Public Health Perspectives on Disability

Donald J. Lollar · Elena M. Andresen
Editors

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Epidemiology to Ethics and Beyond

Springer

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Dedication

This volume would not have come to be except for the vision and will of Allan Meyers. Dr. Meyers taught for numerous years at the School of Public Health at Boston University. His untimely death on Memorial Day weekend in 2001 while enjoying his hobby, mountain biking, came just as the planning stages for this book project were in full swing. We had talked often about the need to have disability included in the public health curricula across the country, and that public health could have a substantial impact on the health and well-being of people with disabilities—if only we could help the profession of public health reframe its view of disability. Allan was convinced that the best way to achieve this was to help each core area of public health find its application to disability. He was adamant about the need to immerse public health students in disability sensitivity and literacy activities, whether or not disability was their primary academic focus. He also envisioned a specific disability concentration within the public health curriculum. Allan was tenacious, unbridled in his enthusiasm, and willing to debate the merits of his plans in any setting. We hope this book provides some semblance of the product Allan envisioned so that public health students and professionals of the future will be better prepared to address the public health needs of all people, including those with disabilities.

Foreword

Disability touches most all our lives. Each of us during our lifetime will be challenged by disability ourselves or in the life of one we love or know well. In my case, I have experienced the challenges of disability and chronic conditions through good friends, such as my roommate in college with childhood diabetes and a lifetime friend who had polio as a child; my own family members, such as my mother with depression and my brother with Parkinson's disease; as well as numerous professional colleagues, several of whom have spinal cord impairments who use wheelchairs for mobility. I also have many friends who have children with special health care needs or disability, including those with physical, mental, sensory and cognitive impairments. Despite these disabilities and chronic conditions, all of these individuals live each day to their fullest by striving to do all functions of daily living well, maintaining good health, and participating in work and community events to the fullest. In most cases, they would say that they are no different than those without disabilities and do not want to be treated as if they have a medical illness or were different from others. Instead, they acknowledge that they have challenges but can do the things everyone else can do if they have the supports and services in their environments to enable them to function fully in all aspects of living, including work and play. And, with the right supports in their respective family and social environments, they can be very productive and have a good quality of life for a long lifetime.

My own views about disability have been shaped through the experiences and challenges of all these individuals with disabilities as they live each day of their lives. As a researcher and policy-maker, however, I have experienced a large disconnect from the experiences of individuals with disability and the larger public community, including those who formulate policies or conduct research regarding disability. Unfortunately, many are still using a narrow medically focused lens on disability and not addressing the larger societal context that is needed to support individuals with disability. Recently, a professional colleague with a physical disability that requires a chair told me that a senior leader in her field said to a younger colleague that one could not make it in the field if they had a disability that limited them to a chair. This discriminatory attitude about disability must be changed and the resulting stigma eliminated so that individuals with disability can thrive in all career paths.

Change in attitude and approach must happen first in the various disciplines, including medicine, that intersect with disability. A public health approach is needed to inform how all of us view and understand disability. Community-based, population-based public health approaches applied to disability will eventually lead to a transformation in the way disability is viewed by the public as well as to improved health and quality of life for all with disabilities. This text book explains the public health approach to disability from a variety of disciplinary and other perspectives.

Societal Importance of Addressing Disability

There are several compelling economic and social reasons why individuals with disabilities can no longer be ignored as they are needed for a productive and successful economy in the United States and globally. A well-educated and productive workforce is needed for a thriving world economy in the future. No longer can we afford to exclude individuals with disabilities and chronic illnesses from productive jobs and well integrated lives in the community. Globalization trends and aging demographics in the United States imply that every child and youth today should be prepared to be a member of a specialized workforce over their lifetime.

During the next few decades it is expected that there will be many fewer younger workers under 35 for every individual that turns 65, many of whom choose to receive social security benefits. The aging of the "baby boom" generation will increase markedly the number of elders in the next few decades. For example, the American Association for Retired Persons (AARP) reports that the population age 65 or older and the population age 85 or older will increase by almost one-half (48 and 43%, respectively) from 2005 to 2020 (AARP, 2006). This aging population of the future will have an increased incidence of chronic illnesses as well as physical and/or cognitive impairments. Currently, it is estimated that about a third (31%) of people age 65 and older has a physical disability, and one out of ten has a self-care disability (AARP, 2006).

