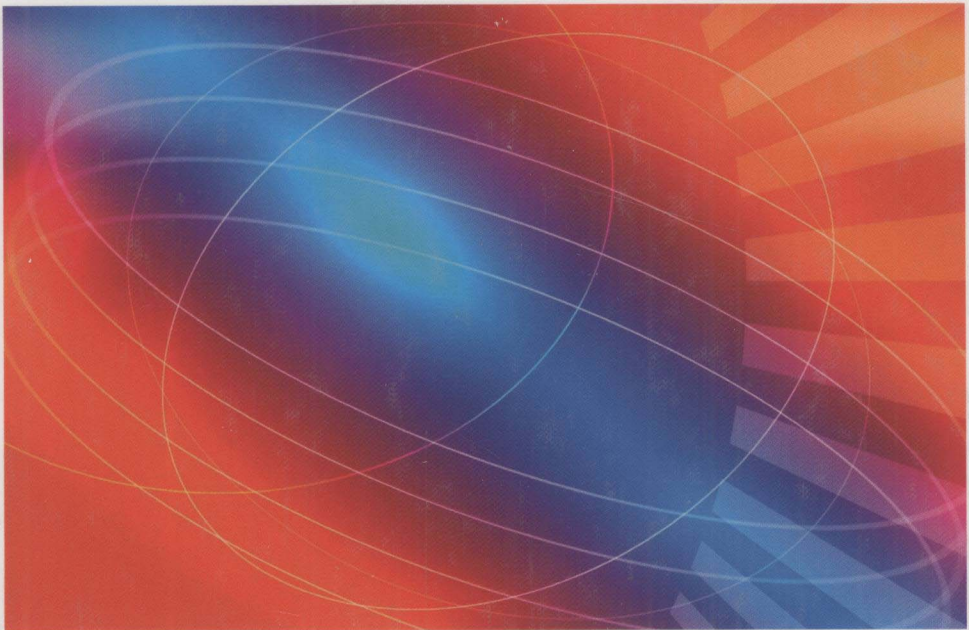


Culture and Disability

Providing Culturally Competent Services



John H. Stone
Editor

Multicultural Aspects of Counseling Series 21



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Providing Culturally Competent Services

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The State University of New York
Editor

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 **SAGE Publications**
Thousand Oaks ■ London ■ New Delhi

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For information:



Sage Publications, Inc.
2455 Teller Road
Thousand Oaks, California 91320
E-mail: order@sagepub.com

Sage Publications Ltd.
1 Oliver's Yard
55 City Road
London EC1Y 1SP
United Kingdom

Sage Publications India Pvt. Ltd.
B-42, Panchsheel Enclave
Post Box 4109
New Delhi 110 017 India

Printed in the United States of America

Library of Congress Cataloging-in-Publication data

Culture and disability : providing culturally competent services/
edited by John H. Stone.

p. cm.

Includes bibliographical references and index.

ISBN 0-7619-3083-3 (hardcover)—ISBN 0-7619-3084-1 (pbk.)

1. Minority people with disabilities—Services for—United States. 2. People with disabilities—Services for—United States. 3. Social work with minorities—United States. 4. Minorities—Services for—United States.

5. Ethnic attitudes—United States. I. Stone, John H. (John Henry), 1943-
HV1569.M55C85 2005

362.4'0453'08900973—dc22

2004011473

04 05 06 07 08 10 9 8 7 6 5 4 3 2 1

<i>Acquiring Editor:</i>	Arthur T. Pomponio
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Series Editor's Foreword

The Multicultural Aspects of Counseling series prides itself on demonstrating the generic importance of a “multicultural” perspective as the first step in developing competence as a service provider. John Stone’s book fits wonderfully into that tradition by presenting a valuable discussion and analysis of disability for the benefit of service providers who work with clients who are disabled or who are perceived by others as being disabled, whether they share that perception or not.

When I brought a team of two resource persons representing the perspective of people with disabilities into my classroom, they demanded from the beginning that the other students avoid using any term to describe persons with a disability other than *inconvenienced*, to emphasize the pejorative meanings society has attached to the alternative terms. Although we are forced to use the term *disability*, it is important to acknowledge the profoundly important feelings and emotions that society has attached to that and other similar terms. Stone’s book is sensitive to the meanings of words and to the importance of relationships in serving persons with a disability. Having a good relationship has emerged in the research literature as the single most important necessary—but not sufficient—condition for competence in counseling and human services. There is a consistent focus on the process variables as well as the content variables in a dynamic interdependent balance.

