

# Introduction

## Examining the Nexus of Race, Culture, and Disability

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### INTRODUCTION

As the ethnic diversity of the population in the United States has increased, so has the number of individuals with disabilities from diverse ethnic backgrounds (Fujiura & Yamaki, 2000). Despite this increase, the topics of race, culture, and disability have rarely been examined together. *Race, Culture, and Disability: Rehabilitation Science and Practice* seeks to fill this void by bringing together the work of leading rehabilitation and disability scholars that focuses on individuals with disabilities from diverse cultural backgrounds. Prior to the publication of this book, researchers, students, and practitioners in the field of rehabilitation have sought to address questions such as: Do the experiences of people of color with disabilities differ from those of White people with disabilities? And, if so, in what ways? What factors are related to poor outcomes for people of color with disabilities receiving vocational rehabilitation (VR) services? What approaches may improve the training of new generations of culturally competent rehabilitation practitioners? What approaches might improve the services provided by practitioners already in the field? What are the next steps for research in the nexus of race, culture, and disability? Given these and other questions, this book was developed with the purpose of informing researchers, graduate students, and practitioners in the field of rehabilitation about the status of current research and practice related to culturally diverse individuals with disabilities. The book also examines conceptual themes and the nature of disparities regarding access to services and rehabilitation outcomes for people from various cultural backgrounds, offering suggestions for research, practice, and teaching.

One of the main challenges of American society as we enter the 21st century is addressing and bridging ongoing differences among our people and moving toward cooperation and solidarity. Americans need to retake the spirit that so impressed Alexis De Tocqueville when he made his observations in 1835. He saw democracy as an equation that balanced liberty and equality, and that had concern for the individual as well as for the community. On the other hand, De Tocqueville also saw the

great injustices that permeated the social structure of this country when he considered the current and probable future condition of the three races that inhabited the territory of the United States at the time:

*The first who attracts the eye, the first in enlightenment, in power and in happiness, is the white man, the European, man par excellence; below him appear the Negro and the Indian. These two unfortunate races have neither birth, nor face, nor language, nor mores in common; only their misfortunes look alike. Both occupy an equally inferior position in the country that they inhabit; both experience the effects of tyranny; and if their miseries are different, they can accuse the same author for them (De Tocqueville, 1835).*

Today, racial differences have been exacerbated by growing economic inequality, leaving poor and underserved communities with limited access to quality employment, education, healthcare, transportation, housing, and other services that impact people's lives. Religious and political differences continue to make it difficult for people to communicate with one another. The dominance of ableism marginalizes people with disabilities and limits their access to employment and other opportunities for full participation in society. Given these many challenges, individuals and service systems need to take greater responsibility for changing the ways in which they interact with individuals with disabilities from different cultural backgrounds.

Racism and its legacy have proven difficult to eradicate. To begin to eradicate racism, individual- and systems-level awareness and knowledge are needed. People of all races need to become aware of their role in maintaining and challenging the status quo. Kivel (2002) makes a good point when discussing the responsibility of White people in a racist society. He says, "You did not choose your skin color, native language, or culture. You are not responsible for being White or for being raised in a White-dominated, racist society. . . . You are responsible for how you respond to racism" (p.12). But White people are not the only ones who discriminate. People of all races, classes, and colors discriminate against each other. African Americans of darker skin color are often looked down upon by those with lighter skin. I grew up in a society, like many others, that discriminated against people on the basis of many different features, particularly social class. People could be discriminated against not only for the color of their skin, but for the brands of clothes they wore, which were a symbol of class status. People were also discriminated against because of the way they talked, the neighborhood they lived in, the brand of car they drove, or the school they attended. Almost any aspect of life—including last names—could be used to set people apart from others and make them endure differential treatment. Disability—especially if it was visible—was another source of discrimination and marginalization. So, it becomes apparent the importance of one's culture and its influence on how we interact with each other.