In addition to the expected increase in the number of older adults with disabilities in our society, about one-fifth (19%) of adults today report a disability due to physical, cognitive or emotional problems (Kaiser Family Foundation, 2008). These disabilities can be attributable to chronic illness, intellectual or developmental disabilities, mental illness, injury, or other underlying conditions. Furthermore, the number and percentage of individuals with disabilities and/or chronic conditions vary by the type of condition (e.g., cognitive impairment, physical impairment, sensory impairment, etc.), geography (e.g., region, state, etc.) and various demographic characteristics (e.g., education, race, gender, age, etc.).

Another compelling reason to successfully address the challenges of disability is related to the medical and societal costs associated with disability. Currently, at least 50% of health care costs are spent on the approximate 20% of the population with disabilities or chronic conditions. This appears to be growing exponentially with the rapid increase of chronic conditions related to the increase in overweight and obesity in our country. The major costs of health care related to chronic conditions increasing must address issues associated with disability or supports needed for functioning in the preferred setting, the community. Currently, the majority of dollars spent on individuals with disabilities in the health care and social support systems are spent on expensive treatments and institutionalized settings such as nursing homes and habilitation settings.

The emphasis on community-based care and services, including the provision of environmental supports, must be accelerated with supporting policies at the local, state and federal levels. Major federal incentives and Medicaid demonstration programs, such as *Money Follows the Person* and *Systems Transformation* grants are needed to propel the funding of community-based options that empower individuals with disabilities to direct and fund the services they need to live productive lives, including full inclusion in work without fear of losing health or other benefits. More resources are needed "upstream" in the health care system to support more prevention and health promotion services for individuals with disabilities so that major complications and secondary conditions do not develop.

Implementation of the new health care legislation (The Patient Protection and Affordable Care Act), enacted in law in March 2010, must successfully address issues related to disability so that new approaches and attitudes towards disability are encouraged and financed. The new health care reform legislation offers opportunities for a public health approach to disability in the establishment of health outcomes, conduct of comparative effectiveness research, development of clinical and community prevention initiatives, implementation of health information technology in clinical and public health settings, and examination of cost control strategies.

Significance of Textbook on Public Health and Disability

This comprehensive textbook on public health and disability is a major breakthrough for the study of public health and the various disciplines involved in public health. Public health, the practice of social justice using science-based strategies to improve population health, has the approaches and congruence of mission that can propel research and advocacy related to disability in the future. The current inequities in access to prevention and intervention services and policies for individuals with disability are a major social injustice in the United States and globally.

The focus on disability from a public health perspective has slowly grown over the past two decades. For example, this relationship between public health and disability is acknowledged by the existence of 16 states having disability and health programs funded by grants from the CDC; and the first office of disability and health was formed in the Massachusetts Department of Public Health in 1997. In addition to the focus in state health departments, there is a newly established journal on disability and health, as well as a section focused on disability in the American Public Health Association. Finally, *Healthy People 2010* included an entire chapter of goals related to disability (Centers for Disease Control and Prevention, 2001).

This textbook is another major step in the establishment of a foundation for public health and disability within the United States. Donald J. Lollar has assembled leading public health experts in the various areas of public health to contribute to this volume which can be used in courses in schools and programs on public health. There are chapters for each of the core competencies required in the MPH curriculum: statistics and epidemiology, social and behavior sciences, environment and health services. In addition, there are chapters related to other key areas of public health: law and ethics, maternal and child health, and international health. This book can be used in any of the relevant courses in each of the areas of public health or can be used as a text for a course on disability.

The application of a public health perspective will facilitate a better understanding of the important roles individuals with disability can play in all aspects of social, political and community life. A public health systemic approach is needed to guide research, interventions, policies and advocacy related to disability in order to fully transform health and social systems. Each of the authors explores how disability is related to each of the core disciplines in public health. In many cases, it is clear how much needs to be done to embrace disability to move the field of public health and disability forward. From a lifespan perspective, public health and disability is in the infancy to toddlerhood stage. This basic text is an important contribution in the establishment of public health and disability as a key area of study in schools of public health.

Major Themes Related to Public Health and Disability

The authors of this textbook describe disability from their various viewpoints and disciplines, showing major points of overlap in perspectives and approaches as well as revealing areas of tension in how disability is defined and approached. They also reveal what needs to be done to integrate the study of disability in public health over time. These struggles and evolving approaches to the study of disability within public health are not surprising since public health has only recently begun to embrace disability as a focus area. The evolving transformation and integration of approaches to disability within a public health perspective will take time as the two fields are merged and approached in a unified population based framework that incorporates social determinants of health and a lifespan perspective.

