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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