Public Health and Disability: Emerging Opportunities

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SYNOPSIS

The public health community has traditionally paid little attention to the health needs of people with disabilities. Recent activities, however, on the part of federal and international organizations mark a shift toward engaging the health concerns of this large and growing population. First, the World Health Organization published the International Classification of Functioning, Disability, and Health (ICF), a companion to the International Classification of Diseases. The ICF describes both a conceptual framework and a classification system, providing the foundation for public health science and policy. Second, a vision for the future of public health and disability is outlined in Healthy People 2010 that, for the first time, includes people with disabilities as a targeted population. The article briefly describes activities and emerging opportunities for a public health focus on people with disabilities with the ICF as a foundation and Healthy People 2010 as a vision. Public health has traditionally responded to emerging needs; people with disabilities are a group whose health needs should be targeted.

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More Americans of all ages are living longer because of the positive impacts of medical research and public health interventions. Newborns of low birthweight are surviving, often with impairments. Individuals who previously would have died from traumatic injuries now live long lives. Our average life expectancy has increased to more than 76 years, from 49 years in 1900.[1] As part of this honorable legacy, an "epidemic of survival"[2] is leading to a substantial increase in the number of people who live with disabilities. A recent analysis of data from the 1994–1995 National Health Interview Survey suggests that 19.3% of the U.S. population has a limitation in one or more activities, e.g., in the areas of mobility, learning, or behavior.[3] Results of an analysis of data from the Medical Expenditure Panel Survey indicate that people with activity limitations account for 46% of medical expenditures (Unpublished 1996 data, John F. Hough, Disability and Health Branch, National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention [CDC]). These data clearly indicate a need for public health attention to the needs of people with disabilities. If we were to use the traditional public health model, we would attempt to assess the incidence of conditions associated with disability, identify their causes, and intervene to reduce or prevent the conditions associated with the limitations. Interventions of this kind include encouraging consumption of folic acid among women of childbearing age to reduce the incidence of neural tube defects, working to eliminate alcohol consumption by women during pregnancy to prevent fetal alcohol syndrome, and encouraging seatbelt use to reduce traumatic spinal and brain injuries associated with motor vehicle accidents. Despite the best public health efforts, children continue to be born with spina bifida and fetal alcohol syndrome and people still experience spinal cord and acquired brain injuries due to accidents. Does the public health community, then, have a role in the lives of Americans who fall through the primary prevention net and live with activity limitations?

The answer to date has not been positive. Activities to promote the health of people who are born with or who acquire limitations of their activities have been sparse. Although major efforts have been made to reduce or prevent the onset of disabling conditions—including efforts to prevent injuries, birth defects, developmental disabilities, and chronic illnesses—few prevention efforts have targeted the unique needs of people who already experience disability. Primary prevention messages, for example, those related to physical activity or nutrition, should be targeted to this group. People with disabilities are more vulnerable than the general population to a range of problems including fatigue, depression, and social isolation[4] and have more limited access to health care.[5] It is now time for the public health community to focus on this large segment of the population. There are signs that sound public health activities are emerging. As public health awareness is emerging in the U.S., there has been a parallel global effort that provides a foundation for research and programs related to disability.

DISABILITY FRAMEWORK

A major deterrent to promoting the health of people with disabilities has been the lack of a clear case definition of "disability." Both surveillance and intervention are predicated on being able to identify people who should be included. The array of federally mandated definitions of "disability" is enormous. Because as many as 50 different legislative definitions may exist, even public health professionals interested in disability issues feel overwhelmed.[6] In addition, operational definitions are often suspect. Andresen et al. concluded that the 2000 Census may not provide an accurate count of people with disabilities in the U.S.[7]

We have traditionally used the term "disability" in ways that are confusing—often without realizing the differences in meaning. Disability can refer to (*a*) diagnosis ("John has a disability, cerebral palsy"), (*b*) activity limitations ("John has a mobility disability"), (*c*) societal participation ("John has a disability that interferes with his ability to hold a 9-to-5 job"), or (*d*) environmental barriers ("John's access to the building is hampered by the lack of ramps"). In view of this fragmentation, there is a need for continuity in terms and definitions. The newly released system from the World Health Organization (WHO) directly addresses this need.