On one hand, there is the “culture of disability,” in which persons with a disability share a unique perspective with one another, acknowledge implicit rules for interaction, use a preferred vocabulary to express meanings, and have other markers of a cultural group that are perhaps unfamiliar to persons who do not have a disability. This unique perspective is celebrated and acknowledged by the community of persons with disabilities as a legitimate group in its own right, without reference to or judgment by those groups who do not belong. On the other hand, there is a treasure of information about similarities and differences in how disability is viewed and managed across the country-cultures of China, Jamaica, Korea, Haiti, Mexico, the Dominican Republic,

and Vietnam. Stone's book takes a global perspective of the topic, providing the reader with both an in-depth/narrow view of disability as a culture and a broad/comprehensive view of different ways disability has been interpreted across cultures.

There are many new ideas in Stone's book. Although the book is primarily focused on the "new immigrant," that construct shares many features with minorities in a society shaped by a unimodal dominant culture. Many of the same problems of language, housing, employment, understanding, and being fairly understood by service providers come up repeatedly. This problem is magnified when so few service providers are themselves from minority groups or are persons with a disability, including physical, occupational, and speech language therapists; vocational rehabilitation personnel; rehabilitation-technology specialists; rehabilitation physicians and nurses; special educators; staff of centers for independent living; and community service providers, in addition to those family members and friends who care for and about the person with a disability. Stone's book will help all service providers develop a competent and meaningful level of service to their clients generally as well as to persons with a disability.

The emphasis is on providing an educational process, but the target reader is not referred to as a "patient" or "client" but more likely as a "student" or as a "consumer," emphasizing the person's role as a user of services. Another important distinction is in the use of the term *culture brokering* as the process of facilitating and mediating between the culture of the consumer and the host-culture of the provider. The importance of service providers becoming directly involved in the helping process, rather than maintaining objectivity and distance in the pretense of neutrality, is rapidly gaining credibility as service providers become more activist and less passive when confronted by injustice.

We are proud to include Stone's excellent book among the library of books in the Multicultural Aspects of Counseling series. When I first read this proposal and later the book, my first thought was "This book will make a difference!" Stone's book will have an influence on those who read it, and there will be a ripple effect throughout the profession, moving the way human services are provided toward a better understanding of the consumer's cultural context.

Paul Pedersen

Preface

The theme of cultural competence has assumed an increasingly important role in the delivery of human services in the United States as well as in other countries with large immigrant populations. Disability services are no exception. Although there may be no universally accepted definition of the term *cultural competence*, the delivery of effective services to persons from other cultures requires an understanding of the ways in which culture may affect one's views of disability, as well as information about specific cultures.

This book attempts to contribute to both of these types of knowledge. The first three chapters describe the relationship between culture and disability as well as the role of service providers in communicating across cultures, whatever those cultures may be. The following seven chapters provide information about the specific cultures of groups that account for large proportions of recent immigration to the United States.

Portions of this book originally appeared as monographs written for disability and rehabilitation service providers. It soon became apparent, however, that many university programs were beginning to include cultural topics within courses that prepare professionals to work with persons with disabilities. This book, therefore, attempts to contribute to meeting the needs of both audiences—persons already working in disability services and students preparing for such careers.

I would like to acknowledge and thank the National Institute on Disability and Rehabilitation Research of the U.S. Department of Education for its support of the work of the Center for International Rehabilitation Research Information and Exchange (CIRRIE), through which much of the original material for this book was prepared. Special thanks are also due to Ms. Kathleen Wisniewski of the CIRRIE project for her dedication during the development of the original monograph series and during the preparation of this book. Ms. Wisniewski performed many tasks during that time, from tracking submissions, to incorporating editorial corrections, to occasionally cajoling procrastinating authors.

Far from intending to be the last word on this subject, I hope that this book will stimulate the generation and dissemination of further resources that will enable us to find better ways to meet the needs of persons with disabilities who have come from other countries.