The following observations or themes about disability and public health need to be addressed and understood more fully in the future. This textbook introduces the reader to these themes and suggests recommendations for the future in furthering research, interventions, and advocacy related to disability and public health.

- Disability does not equate to a medical illness or condition and must be considered in the total context of function within environmental supports. The shift from a medical focus is critical to understanding disability from a public health perspective. Given the influence and power of the medical system in the United States, this will take steady education and persistence to change how the medical profession and the public perceive disability. Public health professionals need to work closely with their clinical and medical colleagues to change attitudes and approaches to disability from the medical paradigm to a public health one.
- A lifespan approach to the study of disability must be embraced. Disability and public health can benefit from a life course perspective since many disabilities begin in childhood and exist into adult hood. In addition, the major transitions in one's life (e.g., entry to school, transition to adulthood, transition to "senior status," etc.) present special challenges for individuals with disability. Disability is uniquely impacted by each development stage in an individual's life resulting in differing expectations of one's family and community.
- Environmental physical and social supports are key to the definition and approach to disability and the transformation from a medical model. The chapter on environmental health fully explains how the concepts of environment are key to a public health approach. The most recent edition of the World Health Organization's *International Classification of Functioning*, *Disability and Health* (*ICF* [WHO, 2000]) fully embraces the environment in its framework for defining disability and functioning. This framework is consistent with the environmental health field and a social-ecological approach to improving population health. The importance of environment requires advocacy for changing environments to accommodate and support individuals with disabilities. The ICF framework supports the notion that it takes a village to support and address disability.
- Prevention in public health must go beyond primary prevention and reflect secondary prevention for individuals with disabilities. The presence of individuals with disabilities in planning prevention initiatives has refocused the prevention agenda in the states that have disability and health programs (http://www.aucd.org/template/page.cfm?id=597). A focus on prevention and health promotion for individuals with disabilities is a major in preventing additional morbidity and disability and improving quality of life for individuals with disabilities. Public health has a science-based and community centered approach to improve population health that will not only prevent disabilities but most importantly improve the lives of all individuals with disabilities in the future if these public health principles and approaches are applied consistently to the study and advocacy related to disability.
- Disability and public health is a global as well as national movement. Just as policy towards the inclusion of individuals with disability has been strengthened in the United States via the Americans with Disabilities Act passed in 1990, strong support for individuals with disabilities globally has been strengthened by the United Nations *Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities.* This first international human rights

treaty in the twenty-first century, established in 2007, the ICF framework, and international programs related to disability are described in depth in the chapter on international health.

- Education and awareness are a critical component of a public health strategy to transform how each of us views "disability."A major campaign is needed to eliminate the stigma surrounding disability so that an individual with a disability is seen as the person first. The campaign needs to include persons with disabilities who are thriving and leading productive lives in many areas. This stigma can also be reduced by inclusion of more individuals in the workplace and community activities.
- Disability should be considered as a major demographic descriptor and not a health outcome. Disability should be included as a descriptor in public health surveillance, management information systems and program outcomes in the future in order that disparities in health outcomes and social participation between those with and without disabilities can be documented and monitored. Just as public health currently focuses on health disparities among racial and ethnic groups and between those in poverty or not, there should also be a focus on inequities by the existence of a disability or not. The documentation of disparities in health outcomes can be used to improve programs and policies for individuals with disabilities. This approach to disability as an important demographic description was first recommended in Healthy People 2010 and fully discussed in the chapter on epidemiology and disability in public health.
- Public health departments at the federal, state and local level need to embrace disability in all its programs and policies. A major initiative funded by the Centers of Disease and Control has successfully funded programs for disability and health in state health departments since the early 1990s. These programs have established offices and coordinators for disability and health, developed and implemented health promotion programs for individuals with disabilities, and established disability descriptors in public health surveillance systems. Public health departments should develop policies and programs using the three core functions and ten essential services in public health. These core activities are described fully in the chapter on environmental health and disability.
- Schools and programs in public health should include the study of disability in core courses for the Masters of Public Health (MPH) as well as other courses in the public health curriculum. This text book includes chapters for each of the core areas of public health as well as those for key specialized areas of public health (e.g., maternal and child health and international health). In addition, schools of public health should consider including a track on disability and public health.
- Statistical and epidemiological methods need to be developed to be used in research and evaluation related to individuals with disabilities. For example, consistent and "standardized" approaches to the definitions of disability across the lifespan need to be developed and used consistently in public health research and surveillance systems. More consistent use of the ICF in public health policies, programs and research could help to standardize a public health approach to disability.