As pointed out by Talley and Donnell (2007), “culture impacts all aspects of our lives, from the way we perceive ourselves, others, and our environment, to the way that we assess and respond to the situations and individuals we encounter” (p. 71). In American society, culture has gained prominence as we struggle with the issue of cultural assimilation versus cultural pluralism. Sue raised several important questions about this issue: Should we advocate Americanization of new immigrants or should we allow ethnic customs, traditions, and diverse cultures to flourish? Is it advisable for immigrants to acculturate in order to enhance functioning? Or should we advocate pluralism, promoting the co-existence of distinct cultural groups in society? There are no simple answers to these questions. Sue (2003) concluded that the environment in which people function has a direct effect on how comfortable people feel about their culture and their interactions with individuals from other cultures.

The growing cultural and racial/ethnic diversity of our nation forces us to engage with individuals who are different from us. Our degree of familiarity with people from various racial/ethnic and cultural groups depends, in part, on our degree of exposure to diversity, our willingness to notice and learn from others who may be different from us, and our desire to enrich our own perspective and culture. We struggle with the term *minority* because it has been associated with the notions of inferiority and deficits. Sue (2003) argues that “the concept of minority implies that a majority exists, but one could argue that the United States has no real ethnic majority groups because Whites can be classified as a mix of many different ethnic groups and Whites are not the majority in the world.” (p. xx). Sue emphasizes that the “minority” status of American Indians, African Americans, Asian Americans, and Latinos is not solely a function of their own cultures or of value discrepancies with mainstream Americans; rather, members of these groups have experienced historical and contemporary forms of prejudice and discrimination that led to their marginalization. Therefore, in this book we have used the terms “diverse” and “multicultural” to refer to the members of ethnic and racial groups in American culture.

Disability is another key human difference that has led to historical discrimination and marginalization. Devlieger, Rusch, and Pfeiffer (2003) indicated that people with disabilities have been portrayed and researched in many ways. These trends, they add, have been ideological, reflecting the role of history on the relationship between a universal phenomenon and a context from which the meaning of disability is constructed. Rehabilitation for individuals with disabilities is a process of helping them function as effectively as possible in their daily lives and helping them become independent and/or productive (Crabtree, Royeen, & Benton, 2006). To recognize that independence, we use the terms “person with a disability” or “people with disabilities.” These terms recognize that the person is primary and thus more important than the disability and that the individual is an independent human being and not fundamentally in the role of a patient, client, or consumer. Crabtree et al. suggest that cultural proficiency in rehabilitation is

necessary for practitioners in order to be able to effectively interact with individuals with disabilities from diverse ethnic/cultural groups and to be able to understand their personal wishes, beliefs, preferences, choices, expectations, and values. Crabtree et al. conclude the following:

*At best, the potential lack of agreement on basic values, beliefs, or attitudes complicates the issues that must be addressed for successful outcomes and confounds the rehabilitation practitioner's efforts to provide competent and effective services. At worst, conflict between ethnic and cultural beliefs, values and attitudes undermine the best intentions of rehabilitation practitioners and the efforts of consumers to lead lives that for them are consistent with their own ethnic and cultural beliefs and values. (p. 4)*

Despite the complexities of the topics of race, culture, and disability in the United States, there are very few books that are dedicated to rehabilitation research and practice as they relate to these topics. This book attempts to help researchers, graduate students, and practitioners address theoretical, practical, and research-based questions by helping them ground their future work in what we currently know about the intersect of race, culture, and disability and its implications for rehabilitation science and practice.

## **OUTLINE OF THE BOOK**

This book is the result of a process of engaging leading rehabilitation researchers in sharing their current work in a national conference organized by the Center for Capacity Building on Minorities with Disabilities Research at the University of Illinois at Chicago and held in Chicago in July, 2007. The conference brought together approximately 100 leading scholars in the field of rehabilitation of individuals with disabilities from diverse ethnic and/or cultural groups and related areas of study. The conference served as a working meeting in the preparation of the book as chapter authors engaged in discussion of their work. The resulting book is organized into four sections:

### **SECTION I: The Nature of the Scientific Research at the Nexus of Race, Culture, and Disability**

This section sets up the conceptual framework for the discussion of issues related to the nexus of race, culture, and disability. It provides an overview of how rehabilita-

tion researchers are addressing these issues and reviews the parallels between the development of African American identity and disability identity.

