had come to the United States. (p. 102)

As such, by 1896 literacy requirements were imposed on all immigrants entering the United States, and by 1903 through 1907, immigration laws were broadened and became more restrictive in scope. It was not until the 1917 revisions to the 1907 Immigration Act occurred that more specific and harsher discriminatory language appeared in legislation. Prior to this, however, in 1903, persons with epilepsy were added to the list, as well as the 1903 wording “persons who have been insane within five years previous [or] who have had two or more attacks of insanity at any time previously” (Baynton, p. 33). Treadway (1925) cites the exclusionary language of the law in the 1907 Act:

The insane; idiots; imbeciles; feebleminded; chronic alcoholics; constitutional psychopathic inferiors; the mentally defective whose defect would modify their ability to earn a living; those with loathsome or dangerous contagious diseases, and those over sixteen years of age who were without a reading knowledge of some language. (p. 351)

The 1907 Act also was the first act where the law required a medical certificate for persons judged to be “mentally or physically defective, such mental or physical defect being of a nature which may affect the ability of such alien to earn a living” (Baynton, p. 33).
Subsequent years saw increasing restrictions, including financial penalties on transport companies and ship captains for the transportation of immigrants considered “unfit” for entry into the United States (Barkan, 1991; Baynton, 2005; Treadway, 1925). In an attempt to gain better control of the immigration situation, ship captains at ports of entry were to examine prospective immigrants for “defects.” Although they were neither physicians or had any medical experience, the purpose of their inspections was to medically examine immigrants. If a disability, either mental or physical, was observed or perceived, the ship captain at transit or the inspector at entry ports was authorized to either deny departure from the immigrant’s country of origin or deny entry into the United States. If an immigrant was granted departure from his or her country of origin and, upon arrival, entry into the United States was denied, the immigrant was to be deported back to his or her country of origin at the expense of the transport company that brought them (Baynton, 2005). For this reason, many ship captains in all likelihood denied numerous individuals for various vague reasons in order to not be fined or potentially lose their jobs. Baynton notes:

Inspectors prided themselves on their ability to make a “snapshot diagnosis” as immigrants streamed past them single file. For most immigrants, a normal appearance usually meant an uneventful passage through the immigration station. An abnormal appearance, however, meant a chalked letter on the back. Once chalked, a closer inspection was required—L for lameness, K for suspected hernia, G for goiter, X for suspected mental illness, and so on. (p. 37)

This process allowed for the discrimination and/or refusal of immigrants based on suspected impairments whether or not any impairment was present. The commissioner general of immigration in his 1907 report regarding the governing immigration laws essentially laid out that the primary reason for the laws was to exclude anyone with a disability or anyone perceived as having a disability. The commissioner wrote, “The exclusion from this country of the morally, mentally, and physically deficient is the principal object to be accomplished by the immigration laws” (Baynton, p. 34). In order to exclude those with physical disabilities, the regulations stated that inspectors were to observe individuals at rest and then in motion to detect any irregularities or abnormalities in gait. Again, the wording for excluding individuals was vague and granted the inspectors full discretion in excluding anyone they wished. Baynton write about an Ellis Island medical inspector who’s job was to “detect poorly built, defective or broken down human beings” (p. 34). A few examples of the physical impairments listed included spinal curvature, varicose veins, poor eyesight, hernia, flat feet, bunions, deafness, arthritis, hysteria and, simply, poor physical development. Once again, as with all age-old debates on eugenics, ethnocentricity, and exactly who are the weaker species, there was never any consensus.

During this period individuals were often excluded based on size or physical stature, or lack thereof, and abnormal sexual development. In addition, the commissioner and IRL, among others, were concerned about the public charge or becoming an economic drain due to perceived discrimination from employers in hiring. The surgeon general in a letter to the commissioner noted that such persons were:

a bad economic risk … known to their associates who make them the butt of coarse jokes to their own despair, and to the impairment of the work in hand. Among employers, it is difficult for these unfortunates to get or retain jobs, their facial and bodily appearance at least in adult life, furnishing a patent advertisement of their condition. (Baynton, 2005, p. 38)

In all, it is difficult to determine exactly how many immigrants were excluded either prior to or upon entering the United States. Baynton (2005) cites statistics that increased over the years and notes that the actual numbers were likely much higher. The number of
individuals excluded because they were likely to become a public charge or were mentally or physically defective in 1895 was 1,720, in 1905 the number was over 8,000, and by 1910 rose to over 16,000. Individuals from certain countries in particular were denied more often than others. Individuals from Slovakia were viewed as slow witted, Jews were seen as having poor physique and being neurotic, and those of Portuguese, Greek, or Syrian ethnicity were described as undersized (Baynton, 2005).