- Individuals with disabilities need to be involved in all things affecting them. Adopting the principles and concepts of community-based participatory research are critical to all programs and research related to individuals with disabilities. Inclusion of individuals with disabilities will lead to changes in attitudes and reduction in stigma as well as the implementation of policies and research that will lead to the most productive and healthy outcomes for individuals with disabilities.

In summary, this textbook is a valuable resource about the emerging field of public health and disability. The adoption and use of this textbook will enable the study of disability policy, program and research from a public health perspective. Inclusion of disability in public health courses will hopefully lead to more awareness and less stigma about disability as well as better health outcomes and functioning for individuals with disabilities. One hope for this textbook which focuses on public health and disability is that it may play a modest role in creating the twenty-first century as the "Age of Disability" – the century in which the medical illness approach to disability is disbanded as there is a growing recognition that addressing the environments of persons with disability are needed to improve health and functioning.

Deborah Klein Walker

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Preface

In 1997 the Office on Disability and Health (ODH) was created in the National Center for Environmental Health (NCEH) at the US Centers for Disease Control and Prevention (CDC). Under the leadership of Dr. Richard Jackson and Bill Parra, NCEH was venturing into new public health territory. The original emphasis at CDC relative to disability had been the traditional public health approach – preventing conditions and risk factors associated with disabling conditions. Disability was seen as the third outcome or worse, as part of all three negative public health outcomes that primary prevention activities were created to address – mortality, morbidity, and disability. This program, called Disabilities Prevention Program, had provided funds mostly for primary prevention activities related to injury prevention (seat belts, for example), chronic disease management and primary prevention for conditions like arthritis, and birth defects prevention related to fetal alcohol syndrome, neural tube defects, and developmental disabilities. All of these activities are important and worthy activities, but in fact, were already a part of major CDC programs and funding streams – the National Center for Injury Prevention and Control, the National Center for Chronic Disease Prevention and Health Promotion, and NCEHs Division of Birth Defects and Developmental Disabilities.

ODH, on the other hand, focused on health promotion and preventing secondary conditions of people already living with disabling conditions. This perspective was so new for CDC and state and local public health agencies that it was clear that internal and external education and experience, and time, were needed to add this approach and this population to public health awareness. Two state public health agencies, the Massachusetts Department of Public Health and the North Carolina Department of Public Health, had already begun to address health and secondary condition prevention with units that included disability and public health together. Led by Dr. Deborah Klein Walker in Massachusetts and Marcia Roth and Donna Scandlin in North Carolina, these programs led the way in highlighting the public health importance of this population. A basic premise of this emphasis challenged a long-held assumption by public health professionals that the presence of a disability equals illness. The notion that people living with disabling conditions can be healthy was and, often continues to be both counter-intuitive and ill-conceived. The new direction, however, found traction and advocates in states working with this population.

In addition to the emphasis on health promotion and preventing secondary problems, three other major changes were made in the OHD programmatic emphases. First, when disability is conceptualized beyond diagnostic boundaries and with an eye toward health promotion, there are fewer distinctions to be made by diagnosis. The way people function in their lived experience is a broader and more inclusive approach to deciding what health promotion approaches will be most universally applicable for people with diverse disabling conditions. Introducing a functional model to complement diagnosis was a challenge in the early years of public health disability that continues up to the present. The World Health Organization's (WHO) classification of functioning (the *International Classification of Functioning, Disability and Health* (*ICF*)) was approved in 2001 and is continuing to grow as a framework for identifying common characteristics across diagnostic groups for the purpose of more efficient and effective surveillance, research, and health promotion interventions. Related to this emphasis was the acknowledgment that environmental factors play an important role in the health and well-being of this population – perhaps even more than the general population. Public health professionals like Dick Jackson intuitively understood that a broader definition of environment that included physical barriers, societal attitudes, and policies should be a part of the public health agenda. Finally, there was a major emphasis placed on improving the science of disability in public health. This direction meant addressing the issues of definition of disability, which was the core impediment to consistent case definitions in surveillance and surveys, and research. With these new perspectives came a need for different thinking. In the present volume, some of the early disability public health educators, researchers, and practitioners further elaborate the journey and resulting thinking of the journey of disability and health in public health.