John Stone, PhD, Director,
*Center for International Rehabilitation
Research Information and Exchange (CIRRIE)*

Introduction and Overview

Since the early 1980s, approximately a million persons have immigrated to the United States every year from other countries. Thirty years ago, approximately 1 in 20 Americans was born outside the United States. Today, the ratio is more than 1 in 10. Many of us can remember a time when contact with other cultures was considered the domain of diplomats, missionaries, and Peace Corps volunteers. Today, nearly everyone in the United States has a cross-cultural story to tell, and those who provide services to persons with disabilities are no exception.

Disability can be a challenge no matter where one is born. For a recent immigrant, the challenge is often magnified. In addition to difficulties with language, housing, and employment, the person with disabilities may also have difficulty understanding and accessing rehabilitation and other disability services. Most service providers recognize this but often experience frustration that arises from miscommunication and differing cultural perspectives. Providers can mitigate such problems, however, by recognizing obstacles that pose difficulties for the foreign-born consumer and identifying ways to overcome them.

Leavitt (1999) pointed out that although ethnic minorities constitute approximately 25–30% of the U.S. population, they make up less than 8% of the population of health and rehabilitation professionals. Although efforts are being made to recruit more service providers from other cultures, within the foreseeable future most foreign-born consumers will be served by professionals whose cultural backgrounds are very different from their own. Therefore, it is critical that all service providers understand how such differences can affect their services.

According to Groce (1999):

Understanding sociocultural models of disability is of more than academic interest. Unless programs for individuals with disabilities are designed in a culturally appropriate way, the opportunity to make real and effective change is often lost.

[The intent is not] to catalogue every known variation in disability beliefs, but rather to alert the practitioners to the fact that the ways in which disability and rehabilitation are conceptualized will have an impact on the manner in which rehabilitation professionals are received, regarded and able to serve their patients. (p. 38)

There are two types of understanding that are useful in providing effective services to persons from other cultures. One is knowledge about the specific culture of the persons with whom we are working. To provide practitioners with information about specific cultures and their perspectives on disability and rehabilitation, CIRRIE—the Center for International Rehabilitation Research Information and Exchange at the State University of New York at Buffalo—developed a series of monographs on the cultures of 11 of the countries from which most immigrants to the United States originate. Material from several of these monographs has provided the basis for the chapters in this book on the cultures of China, Jamaica, Korea, Haiti, Mexico, the Dominican Republic, and Vietnam.

The second type of understanding useful to those working in cross-cultural rehabilitation settings relates not to specific cultures but to the general process of working with persons with disabilities from different cultures, whatever those cultures may be. Several chapters offer insights and meanings that expand the reader's understanding of this process and help develop stronger and more effective cross-cultural skills. Although the focus of this book is on persons who have recently immigrated to the United States, many of the concepts also apply to persons who were born in the United States but are from a culture other than the dominant one.

Included in the term *disability service providers* are physical, occupational, and speech language therapists; vocational rehabilitation personnel; rehabilitation technology specialists; rehabilitation physicians and nurses; special educators; staff of centers for independent living; and community service providers. While providing examples from several fields, the authors of the chapters have attempted to avoid technical terminology specific to any one of them.

Throughout this book, we have generally used the term *consumer* to describe a person with a disability who uses the service system. We recognize that the term *patient* is commonly used in the context of medical rehabilitation and that *client* is often used in other rehabilitation fields. *Student* is the preferred term within special education. *Consumer*, however, is a generic term, and besides being the term preferred within the disability community, it expresses the notion that the person is a user of services and therefore is empowered to make the same kinds of choices and decisions as those who use other kinds of services.

The first chapter, “Immigrants, Disability, and Rehabilitation,” is by Nora Groce, one of the prominent scholars of cultural aspects of disability. A medical anthropologist specializing in disability beliefs and practices, Dr. Groce has identified many variations in disability beliefs among the cultures of the world. Her historical perspective of this field and her comprehensive vision of disability in a cross-cultural context provide useful starting points to a book such as this.

The second chapter, “Culture and the Disability Services,” examines the rehabilitation system in the United States and describes its cultural underpinnings. It also shows why some consumers from immigrant groups may find it difficult to identify with many of the cultural values and practices that they encounter when interacting with disability service providers. The authors of this chapter are uniquely prepared to write on this subject. Paula Sotnik has worked for many years with foreign-born persons from diverse cultures in the context of rehabilitation services. She has also been the lead trainer in the CIRRIE workshop series *Culture Brokering: Providing Culturally Competent Disability Services*.