For those individuals who were somehow allowed entry to or were born in the United States with any type of perceived or real impairment, life was not generally favorable regarding societal attitudes. Specifically, Longmore and Goldberger (2000) noted court rulings where railroads and public transit systems were essentially granted permission to deny access to transportation for these impaired people. School laws were upheld segregating PWDs, not allowing them to attend school, or they were taught in a segregated room. Employers were also permitted to discriminate in hiring those with disabilities, and all public venues such as restaurants, theaters, and so on could deny access and frequently did so. For all intents and purposes, many of those with disabilities during the early 20th century were relegated to being shut-ins in their own homes, and when venturing out, were subject to ridicule and indignant comments.

PWDs were outraged by political and societal attitudes and the blatant efforts to prejudice and discriminate against them. For many, it was not only the negative attitudes of being devalued and dehumanized but also the discrimination of being excluded from the workforce. Longmore and Goldberger (2000) cite the historic accounts during the spring of 1935, after five years of the Great Depression, where a number of persons with physical and other disabilities demanded their voices be heard and protested against New York City’s Emergency Relief Bureau demanding jobs. Forming the League of the Physically Handicapped (LPH), this group focused on discrimination issues as opposed to their medical impairments. Media coverage back then was also largely discriminatory and prejudice. Longmore and Goldberger cite how media and popular culture portrayals during the 1920s and 1930s perceived PWDs as villains, victims, sinners, charity cases, unsightly objects, dangerous denizens of society, and unworthy citizens (p. 896).

Franklin D. Roosevelt was a member of the LPH, and although he largely hid his own paralysis from polio at age 39, he strived for the rehabilitation of those with disabilities. He epitomized what persons with a disability “can” do and is arguably one of America’s greatest presidents, having presided for 12 years over troubling times including the Great Depression, the signing of the 1935 Social Security Act, and being the successful Commander and Chief through World War II (Gallagher, 1994). In his book titled FDR’s Splendid Deception, Gallagher cites how Roosevelt was intuitively aware of the negative societal attitudes toward disability and aware that if the public knew of both the extent of his disability and chronic pain, he would be perceived as a weak, ineffective leader. As such, Roosevelt had agreements with the media not to photograph or film him in his wheelchair or while ambulating with his leg braces. Ironically, he did not really have a disability agenda and in fact tried to reduce vocational rehabilitation funding by 25%, which was ultimately not supported by Congress (Gallagher, 1994).

THE EUGENICS MOVEMENT IN AMERICA

Driving the early immigration acts ideology was Charles Darwin’s 1859 book The Origin of Species by Means of Natural Selection or the Preservation of Favored Races in the Struggle of Life, which initially set out to explain the concept of heredity in plants and animals. Darwin refrained from applying his beliefs to humans out of fear of the reaction from...
History of Treatment Toward Persons With Disabilities in America

the ruling religions. Sir Francis Galton, a cousin of Darwin’s, whose own studies primarily focused on mathematics and meteorology, was inspired by Darwin’s work and the implications of it. Galton applied mathematics to the study of heredity as a whole, and through this application Galton established not only some of the techniques of modern statistics but also the basis for what he later called “eugenics” (Pearson, 1995). Galton, who coined the term “eugenics” in 1883, believed that natural selection could rid mankind of problems such as disease, criminality, alcoholism, and poverty (Farrall, 1978). Farrall states that when Galton introduced the word “eugenics” in 1883 he did so with the following explanation:

We greatly want a brief word to express the science of improving stock, which is by no means confined to questions of judicious mating, but which, especially in the case of man, takes cognizance of all influences that tend in however remote a degree to give to the more suitable races or strains of blood a better chance of prevailing speedily over the less suitable than they otherwise would have had. The word eugenics sufficiently expresses the idea; it is at least a neater word and a more generalized one than viriculture which I once ventured to use. (p. 112)