It became clear that with this new emphasis brought a new challenge to public health education. There were few, if any, individuals trained in traditional public health programs who understood the issues affecting the health and well-being of people with disabilities. Into this challenge came Dr. Allan Meyers, Professor of Public Health at Boston University. Dr. Meyers brought to the attention of the CDCs ODH the need for courses in the public health curriculum to address the varied problems of this population. He championed the need for courses that would include disability issues across the core public health areas and the need for specific courses addressing disability issues and including examples of people with disabilities. As a result, Dr. Meyers received funding from CDC to survey schools of public health to describe the status of disability-focused courses. The results of that survey of the members of the Association of Schools of Public Health showed the lack of attention given to this area of study (Tanehaus, Meyers, & Harbison, 2000). A small conference after that study produced the first attempts to identify an approach to infusing disability into public health curricula.

Dr. Meyers, along with a team from Oregon Health and Science University, successfully competed for funding from CDCs ODH to develop materials for disability in schools of public health. The OHSU team, led by Drs. Charles Drum, Gloria Krahn, and Hank Bersani published the first book on disability and public health in 2009 – *Disability and Public Health.* The emphasis in that volume is on what public health professionals should know about disability issues. This volume, on the other hand, emphasizes the place of disability in each of the core areas of public health, as well as major emphases and common cross-cutting competencies taught within public health curricula (Institute of Medicine, 2003). The books are complementary, and provide different emphases. The two titles reflect the difference in attention – *disability* and public health for the one; *public health* and disability for the other.

Dr. Meyers had framed the potential chapters and had recruited an initial group of chapter authors. When Allan died, a long-time colleague, Dr. Debbie Allen, who had just come to Boston University from the Massachusetts Department of Public Health, took responsibility for the pioneering book effort. Dr. Allen recruited Whit Garberson, a maternal and child health professional, to assist her in coordinating the work. Mr. Garberson worked with Dr. Allen until his death in 2008. At this point, the authors who had committed to writing chapters were finishing the initial drafts of their chapters. As one can see, this volume has had substantial obstacles to overcome. It is because of the dedication and commitment of all these individuals, however, and the importance of the topic that this volume must be completed. Drs. Lollar and Andresen have been involved with this project from the beginning, Dr. Lollar as the CDC project officer and Dr. Andresen as the author of the epidemiology chapter.

Framing disability issues for public health training is a more delicate balancing act than might be immediately evident. On the one hand, the public health profession has, as mentioned previously, conceptualized and implemented science, policy, and practice on the assumption that disability is a negative health outcome to be prevented. Therefore, the disability emphasis must acknowledge this tradition, but help the public health profession and its academic foundations to accept broader health-related assumptions and draw different conclusions. The emphasis, then, is on showing how the various public health competencies and academic areas can be enhanced by including disability.

On the other hand, out of sight of the public health community, there is a strong disability community that emphasizes an area of study and influence called "disability studies." From the disability studies perspective, public health is yet another area insensitive to disability issues. Professionals in public health need education about the range of disability issues including the history of the movement for civil rights, the discrimination of this minority by the society, the need for advocacy in policy related to health care access and disparities, as well as general disability policy. This framework is similar to that taken in curricula focusing on women's studies, Latino or African-American studies. This is an altogether appropriate area of academic study. While this approach is a useful point of view for any student or professional, it often does not provide sufficient depth for a specific profession such as public health. Balancing the need for a disability perspective with the need for public health content in the major areas of academic preparation has been the intent of this volume from the time it was conceived by Dr. Meyers.

Finally, the relationship between disability and rehabilitation can be confusing because professionals in rehabilitation – whether medical, rehabilitation, educational, or psychiatric – can equate the rehabilitation process with disability. Rehabilitation is a set of services and programs that address specific areas of dysfunction of individuals who experience disabling conditions. It is usually time-limited and focuses services in a specific setting. Disability, on the other hand, describes the lived experience of the person and is substantially broader than the rehabilitation services or programs. Rehabilitation professionals, as well as public health professionals, can mistakenly assume that working with individuals with disabling conditions in a rehabilitation setting equates to working in disability. While it is accurate to describe rehabilitation as part of the experience of those living with disabilities, their experience outdistances the rehabilitation process. Public health has the opportunity and responsibility to address the array of issues related to the health and well-being of this population. This volume attempts to address those areas and specific tactics for introducing disability to public health professionals and those training in this discipline.