The coauthor of the second chapter is Mary Ann Jezewski, an anthropologist who developed a model of culture brokering and adapted it for rehabilitation service providers. She defines culture brokering as the process of facilitating and mediating between the culture of the foreign-born person and the culture of the host country as well as the culture of the rehabilitation service system itself. It is this concept that forms the core of the third chapter, “Disability Service Providers as Culture Brokers,” also coauthored by Jezewski and Sotnik.

In speaking of a therapist’s role, Miles (1999) has written:

It is hardly the therapist’s job to try to change a client’s fundamental beliefs—to do so might be seen as unprofessional conduct. Yet for most therapists, their work is more than a bag of techniques and gadgets. The therapist cannot avoid some engagement with clients’ efforts to make sense of their disabilities, or those of their relatives. To listen attentively and with understanding requires the competent therapist to have some broad awareness of the range of human beliefs in the disability area, and at least an outward tolerance of some that may seem personally repugnant. One benefit of studying a little further is that it may be possible to hint at paths that would take clients toward a more positive position within their own belief system. (p. 55)

It is usually not possible for busy service providers to learn several new languages or develop a deep knowledge of all cultures. Nevertheless, if providers understand some of the basic principles and common themes of a culture, they will have a better sense of how their clients perceive disability and what they

consider to be appropriate goals and methods of rehabilitation. The next several chapters of this book examine cultural and disability from the perspectives of the cultures of seven prominent immigrant groups: China, Jamaica, Korea, Haiti, Mexico, the Dominican Republic, and Vietnam.

Although China is the most populous nation on our planet, historically, due to strict immigration quotas, Chinese immigration to the United States was limited compared with immigration from Europe. In recent decades, however, that has been reversed. Currently, China, including Hong Kong and Taiwan, is one of the principal countries of origin of immigrants to the United States.

Despite the large numbers of Chinese in the United States, most Americans have a very limited knowledge of Chinese language and culture. Therefore, like other recent immigrants, persons born in China may have difficulty using rehabilitation services in this country. The goal of the chapter “Best Practices: Developing Cross-Cultural Competence From a Chinese Perspective” is to provide an introduction to Chinese culture, focusing on information that may help rehabilitation service providers to better serve this population.

The author is very well qualified to write on this subject. A first-generation immigrant from the People’s Republic of China, Gloria Zhang Liu has worked with people with disabilities in various capacities, including those of counselor and bilingual case manager. These activities have given her a keen insight into the difficulties in bridging the cultural gap between the rehabilitation service provider and persons from China, as well as strategies for overcoming these difficulties. Most of the case examples presented in this chapter are derived from the author’s own experience.

Among the 10 principal countries of origin for immigration to the United States, Jamaica is the only one in which English is the principal language. Partly for this reason, Jamaicans in the United States are not always thought of as a distinct cultural group. They are often identified with African Americans, and it is sometimes assumed that they share similar values and perspectives. Jamaicans, however, have a distinct history and culture. Professionals providing human services to Jamaicans in the United States may benefit from an introduction to some of the basic themes that run through Jamaican culture.

Jamaicans are often stereotyped as carefree and fun loving. Although most Jamaicans do value a sense of humor, as well as music and dance, they also have a tradition of hard work and a strong respect for education. A history of slavery and resistance to it has resulted in an independent spirit that sometimes is manifested in a distrust of establishment organizations if these are perceived as intrusive. Health and other human services are sometimes not sought until there is a dire need.

The history of slavery, as well as poverty, has had an impact on family structure and gender roles. The need to seek employment in locations distant from their families, both within Jamaica and abroad, has frequently resulted in households run by mothers or grandmothers.

The chapter “An Introduction to Jamaican Culture for Rehabilitation Service Providers” reviews some of the historical influences on Jamaican culture and examines the cultural implications for the delivery of disability services to Jamaicans in the United States. The author of this chapter, Doreen Miller, was born in Jamaica and lived in both urban and rural Jamaican communities. She holds a doctorate in rehabilitation counseling and has been a faculty member in the United States for many years.