The concept of eugenics reached America around 1900, and many prominent politicians, physicians, and academics in the United States agreed with Galton’s premise of essentially restricting the promulgation of those considered the weaker of the species. The notion of protecting and preserving healthy American bloodlines for the betterment of future generations was idealistic in theory and would later prove extremely difficult to implement. The central question contemplated for these powerful and predominantly Caucasian White males was to decide who exactly was the weaker species, and how exactly could these undesirables be restricted from bearing children (Marini, 2011a). President Theodore Roosevelt also embraced eugenics in the United States along with other highly influential people such as Alexander Graham Bell, John Harvey Kellogg, and J.C. Penny to name a few (Pearson, 1995).

STERILIZATION IN THE UNITED STATES

Evidence of eugenic ideals became more obvious with the passage of sterilization laws in the early 20th century, the primary goal of which was to “improve the quality of the nation’s citizenry by reducing the birth rate of individuals they considered to be ‘feebleminded’ ” (Largent, 2002, p. 190). The term “feebleminded” was used at this time to describe anyone with any type of observed or perceived mental or physical disability. Eugenics continued to gain strength and support through the first quarter of the 20th century with 27 of the 48 states adopting sterilization laws (Farrall, 1979). The state of Indiana was at the forefront of the sterilization movement, being the first to implement eugenic sterilization laws in 1907. Although the first sterilization law was passed in 1907, Osgood (2001) noted that unauthorized sterilization of the so-called defectives had already occurred in institutions in several states as early as the 1890s (p. 257). In 1909, the state of Oregon implemented eugenic sterilization laws, five years after Dr. Bethenia Owens-Adair had proposed sterilization in Oregon as a means of dealing with persons considered to be criminals and/or insane (Largent, 2002). Noll (2005) reports that the use of intelligence testing in the 1920s allowed medical and mental health doctors to more accurately identify “feeblemindedness.” As the years progressed, more states adopted eugenic sterilization laws, and as the United States entered World War II, the nation’s state mental health and prison authorities reported over 38,000 sterilizations (Largent, 2002, p. 192). In the 1920s, the most notable Supreme Court sterilization case was *Buck v. Bell*. In 1927, Carrie Buck, a 17-year-old Virginia girl became pregnant and was institutionalized by her foster parents in the
Virginia State Colony for Epileptics and Feeble-Minded. Carrie’s mother had already been committed and was deemed feebleminded and subsequently sterilized. Because Carrie’s mother was deemed feebleminded, Carrie was also deemed feebleminded and was sterilized as well. Carrie had a younger sister who, under the pretence that she was undergoing an appendectomy, was also sterilized as a result of her mother’s perceived mental capacity. Although there was no evidence to the accusations that Carrie Buck was promiscuous, the case went to the U.S. Supreme Court where Judge Oliver Wendell Holmes, Jr. reported in an 8–1 decision, that the state of Virginia was supported by its sterilization law and further stated, “three generations of imbeciles are enough” (Carlson, 2009, p. 178). The case of Carrie Buck was not an isolated incident at the time, and although other cases similar in nature were found in other states to be unconstitutional, Buck v. Bell was never overturned. Despite the injustice associated with forced sterilization of people considered to be developmentally disabled, mentally ill, or simply criminals, sterilization laws lasted well into the 1980s in some states (Largent, 2002). While there was a focus on eugenic sterilization laws, other laws that specifically targeted persons with mental and physical disabilities were being passed.

THE UGLY LAWS

Any person who is diseased, maimed, mutilated or in any way deformed so as to be an unsightly or disgusting object, or an improper person to be allowed in or on the streets, highways, thoroughfares or public places in this city shall not therein or thereon expose himself or herself to public view under penalty of one dollar for each offense. On the conviction of any person for a violation of this section, if it shall seem proper and just, the fine provided for may be suspended, and such person detained at the police station, where he shall be well cared for, until he can be committed to the county poor house. (Coco, 2010)