Public health culture is changing, as the history above and as this volume demonstrates. The place of disability in our popular culture also is changing – in some areas dramatically. Three examples we find useful in teaching about the changing view of disability are described below.

The first example is from the nearly universal appeal of annual Super Bowl® commercials that in themselves become fodder for popular cultural icons. In Super Bowl® 2008 there was a wonderful commercial for Pepsi using deaf men to make a comical point on hearing (To see the commercial and a "making of" the video, visit http://www.youtube.com/watch?v=cD7uLrjKpuY). Two deaf guys are trying to find a friend's house for the Super Bowl football game and use the example of bothering hearing people with their car horn to locate the house of their deaf friend. The ad portrays the deaf community in a realistic way that also makes light of the hearing community's responses to sound.

The second example is based on the iconic Barbie® doll. Barbie® is universal and there are Barbie dolls that appeal to many whims and groups. So of course there is a wheelchair Barbie® who was introduced in 1997 (called Share A Smile® Becky®), although the expensive model Barbie dollhouse was apparently not accessible and required some redesign (see the Los Angeles Times; White, 1997). Does it bring a smile to our faces to find humor and universal appeal with disability images? We hope so.

The third example is based on the popularity and appeal of public figures and events that feature images of successful people with disabilities. The growing interest in the Paralympic Games that follow the Olympics games, the inclusion of actors living with disabling conditions in movies and television shows, and the continuing changes in city planning, architectural design, and policy changes across levels of government attest to the changes in our society. Attention to this population in public health curriculum will be an additional step in breaking out of traditional ways of defining this population.

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About the Authors

Donald J. Lollar, Ed.D., is Professor of Public Health and Preventive Medicine, Division of Health Services, at the Oregon Health and Science University. He also directs the University Center for Excellence in Developmental Disabilities at OHSU. Prior to coming to OHSU, Dr. Lollar was a Senior Health Scientist in the National Center on Birth Defects and Developmental Disabilities (NCBDDD) at the US Centers for Disease Control and Prevention (CDC) in Atlanta, Georgia. During his 13 years at CDC, Dr. Lollar served in a variety of leadership positions at the CDC/NCBDDD including directing the Office on Disability and Health and the Office of Extramural Research. His most recent writings include editing *Launching into Adulthood*, a book on transition for adolescents, and articles for the Annual Review of Public Health, Public Health Reports, the Journal of Developmental and Behavioral Pediatrics, and Rehabilitation Psychology. He has been a leader in the development and implementation of the *International Classification of Functioning*, *Disability and Health* (ICF). He was a practicing psychologist for 25 years before being recruited to the CDC. Dr. Lollar received his graduate degrees (M.S. and Ed.D.) in Rehabilitation Counseling from Indiana University.

Elena M. Andresen, Ph.D., is Professor and Chair of the Department of Epidemiology and Biostatistics at the University of Florida's College of Public Heath and Health Professions. Dr. Andresen received her Ph.D. in epidemiology from the University of Washington. She is a disability epidemiologist, with research interests in chronic disease among older adults, disability, and outcomes research in rehabilitation and disability. She is the Director of the CDC-funded Florida Office on Disability and Health. Dr. Andresen served as a committee member on the Institute on Aging committee on "Disability in America." She has many years of graduate teaching experience, including epidemiology methods courses and disability epidemiology courses.

Dr. Deborah Allen directs the Bureau of Child, Adolescent and Family Health at the Boston Public Heath Commission (BPHC). She is responsible for programs addressing birth outcomes and early childhood wellbeing, youth health and development, women's health, and prevention of violence affecting children, youth and families. New programs developed since her arrival at BPHC in 2008 address the needs of Boston children with autism spectrum disorders and of young children with special mental health or behavioral needs. Dr. Allen came to BPHC from Maternal and Child Health at the Boston University School of Public Health, where her research and teaching focused on family-centered care for children with special health care needs. She continues to teach a course on this topic at BU and to provide consultation to the BU-based Catalyst Center, a national center on financing of care for children with special health care needs. Dr. Allen served as the Massachusetts Title V Children with Special Health Care Needs Director from 1991 to 2002. During that time, she reconfigured the CSHCN program to address needs of adults, as well as children, with disabilities. Dr. Allen has master's degrees in Health Policy and Management and Maternal and Child Health and a doctorate in Maternal and Child Health from the Harvard School of Public Health.