In 1997, 591,000 Korean-born persons were living in the United States (Schmidley & Campbell, 1999), making Korea one of the top 10 countries of origin for immigrants to this country. Despite various obstacles, many Koreans have been quite successful in the United States. The average American’s knowledge of Korean culture is very limited, however, and some first-generation Koreans do not have strong English language skills. The result is the possibility of miscommunication between the newly arrived and native-born Americans. Cultural and language barriers can arise between disability service providers and their Korean-born clients that may hamper the progress of rehabilitation.

The author of the chapter “Disability and Korean Culture” is well qualified to help American service providers understand Korean culture and the perceptions of disability and rehabilitation that prevail within that culture. Weol Soon Kim-Rupnow was born in Korea and is a faculty member and service provider. She also directs the National Technical Assistance Center for Asians and Pacific Islanders with Disabilities at the University of Hawaii.

Many persons have come to the United States from Haiti for economic reasons, to escape one of the poorest economies in the Western Hemisphere. Others have fled for political reasons. Haitian culture is quite distinct and less familiar to most Americans than many other cultures (Latino cultures, for example). Haitian culture and language are also quite distinct from those of other Caribbean peoples. Often, these distinctions are not recognized. Most persons in the United States have very little information about Haitian culture and history. Perceptions often are influenced by simplistic Hollywood depictions.

For disability service providers who work with Haitians, it is imperative to become familiar with the Haitian understanding of the nature of disability and the shame and social stigma that often are attached to those individuals in the Haitian community who have disabilities. These attitudes prevent Haitian families from seeking support and social inclusion of their sons and daughters in community activities and programs, and families may never take advantage of social programs and services that are available. Many children with

disabilities become socially isolated, and the families live a life apart from their community. Educators and health specialists who have an understanding of Haitian beliefs about disabilities will be in a better position to build bridges for Haitian families and to shape programs and services that account for their belief system. A better understanding of the nature of the social stigma that parents and children live with will also allow non-Haitian professionals to join forces with Haitian colleagues who are attempting to change their community's attitudes toward disability. Erik Jacobson, the author of the chapter "An Introduction to Haitian Culture for Rehabilitation Service Providers," is a literacy and community-based education specialist who has worked with the Haitian community of Boston for 9 years in a variety of capacities.

Mexico is by far the leading country of origin of immigrants to the United States. In 1997, more than 7 million Mexican-born persons lived in the United States, representing 28% of its foreign-born population. The immigrant population from Mexico is nearly six times that of the next highest country. The Mexican-born population in the United States increased from 0.8 million in 1970, to 2.2 million in 1980, to 4.3 million in 1990, to 7.0 million in 1997. (Schmidley & Campbell, 1999). In light of the large number of Mexican-born persons in the United States, it is surprising that Mexican culture is not well understood by many Americans.

The Mexican-born population differs from other foreign-born groups in the United States in several ways. Only 15% of U.S. residents born in Mexico are U.S. citizens. This contrasts sharply with the U.S. citizenship rates for persons born in Europe (53%) and Asia (44%), and even for those from other parts of Latin America.

Mexican-born persons in the United States tend to differ from other Latino groups in other ways as well. Forty-seven percent of all Latin American-born U.S. residents have a high school diploma. Among Mexican-born residents, the rate is 31%. Only 6% of the Mexican-born persons in the United States are employed in managerial and professional specialty occupations, compared to 23% of those from South America. The median annual earnings of U.S. workers born in Mexico were below those of workers born in the Caribbean or South America. The poverty rate for those born in Mexico is 34%, while for those born in South America it is 15%. Only 46% of the U.S. population that is Mexican-born has health insurance, compared to 69% for the Caribbean-born and 66% for South American-born. The average size of household was also larger for the Mexican-born (4.38 per household) than for those born in South America (3.17) (Schmidley & Campbell, 1999).

This profile indicates that many Mexican-born persons in the United States are poor, are not highly educated and lack access to many important services, even when compared to those from other parts of Latin America.

Individuals in such circumstances may experience difficulty accessing and using health, rehabilitation, and human services. It is particularly important that professionals in these fields develop at least some familiarity with Mexican culture if they are to provide effective services to this vast population in need of their services.

The authors of the chapter “An Introduction to Mexican Culture for Service Providers” are well qualified to interpret Mexican culture for rehabilitation service providers in the United States. Sandra Santana-Martin is a clinical psychologist who works with the Mexican farmworking community in a community health center in California. Felipe O. Santana is a clinical psychologist with 38 years of experience, including extensive experience with clients of Mexican origin.