This is a City of Chicago ordinance, originally passed in 1881. Unsightly beggar ordinances passed between the years 1867 and 1913 were otherwise known as “Ugly Laws.” The first unsightly beggar ordinance was passed in San Francisco in 1867. Although these ordinances had been in place for 14 years prior to the passage of the Chicago ordinance, it is the most well known and considered “the most egregious example of discrimination against people with physical disabilities in the United States” (Coco, 2010, p. 23). The passing of these ordinances and laws allowed some insight into how disability was perceived. PWDs were generally thought of as burdens to society and lacked the ability to care for themselves or contribute in any way to society. This perception, however, was largely contingent upon one’s social standing and contribution to society (Schweik, as cited in Coco, 2010). While unsightly beggar ordinances were commonplace in cities throughout the country, Chicago’s unsightly beggar ordinance remained on the law books until 1973 (Coco, 2010).

Returning soldiers with various disabilities from World War II, however, was a good example of how some PWDs were perceived. For example, soldiers were often viewed with sympathy but were nevertheless respected because of their contribution, whereas a civilian born with a disability would often not be perceived in the same way. The Industrial Revolution in the United States further increased the number of Americans with disabilities, as factory workers began to sustain injuries leading to chronic conditions. Without effective workers compensation laws early on, injured workers had to sue their employers, with the vast majority often losing their suits for contributory negligence and for knowingly accepting the hazards of the job, otherwise known as “assumption of risk” (Marini, 2011b).
For some PWDs with facial or physical deformities, performing in circus freak shows became the only employment they could obtain. These PWDs appeared to be more highly regarded and were often considered to be prominent citizens despite the fact that in certain parts of the United States, where Ugly Laws were adopted, they were unable to show themselves in public.

**MOVEMENT TOWARD EQUALITY**

As disability discrimination and sterilization laws were being passed concerning PWDs, helpful legislation was also being passed. The 1920s brought about the Smith-Fees Act (P.L. 66–236), allowing services to PWDs such as vocational guidance, occupational adjustment, and placement services. In 1935 the Social Security Act (P.L. 74–271) was passed and the State-Federal Vocational Rehabilitation Program was established as a permanent program (Parker, Szymanski, & Patterson, 2005). Despite this early legislation and numerous additional laws over time designed to protect and employ PWDs in the workforce, the unemployment rate for PWDs has dismally held at around 70%. Yelin (1991) noted that the lowest unemployment rate for PWDs was actually during World War II since many able-bodied Americans were involved in the war and manufacturing jobs for the war effort increased dramatically. Once the war was over, however, men and women in the armed services returned home and thousands of workers with disabilities were displaced. There was a shift in who was entering the workforce in the United States (Longmore & Goldberger, 2000).

The year 1943 marked the passage of landmark legislation with the Vocational Rehabilitation Act Amendments (P.L. 113), essentially increasing the amount of state vocational services available to PWDs (Parker et al., 2005). The Vocational Rehabilitation Act Amendments also broadened the definition of disability, allowing persons with mental illness or psychiatric disabilities to be eligible for services. Disability rights continued to make progress for the next 30 years, without much fanfare, but unemployment rates remained relatively the same.

The 1973 Rehabilitation Act was also considered to be landmark legislation for PWDs, especially since President Nixon was considering abolishing the State-Federal Vocational Rehabilitation program altogether. After much debate and considerable outcry from disability groups, President Nixon signed into law what is believed to be the first civil rights laws for PWDs from which the 1990 Americans with Disabilities Act (ADA) was designed. Again, there was increased funding for public vocational rehabilitation programs and affirmative action in the hiring of federal employees (Parker et al., 2005). Sections 501-504 of the act also addressed access to transportation, removal of architectural barriers, and physical access to all newly constructed federal buildings. Perhaps, one of the most criticized aspects of the 1973 Act was the fact that there was no enforcement entity designed to check whether policies were being followed.

In 1975, the Rehabilitation Act was combined with the Education for All Handicapped Children Act (P.L. 94–142), now known as the Individuals with Disabilities Education Act or IDEA. IDEA allowed for opportunities such as equal access to public education for all children with disabilities in the least restrictive environment. IDEA also allowed for children with disabilities to be tested through multiple means, such as being tested in their native language. The law also gave parents the right to view their children’s school records (Olkin, 1999). The 1986 revision of IDEA extended services to provide early intervention for children from birth to preschool, help with equipment purchases, and legal assistance to families with children with disabilities (Olkin, 1999).