Dr. Jerome Bickenbach is a professor in the Department of Philosophy and Faculties of Law and Medicine at Queen's University, and is currently the Unit Head of the Disability Policy Unit of the Swiss Paraplegic Research centre in Nottwil, Switzerland. He is the author of *Physical Disability and Social Policy* (1993) and the co-editor of *Introduction to Disability* (1998), *Disability and Culture*: *Universalism and Diversity* (2000), *A Seat at the Table*: *Persons with Disabilities and Policy Making* (2001), *Quality of Life and Human Difference* (2004), and numerous articles and chapters in disability studies, focusing on the nature of disability and disability law and policy. He was a content editor of Sage Publications' 5 volume *Encyclopedia of Disability*, and is the author of the upcoming Sage resource volume on Disability Law, Policy and Ethics. His research is in disability studies, using qualitative and quantitative research techniques within the paradigm of participatory action research. Most recently his research includes disability quality of life and the disability critique, disability epidemiology, universal design and inclusion, modelling disability statistics for population health surveys, the relationship between disability and health, and the ethics and policy implications of summary health measures, disability and bioethics, disability and ageing, and international human rights and anti-discrimination law and policy. As a lawyer, Dr. Bickenbach was a human rights litigation, specializing in anti-discrimination for persons with intellectual impairments and mental illness. Since 1995 he has been a consultant with the World Health Organization working on the revision of the ICIDH, from alpha and the beta drafts, to the final draft leading to the ICF. He has participated in nearly all revision activities, and continues to consult with WHO on ICF dissemination and international disability social policy.

Erin DeFries Bouldin, M.P.H., is a Lecturer in the Department of Epidemiology and Biostatistics at the University of Florida's College of Public Heath and Health Professions. She received her MPH in epidemiology from the University of Florida, Gainesville. Her training and research interests include disability, nutrition, and maternal and child health, and her current work focuses on the health impacts of caregiving and improving the health and quality of life of Floridians with disability through the Florida Office on Disability and Health.

Dr. Charlie Bullock has been involved in issues of recreation and disability throughout his career. He has taught undergraduate, graduate, and professional courses on general disability issues and disability policy. Dr. Bullock is Professor and Dean of the College of Applied Sciences and Arts at San José State University (SJSU). He came to SJSU in January 2009 from the University of Nevada, Reno (UNR) where he had been the Dean of the College of Health and Human Sciences. Prior to UNR, Charlie had been on faculty for 17 years at the University of North Carolina at Chapel Hill. He received his Ph.D. at the University of Illinois at Urbana-Champaign in 1984. Dr. Bullock was founder and director of the Center for Recreation and Disability Studies at the University of North Carolina at Chapel Hill (UNC-CH) He is past president of the National Consortium of Physical Education and Recreation of Persons with Disabilities and a Fellow in the Academy of Leisure Sciences. He has written, presented, and consulted extensively in the area of disability and health. During his professional career, Charlie has received over seven million dollars in grant funding to conduct training, research and demonstration projects in the area of disability and health. He has authored two books and published over 65 articles in refereed journals. In addition, he has authored 19 training manuals and has produced four videotapes. He has made over 100 presentations at local, state, national, and international professional conferences.

Dr. Mary Chamie, private consultant with Population Associates, Inc., is the former assistant director of the United Nations Statistics Division and Chief of Branch of Demographic and Social Statistics. She coordinated the development of internationally agreed standards and methods for the collection of official demographic and social statistics through the use of population and housing censuses national household surveys and civil registration systems. She has worked extensively in the area of statistical classifications, with special attention to human functioning and disability. Dr. Chamie developed the international statistical program on disability for the United Nations Statistics Division and since her retirement from the United Nations continues to lecture and consult on this subject matter. She has published numerous reports and articles on disability in scientific journals and has also prepared a series of books and reports on human functioning and disability under the authorship of the United Nations.