*Fujiura and Drazen* review the concept of research focused on the intersection of race and disability. Their analysis of the literature originated from a sense that disability and rehabilitation scholars have yet to engage in a systematic dialogue over the meaning of race and ethnicity in their research. The authors ask how research questions translate into different forms of thinking about the nexus of race, culture, and disability. This chapter examines in detail three possible responses to this question: (a) studies of the efficacy of an intervention on racial or ethnic minority samples; (b) studies in which race, disability, or a combination is implicitly framed as the independent variable; and (c) queries about how race, disability, or a combination moderates or mediates other cause and effect relationships.

*Gill and Cross* examine points of convergence, divergence, and interplay among racial/cultural identity development and disability identity development. The authors discuss three patterns of socialization and identity acquisition in the African American community (*viz.*, traditional, conversion as resocialization, and recycling). These patterns are contrasted with current research on disability identity development. The authors conclude with ideas for practice suggested by links between disability identity and black identity (e.g., acknowledging diversity within the group; accepting that disability can be a stimulus of community-building, pride, and culture; and considering in-group representation and issues of power).

## **SECTION II: The Nature of Disparities in Outcomes for People with Disabilities from Diverse Backgrounds**

This section has seven chapters, starting with analyses of issues that cross racial/ethnic cultural groups, like the appropriateness of psychological assessments for people of color, access to VR services for people of color, challenges for providing culturally appropriate care, and challenges in providing psychiatric care. The section ends with population specific issues, like employment challenges for Native Americans and women of color with disabilities, and the challenges in accessing VR services for Asian Pacific Americans with disabilities.

*Hernandez et al.* examine the appropriateness of four commonly used psychological tests when assessing people of color with disabilities [i.e., the Wechsler Adult Intelligence Scale (WAIS III); the Minnesota Multiphasic Personality Inventory (MMPI); the Rorschach Inkblot Test (RIT); and the Beck Depression Inventory (BDI)]. The authors consider the extent to which these tests have been standardized with

culturally diverse populations and examine the reliability and validity of the instruments. The authors also review the empirical studies related to these tests and the performance of multiethnic populations on the tests (namely African Americans, Asian Americans, Latinos, and Native Americans).

*Wilson and Senices* hypothesize that skin color could be a predictor of rehabilitation outcomes. In order to support their point, the authors examined data on Black Latinos' outcomes within the VR system. The authors discuss the implications of colorism in VR practice and research. They acknowledge the need to expand the research in this area, including more objective measures of people's skin color given that most studies utilize subjective measures (self reports) that could be unreliable.

*Hill-Briggs et al.* address issues that apply to the inpatient physical medicine and rehabilitation care of African Americans. First, they examine the challenges of diagnostic accuracy, appropriateness, and effectiveness of treatments with African Americans from the broader mental health literature. Second, they consider how to provide culturally proficient psychological care to African Americans in rehabilitation. Third, they offer three examples of promising health-related research directions leading to more effective assessment and intervention with African Americans. They suggest that these approaches can be adapted to rehabilitation settings serving people with disabilities. Finally, they propose a research agenda for further examining disparities and developing evidence-based practice for delivering effective care to African Americans in inpatient rehabilitation settings.

*Cook et al.* define cultural competence in the field of mental health and discuss six ways in which specific features of mental illness and its sociocultural context create challenges for mental health and rehabilitation professionals working with people with psychiatric disabilities from different cultures. These include: (a) cultural variations in the view of mental illness; (b) cultural diversity in help-seeking behaviors for mental health difficulties; (c) cultural variations in the use of language and verbal communication; (d) cultural attitudes toward the use of Western psychotropic medications; (e) lack of cultural diversity in the mental health workforce; and (f) use of indigenous healers for mental health problems. The authors argue that unless the fields of mental health and rehabilitation begin to address some of these issues specifically and concretely, attempts to assess and promote cultural competence will miss the mark and recovery of individuals with psychiatric disabilities will continue to lag behind that of individuals with other types of disabilities and medical conditions.