Perhaps the single most important legislation to date concerning the civil rights of PWDs was the 1990 passage of the ADA by President George H. W. Bush. The act contains five titles: employment, extended access to state and federal government services including
Historical Perspectives on Illness and Disability

public or paratransit transportation access, public accommodations for physical access to all public venues (e.g., restaurants, theaters, sporting events), access to telecommunications (e.g., closed captioning, theater audio loops), and a miscellaneous title. The ADA has arguably been deemed a success as far as making communities more accessible; however, there continues to be complaints and lawsuits filed daily due to employers and businesses that continue to knowingly or unknowingly discriminate (Blackwell, Marini, & Chacon, 2001). Some PWDs continue to see the glass as half empty regarding physical access and societal attitudes; others see it as half full (Marini, 2001).

CURRENT PULSE ON AMERICA REGARDING DISABILITY

Attitudes, physical access, and the laws regarding PWDs have unquestionably improved in the last century. The eugenics movement essentially died down after World War II, primarily due to Social Darwinism and the Nazi extermination of an estimated 250,000 German citizens and war veterans with disabilities (Marini, 2011a). In America, many eugenicists realized that this extremist version was essentially a slippery slope and that the continued forced sterilization and forbidding those with epilepsy, mental illness, or mental retardation from marrying, could potentially lead them down a similar path.

Current attitudes of Americans without disabilities toward those with disabilities suggest contradictory sentiments of both admiration and pity (Harris, 1991). Most likely influenced by media portrayals, the admiration sentiment can be easily explained when we watch a documentary on FDR, Wilma Rudolf, Christopher Reeve, or Stephen Hawking. Conversely, the pity sentiment occurs when one watches any televised charitable event, particularly Jerry’s Kids—Muscular Dystrophy Labor Day telethon. Although Americans generally believe that it is right to hire a qualified individual with a disability, many non-disabled persons still believe that PWDs are fundamentally “different” from those without disabilities (Harris, 1991).

As previously noted, how much better conditions and attitudes toward those with disabilities have gotten is open to debate. Although many outside observers anecdotally will argue that PWDs get free benefits and health care without making a contribution to society, others are quick to point out a different reality. Specifically, with an approximate 65% unemployment rate and two-thirds of those with disabilities indicating they would work if they could, this population has one of the highest poverty rates in America (Rubin & Roessler, 2008). Single minority females with children having a disability have the highest rate of poverty.

Although physical barriers and community access have improved exponentially since the 1990 ADA, several studies of persons with physical disabilities suggest that the United States still has a long way to go to become barrier free. Specifically, two recent studies have found that even 22 years after the ADA was signed into law, persons with physical disabilities still cite physical access barriers as the number-one frustration (Graf, Marini, & Blankenship, 2009; Marini, Bhakta, & Graf, 2009). Negative societal attitudes were not far behind in the rankings.

Eugenics has taken a different form in the twenty-first century. Today, scientists are improving medical technology to remove the so-called defective genes responsible for various neuromuscular diseases while an unborn fetus is still in the embryo stage (Marini, 2011a). Likewise, parents are now able to abort a fetus that may result in a child having a developmental disability and essentially start over. Designer babies are also on the horizon when parents will be able to select eye and hair color. In one extreme example of the quest for the perfect human, a playboy photographer auctioned off a
supermodel’s egg and 5 million people visited the website in one morning, offering $42,000 for the egg (Smart, 2009).

The survival-of-the-fittest concept and natural selection in the 21st century appear to have morphed into a survival of the financially fittest ideology. The ramifications of the 2008 great recession, continual middle-class decline into poverty, and historical government reaction recoil to cut social programs like Social Security, Medicare, and Medicaid, ultimately leaving those who need the most assistance to fend for themselves (Huffington, 2010; Reich, 2010). With the aging of America and millions of baby boomers moving into their golden years, their financial portfolio will dictate what the quality of their lives will entail like no time ever before in American history. Although Americans are living longer and healthier lives, those with disabilities and little income may face even greater precarious times ahead.

REFERENCES


12 | Historical Perspectives on Illness and Disability