John E. Crews, **D.P.A.**, has over 30 years of experience in vision rehabilitation and research. He managed a clinical program for older people with visual impairments in Michigan between 1977 and 1992. He then became the Acting Director of the Rehabilitation Research and Development Center on Aging at the Department of Veterans Affairs in Atlanta. After that, he served as the Executive Director of the Georgia Governor's Council on Developmental Disabilities. In 1998, he joined the Centers for Disease Control and Prevention in Atlanta. Dr. Crews' specialties are vision impairment and aging and caregiving and disability his research interests also include health disparities among people with disabilities and aging with a disability. He has nearly 100 publications, including recent papers in the *American Journal of Public Health* and the *Annual Review of Public Health*. His first book, *Vision Loss in an Aging Society*, was published in 2000 and translated and published in Japan in 2003. His second book, *The Multiple Dimensions of Caregiving and Disability*, will be released in the fall 2010 by Springer. He has entries in the *Encyclopedia of Disability* and the *International Encyclopedia of Public Health*. He has served on the Board of Trustees of the American Foundation for the Blind and on board committees of Lighthouse International. He was board chair of the National Literacy Center of the American Foundation for the Blind in Atlanta. He currently serves on the Editorial Board of the *Journal of Visual Impairment and Blindness*, and he serves on the National Commission on Vision and Health. He has provided Congressional testimony three times to advance services for older people with vision loss. His work has been nominated three times for the Charles C. Shepard Science Award for Assessment and Epidemiology at CDC. In 2006, he received the Raymond Melhoff Award for his work in developing state programs for older people with vision loss, and in 2007, he was awarded the Distinguished Alumni Award from Western Michigan University.

Dr. Paul Devereux has been an Associate Professor at the School of Community Health Sciences, University of Nevada, Reno since 2005. Prior to that he worked at UNRs Center for Program Evaluation, Center for Applied Research, the Disability Resource Center, and as a Jesuit Volunteer at a homeless shelter in Spokane, WA. He obtained a Ph.D. in Social Psychology from the University of Nevada, Reno in 1998. He will earn his Master of Public Health in community health education from San Jose State University in August 2010. Dr. Devereux is committed to community engagement research approaches and he studies emotion in older adults and the assets and barriers which contribute to or hinder health screening behavior. His research on disability focuses on the impact of social support and isolation. He has received funding from NIH/NIA, NIH/NCRR, CDC, HRSA and from private foundations. He is the former President of the Nevada Public Health Association and was awarded Nevada Public Health Leader of the Year in 2005.

Dennis Heaphy is a healthcare analyst at the Disability Policy Consortium of Massachusetts. His experience includes serving as the Americans with Disabilities Act Project coordinator for the Department of Public Health. In this role he was point person for the development and implementation of ADA compliance requirements for healthcare entities funded by DPH. Dennis has also worked as a consultant, creating training materials and educating stakeholders on health disparities and cultural competency as these issues apply to persons with disabilities. He is particularly interested in the "double jeopardy" faced by persons with disabilities within ethnic and minority populations.

Dr. Monika Mitra is a Research Scientist with the Disability and Employment Policy Unit, in the Center for Health Policy and Research, University of Massachusetts Medical School. Prior to joining University of Massachusetts, Dr. Mitra worked as Senior Epidemiologist with the Office on Health and Disability at the Massachusetts Department of Public Health where she played a vital role in the integration of disability in the Department of Public Health's programmatic and surveillance initiatives. For more than a decade she has been researching health disparities between persons with disabilities and the general population and the epidemiology of secondary conditions among persons with disabilities. At the University of Massachusetts she is continuing her research on health, health-related quality of life, employment and disability.

Carol Tobias, **M.M.H.S.**, is the Director of the Health and Disability Working Group (HDWG) and Assistant Professor at the Boston University School of Public Health. HDWG conducts research, training, and technical assistance in the design of effective health care systems for people with disabilities and chronic illnesses, including people living with HIV. Prior to her employment at Boston University, Ms. Tobias served as the Director of Public Health AIDS Program for the City of Boston, and as the Assistant Director of Ambulatory Programs for the Massachusetts Medicaid Program) with responsibility for managed care and programs serving adults and children with disabilities. She has a master's degree in human services management from Brandeis University.

Deborah Klein Walker, **Ed.D.** is Vice President and Practice Leader for Public Health and Epidemiology in the Health Division, Abt Associates, Inc., 55 Wheeler Street, Cambridge, MA 02138, USA. Dr. Walker received a doctorate in human development from Harvard University in 1978. She is currently an Adjunct Lecturer on the faculty at the Harvard School of Public Health and Adjunct Professor at the Boston University School of Public Health. Before joining Abt, she was on the faculty at Harvard University full time from 1976 to 1988 and the Assistant/Associate Commissioner at the Massachusetts Department of Public Health from 1988 to 2004. Dr. Walker has authored over 100 journal articles and three books on a range of issues related to child health and development, community health systems, disability and chronic conditions, program implementation and evaluation, and health outcomes and data systems.

Part I
Introduction