*Clay et al.* examine inadequacies in the infrastructure for supporting the employment of Native Americans and Alaska Natives with disabilities. They argue that these

challenges must be addressed to create sufficient employment and rehabilitation opportunities for tribal members with disabilities. They propose that this can be accomplished through partnerships across tribal sectors but warn that solutions cannot be imposed from the outside. Rather, tribes need to address gaps in employment infrastructure, including utilizing technical assistance to develop solutions that fit their circumstances, which are culturally relevant and respect tribal sovereignty. The authors propose the Tribal Disability Actualization Process (TDAP), which is a model for self-directed disability and rehabilitation service development.

*Smith and Alston* argue that there is a dearth of research focusing on issues of employment and rehabilitation of women of color with disabilities. Their chapter presents information regarding employment issues of women with disabilities. Also explored are issues concerning women, ethnically diverse individuals with disabilities, and women with disabilities in general. The authors propose a supply and demand approach for employment of women of color with disabilities. Finally, the authors make some suggestions for rehabilitation professionals regarding how best to address some of the issues faced by women of color with disabilities in a culturally sensitive manner.

*Hasnain and Leung* present an overview of the issues experienced by Asian Pacific Americans in dealing with vocational and other rehabilitation service systems. They start by pointing out the complexity of this racial category, which includes multiple and diverse countries of origin, different migratory experiences over time, and multiple variations in culture and ethnic identification. The authors consider the reasons why this group is underserved, under-reached, and under-researched, despite or perhaps in part because of the misconceptions about being the “model minority group.” They also examine cultural issues among these groups, such as beliefs about disability and perceptions of stigma and shame associated with it, reliance on the family for support, and the role of acculturation.

### **SECTION III: Models to Improve Rehabilitation Services for People with Disabilities from Diverse Backgrounds**

This section includes six chapters divided into two subsections. The first subsection includes three chapters and refers to *Models for training rehabilitation providers in post-secondary and professional training programs*. This includes the formation of future rehabilitation professionals in university settings and the training of students and professionals on ethical issues.

*Matteliano and Stone* identify educational approaches that could be effective in preparing future service providers to work with clients from other cultures. They

first review data on immigration trends and the ethnosocial composition within the rehabilitation profession, and then briefly review the definitions of cultural competence and some of the conceptual models that guide rehabilitation practice. The chapter also includes a brief review of measurement instruments of cultural competence, pointing out the scarcity of outcome measures in this area. The authors describe their approach for teaching cultural competence at the college level, which includes: (a) integrating cultural competency into existing courses; (b) developing a cultural competence curriculum that is profession-specific rather than generic; (c) utilizing multidisciplinary case studies for students to practice; and (d) making the materials widely available to instructors.

*Lewis and Shamburger* propose a three-factor model to help VR counselors determine what to consider in order to provide effective services to consumers who are culturally different from the counselor. The factors require counselors to consider: (a) the developmental stage of the consumer; (b) the stage of cultural identification of the consumer; and (c) the way in which the consumer defines optimal adjustment to the impairment. There are also some key activities that aid in establishing a positive relationship with the consumer by learning who the consumer is, and by determining the fit between the counselor and the consumer. The authors provide several strategies that counselors can use to implement the model with their current consumers and examples of model implementation with different consumer groups.

*Garcia* describes theoretical, ethical decision-making models and summarizes empirical research geared toward evaluating or testing these models from a multicultural perspective. The author discusses potential applications of these models, particularly the trans-cultural integrative model that he developed. He provides examples to illustrate how the model works and summarizes some of the main findings from an evaluation of the model with 60 VR counselors who participated in the study. Finally, the author addresses the implications of the current research for educators and practitioners, as well as the need to conduct research that expands knowledge about multicultural ethics.

The second subsection, *Models for rehabilitation practice*, also includes three chapters. These address models of cultural competence training of rehabilitation professionals in the field, a culturally and contextually grounded model for evaluation capacity building, and a systems approach to placement for culturally diverse individuals with disabilities.