Immigrants from the **Dominican Republic** are also among the 10 largest immigrant groups in the United States. Dominicans have settled largely on the East Coast of the United States. They are the second largest Hispanic/Latino group in New York City, with Puerto Ricans being the largest. Many persons in the United States identify the Dominican Republic as a land that produces great baseball players and as a country with tropical beaches. Few persons in the United States understand well the nature of the Dominican culture, the reasons for Dominican immigration to this country, or the difficulties encountered there. Rehabilitation service providers in the United States might be better equipped to work with Dominicans with disabilities if they were provided more information about Dominican views of the nature and origin of disabilities, the role of families, and other factors that can influence the success of disability services. The authors of the chapter “An Introduction to the Culture of the Dominican Republic for Disability Service Providers” are themselves immigrants from the Dominican Republic. Ana López-De Fede teaches and conducts research on the relationship between health and family well-being. She is actively involved in consulting on the development of programs that address the needs of individuals from the Caribbean basin. The second author, Dulce Haeussler-Fiore, came to the United States at the age of 37 and was surprised to see persons with disabilities working. She eventually worked as a case manager for 4 years and as a service coordinator for 6 years, as well as a clinician in a mental health clinic in Lawrence, Massachusetts.

In this chapter, the authors trace the history of Dominican emigration to the United States and its causes. Through numerous case studies, they demonstrate the impact of cultural variables on the experience of disability by Dominicans. They explain certain traits of Dominican families that have children with disabilities: the fear of children being removed from the home, shame over disability, and the tendency to hide children with disability. The authors also describe the great support and assistance provided by the families

to providers of disability services, once the families understand the system and the purpose of the services.

Since the second half of the 20th century, Vietnam has been a country very much in the American consciousness. Despite the fact that many Americans have been to Vietnam and despite the large number of immigrants who have come to the United States from Vietnam since the war, Vietnamese culture is not widely understood in the United States. Vietnamese culture is complex, having been influenced by many foreign invaders over the centuries. It has foundations in Confucian and Buddhist philosophies. Its collectivist worldview values group harmony over individual goals. Because Vietnamese patterns of respect differ from many American behavioral patterns, recent immigrants from Vietnam may often misunderstand American behavior and speech.

The purpose of the chapter "An Introduction to Vietnamese Culture for Rehabilitation Service Providers in the United States" is to help rehabilitation service providers to understand some of the main elements in Vietnamese culture, especially those that relate to disability. The author of this monograph, Peter Cody Hunt, is of Chinese origin but was born in Vietnam. He came to the United States when he was 9 years of age. His interest in disability stems from his own personal experiences as a person with an acquired disability. Over the years, he took the responsibility for arranging services for two other family members with disabilities. As a result, he became aware of the deficits and shortcomings in the health care delivery system and rehabilitation services, especially for persons with disabilities from cultural minorities.

The concluding chapter, "Understanding Immigrants With Disabilities," discusses some of the multiple factors that may simultaneously affect the immigrant with disabilities. One of these is the phases of culture shock through which most persons pass when they find themselves surrounded by a new culture. Another is the phases of adaptation to disability. The chapter also summarizes some of the values and perceptions related to disability and rehabilitation that seem to be common to many of the cultures of recent U.S. immigrant groups.

The author of this chapter is John Stone, who is also the editor of this volume. A member of the Rehabilitation Science faculty at the State University of New York at Buffalo, he is the Director of the Center for International Rehabilitation Research Information and Exchange (CIRRIE) and editor of the 12-volume CIRRIE monograph series on culture and disability. His interest in other cultures began as a Peace Corps volunteer in India in the late 1960s. It was further developed through a sojourn in Greece with the Experiment in International Living and through 17 years in Brazil as a faculty member in Brazilian universities. In those countries, he received guidance on several occasions from certain local individuals who instinctively understood that a person

from another land might need help in understanding and adapting to the local culture. These “culture brokers” served him as examples for understanding the need for similar guidance for recent immigrants in the United States.

The contributors share my hope that this book will be useful to service providers in their work with individuals from diverse cultures, especially those who are foreign-born. We are becoming an increasingly global community. It is our hope that the concepts presented in this book will help make all of us better citizens of that community, particularly in our ability to adapt services to meet the needs of foreign-born persons with disabilities.

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