# SOCIAL AND CULTURAL PERSPECTIVES ON BLINDNESS

## **Second Edition**

# SOCIAL AND CULTURAL PERSPECTIVES ON BLINDNESS

# **Barriers to Community Integration**

By

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We dedicate this edition to the memory of Kenneth Jernigana person who dedicated his life to improving the social and cultural situation of blind and visually impaired individuals.

### **PREFACE**

Much has changed in the world of vision loss and blindness during the past 20 years. Self-advocacy has become an increasingly important feature of organized blind movements in diverse nations around the world. The rapid development of technology enabling blind people to access written material in various forms has greatly expanded educational and employment opportunities. One unresolved challenge is the digital gap for blind people in general and for lower-income blind people in most parts of the world.

Many of the ideas in the first edition are still relevant. Each of the original chapters has been updated. In addition, there is a new chapter dealing with digital communication. This new edition is coauthored by Fredric K. Schroeder, Ph.D. Professor Schroeder has worked in almost every aspect of the rehabilitation and education of blind people. For seven years, under President William Jefferson Clinton, Dr. Schroeder served as Commissioner of the Rehabilitation Services Administration in Washington, D.C. Currently, he serves as the president of the World Blind Union, the Executive Director of the National Rehabilitation Association, Research Professor at the Interwork Institute, San Diego State University, and Policy Consultant for the National Council of State Agencies for the Blind.

Between them, the authors of this second edition have approximately 100 years of experience in dealing with almost every aspect of the education and rehabilitation of the blind and visually impaired. They have worked as researchers, teachers, program evaluators, and policy advisors in a wide array of public and nongovernmental organizations. Both have experienced the rehabilitation industry as consumers and as its critics. Each has been active at every level of the National Federation of the Blind in the United States. Hopefully, their joint experience further enriches this second edition.

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# SOCIAL AND CULTURAL PERSPECTIVES ON BLINDNESS

## Chapter 1

## WHY STUDY REHABILITATION AND BLINDNESS FROM A CROSS-CULTURAL PERSPECTIVE?

Blindness is a physical condition, and it brings with it certain limitations, but those limitations and their importance are greatly exaggerated by people who assume that blindness presents unsurmountable obstacles to education, employment, and social integration. At its heart the struggle of the blind for full integration into society is the struggle of all disenfranchised people to win social acceptance. The physical aspects of blindness can be managed. History is replete with examples of blind people who have found ways of learning, working, and living as others—blind people who marry, raise children, and participate actively in their community. History is also replete with examples of socially constructed limitations, limitations rooted in tradition and stereotypes that have denied blind children and adults their most fundamental civil and human rights. But rather than cursing the dark, we will show how the condition of the blind has been and continues to be changed and how blind people combat low expectations and assert their right to equal opportunity.

#### FROM POVERTY TO OPPORTUNITY

The last century has witnessed remarkable changes in the life choices available to many women and men who are blind. Some blind people around the world are well employed and are participating in their societies. Others struggle at the very edge of existence, continuing to live by receiving food and shelter from others. In many places, a life of mendicancy is the only way of earning one's bread. Hope abounds, but sometimes reality is brutal. Many blind people can identify with the sentiments reflected in the opening paragraph of Dickens's *A Tale of Two Cities* (1859): "It was the best of times, it was the worst of times, it was the age of wisdom, it was the age of foolishness, it was the epoch of belief, it was the epoch of incredulity, it was the season of light, it was the season of darkness, it was the spring of hope, it was the winter of despair, we had everything before us, we had nothing before us. . . ."

Dickens's words capture the condition of the blind around the world. For far too many blind people, it remains the worst of times but not for all. For some, it truly is the best of times, not perfect but better than at any time in history, and that is the foundation of hope–knowing that conditions can and do change.

It is difficult to be precise about the epidemiology of blindness. The World Health Organization produced the following data: 285 million people are estimated to be visually impaired worldwide, 39 million are blind, and 246 million have low vision. Eighty-two percent of people living with blindness are aged 50 and above. About 90% of the world's visually impaired live in low-income settings. (World Health Organization, 2014). On August 3, 2017 the British Broadcasting Corporation reported in a news article that the worldwide population of blind people will triple by 2050, mainly due to the demographic shift toward an aging population (www.bbc.com/news/health-40806253).