*Balcazar et al.* provide a rationale for promoting cultural competence, analyze the various definitions of cultural competence, and conduct a systematic review of existing cultural competence models in the fields of health, counseling, and rehabilitation. The authors identified 18 cultural competence models and based on their analysis,



propose a model that synthesizes the most common components of the models identified in the literature. The authors also identified 23 factors that influence diversity (both observable factors such as race, gender, age, appearance, or physical disability and non-observable factors such as level of education, degree of acculturation, socioeconomic status, etc). The authors conclude that cultural competence is a process of “becoming” that implies both a desire and a professional obligation to effectively serve individuals from different cultures.

*Suarez-Balcazar et al.* provide a culturally- and contextually-grounded framework of evaluation intended to build the capacity of organizations to track outcomes for people with disabilities from diverse backgrounds. Based on an analysis of the literature, the authors proposed a framework for evaluation capacity building that includes organizational (viz., leadership, climate, learning, and resources) and individual factors (viz., readiness, motivation, and competence). These factors are grounded in contextual and cultural factors (viz., cultural competence, funders’ pressures for evaluation, changes in consumer’s needs, public opinion, and geographic location). The authors present an example gleaned from a community-based organization serving primarily Latino individuals with developmental disabilities. They conclude that the framework allows individuals to recognize the complexity of the cultural and sociopolitical environment that surrounds and influences the organization and its evaluation activities.

*Kundu and Dutta* describe a contextually sensitive systems theory as it is applied to the placement process of culturally diverse people with disabilities.. The process gives credence to two instruments: A Systems Approach to Placement: Self-Assessment by Students and Counselors (SAP: SASC) and the Systems Approach to Placement: Intake Assessment and Outcome Evaluation (SAP: IAOE). The SAP: SASC identifies the training needs of students and professionals of diverse backgrounds. The SAP: IAOE identifies the holistic service needs of individuals with disabilities. It also assists in developing a functional individualized plan for employment for optimal service delivery, and increases the probability of long-term placement outcomes.

## **SECTION IV: Integrative Commentaries**

This book is enriched by the perspectives of the scientists who conduct research, the practitioners who work with people with disabilities from diverse backgrounds and the students and recent graduates who have learned and want to learn more about this area of work. These perspectives are presented in three commentaries.

*Arango et al.* consider the potential impact of the chapters on the directions for future research and theory development in the field of rehabilitation. They conclude by emphasizing the need to focus research on individual, system, and community level changes regarding the services and supports provided to individuals from diverse backgrounds.

*Garate et al.* examine the practical applications of the chapters from the perspective of a VR counselor, two Centers for Independent Living advocates, and a special educator. They emphasize the importance of helping service providers address the needs of culturally diverse individuals with disabilities.

*Rodakowski et al.* reflect on the previous chapters in discussing opportunities and challenges related to conducting research with culturally diverse populations with disabilities and examine the implications for the training of future researchers and practitioners in the field of rehabilitation.

*Keys* concludes by reflecting on how the science in this important intersection of race, culture, and disability has clearly demonstrated major disparities in service access, retention, and outcomes for people with disabilities from diverse backgrounds. He suggests that current research, training, and practice can be improved by adopting and building upon the work presented in this book. This work involves integrating the complexities of disability into the research to complement the developing complexities in our understanding of racial and ethnic diversity. It also concerns integrating cultural insights about race/ethnicity and disability into our educational, practice, ethical decision-making, and evaluation activities in rehabilitation.

This book identifies disparities in outcomes for ethnically diverse individuals with disabilities, a critical challenge facing rehabilitation systems and professionals today, and suggests strategies to improve rehabilitation services for this population. This book is of interest to current rehabilitation scholars and graduate students seeking to understand research and practical issues related to race, culture, and disability. It is also of interest to those looking to improve rehabilitation services for individuals with disabilities from ethnic minority backgrounds. The book serves as the leading source on the research knowledge for scholars, faculty teaching courses on diversity issues, graduate students, and professionals who seek to understand the nature of the disparities in outcomes between individuals with disabilities from diverse cultural backgrounds and strategies for addressing these disparities. It is our intent that this volume will move the field forward and contribute to improving the quality of life of people with disabilities from diverse backgrounds.

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