Some countries are so economically poor relative to others that almost no public resources are available for the education and rehabilitation of blind people. Even worse, the poorest nations are often those experiencing the highest levels of military and political conflict, where the situation of blind people is even more perilous. On the other hand, some nations, usually the most prosperous, have dedicated significant levels of private and public finances to improve the lives of blind people. In many instances, international and private nongovernmental organizations are sharing their wealth and philosophy about blindness with less economically developed countries. These organizations are transmitting their philosophies and programs where they are grafted on to local cultural traditions.

In the midst of all this, some blind people have become active participants in determining their own fates. Many individuals have thought

about issues of fairness, justice, human rights, and the full development of their human potential and have created organizations of blind people to pursue common goals. In some countries, the organizations are autonomous, well organized, and well financed by blind people themselves. In other places, organizations for blind people are still managed by outside interest groups and professions.

Why are there, almost everywhere in the world, barriers that limit the participation of blind people in their communities? To answer this question, one can analyze the unfolding of modern ideas and practices associated with blindness. Institutional arrangements and organizations develop over decades and even centuries. For example, the sentiments growing out of traditions of noblesse oblige and the Age of Enlightenment developed a rationale for separating blind people from others feared or reviled by society. For instance, asylums for the blind were created. At that time, asylums were viewed as a positive alternative to housing blind people in poor houses or with public offenders of all types. Special schools for the blind soon emerged to provide social and recreational services. These institutions and ideas received additional legitimization with the "medicalization" of blindness. During the twentieth century, the profession of medicine reached new status when it donned the mantle of being "scientific." The profession gained control of the use of medications and drugs through prescriptions. Physicians became the gatekeepers for admission to publicly provided services through medical examinations for visual acuity. "During this same time, the newly developing profession of social work provided its own rationale and understanding of what blind people needed to participate in society. Psychologists chipped in with research on how blindness affected the intelligence and personality" (Vaughan & Omvig, 2005, p. 10).

The French historian Michel Foucault, (1926–1984) devoted much of his work to analyzing the unfolding patterns of social domination—how ideas, discourse, and institutional arrangements become interconnected. He analyzed many different aspects of society, focusing on subgroups such as prisoners, the insane, and soldier recruits. Foucault was interested in the resulting or associated patterns of social domination. He was interested in how patterns of language facilitate social control. "It seems to me that the real political task in a society such as ours is to criticize the working of institutions which appear to be both neutral

and independent; to criticize them in such a manner that the political violence which has always exercised itself obscurely through them will be unmasked" (Foucault, p. 171). "Power" refers to the control that some have over others. It may become manifest in prison walls, or, as is more usually the case, in the minutiae of social arrangements. Foucault analyzed scientific discourse about sexuality during the Victorian era. He reviewed the rise of medical language, which gave increasing power to physicians, psychiatrists, and men, in general, over women. In the following quote from Foucault, we are substituting the word blindness for sex.

The object, in short, is to define the regime of power-knowledge-pleasure that sustains the discourse on human blindness in our part of the world. The central issue, then (at least in the first instance), is not to determine whether one says yes or no to blindness, whether one formulates prohibitions or permissions, whether one asserts its importance or denies its effects, or whether one refines the words one uses to designate it; but to account for the fact that it is spoken about, to discover who does the speaking, the positions and viewpoints from which they speak, the institutions which prompt people to speak about it and which store and distribute the things that are said. (Foucault, 1978, ibid., p. 11)

Social and cultural arrangements do change, as interest groups change and as blind people organize to define and promote their own interests. In 1984, the World Blind Union emerged as part of the effort to improve economic and social opportunities for blind people around the world. (See Chapter 8.)

The results of self-organization continue to ferment worldwide, spreading hope and optimism. But the pace of change depends on many conditions including the level of economic development, local cultural traditions about blindness, the particular historical "accidents" of a given country, different degrees of technological development, and the emergence of a growing number of well-educated blind people who are providing leadership in the struggle for self-determination. This book is about the social origins of these developments. It describes different perspectives regarding blindness and the social arrangements created for and by blind people. The viewpoints of blind people themselves receive prominent attention in this book.