WHO has completed a revision of its classification system for disability, a companion to its International Classification of Diseases.[8] The system, the *International Classification of Functioning, Disability and Health* (ICF)[9] conceptually differentiates components of the disabling process. The ICF distinguishes health and health-related components at the levels of (*a*) body structures and functions and (*b*) activities and participation. Additionally, the framework includes a critical element influencing health—namely, environmental factors. Using this perspective, public health professionals will be able to identify which component(s) of the process are being assessed or addressed. Consistent use of shared terminology and a coherent classification and coding system will improve both the science of disabil-

ity within public health and the ability to communicate that science.

For example, a diagnosis of spinal cord injury is associated with the neurological functions of the body, may limit a person's ability to move around, and, according to severity, affect one's ability to dress or bathe without assistance. Participation in work settings may be restricted because of the attitudes of staff in the work environment. The ICF differentiates among these various components and uses neutral terms to describe them. Beyond the conceptual framework, the system also includes a classification of each component—body functions, body structures, activities (personal), participation (societal), and environmental factors. The classification of each component can be operationalized as follows:

(*a*) Body functions and structures are classified by physiological functions (e.g., mental, sensory, digestive, neuromusculoskeletal) or anatomical parts of the body (e.g., eye, ear, skin, limbs).

(*b*) Activities are classified by person-level tasks or actions (e.g., learning, moving around, personal care).

(*c*) Participation is classified by life situations (e.g., work, school, community, leisure).

(*d*) Environment is classified by the physical, social, and attitudinal factors that form the background for a person's life (e.g., natural surroundings, buildings, societal attitudes, government policies).

A coding system, including qualifiers for each component, completes the ICF.

It is noteworthy that the WHO framework uniquely recognizes the importance of the environment as it affects the health and well-being of people with disabilities. Whereas the traditional public health emphasis on the environment targets safe air, water, and food, additional characteristics of the environment influence the lives of people with disabilities. These include aspects of architectural and communication environments, such as ramps or telephones for the deaf; of policy environments, such as the loss of medical benefits if a person begins to work; and of attitudinal environments, such as discrimination. The ICF acknowledges the importance of physical access to health care facilities, policy access to medical coverage, and the attitudes of health personnel and coworkers. Assessing environmental factors is crucial for targeting public health interventions.

Just as the International Classification of Diseases is the foundation for understanding, classifying, and coding health conditions,[8] the ICF is the foundation for understanding, classifying, and coding functioning and disability. Although foundations are important, the next step is to outline where the field of public health should be going to improve the health of people with disabilities.

A VISION FOR DISABILITY AND PUBLIC HEALTH

Healthy People 2010 is the national agenda for improving the health of Americans during this decade.[10] An indication of the emerging public health emphasis on disability is the inclusion of Chapter 6, "Disability and Secondary Conditions." This is the first time in the history of the Healthy People initiative that people with disabilities have been included. In addition, disability status is a descriptor variable, along with sex, "race," ethnicity, education level, and socioeconomic status, in more than 100 objectives among the 467 objectives in the document. Disability status is included because data suggest that disability is a risk factor for other health-related conditions, including low levels of physical activity and obesity, and for restricted access to clinical preventive services.[11] This argues for a focus on people with disabilities in terms of meeting one of the two overarching goals of Healthy People—to eliminate health disparities.

Healthy People 2010 provides the broad outline for public health activities. The "Disability and Secondary Conditions" chapter, framed by the ICF, establishes specific objectives for disability and health. The chapter's first objective calls for inclusion of a standardized set of questions that would act as a case definition for disability status in any survey focusing on the health and well-being of Americans. Baseline data will then be available to determine the health characteristics and status of people with disabilities. These data will be even more powerful as standard questions are used across surveys. Of the remaining 12 objectives in Chapter 6, several focus on adults with disabilities, addressing mental health and support systems and societal participation. Other objectives address the needs of children with disabilities, focusing on meeting their mental health needs, increasing their inclusion in regular education, and reducing the number of children with disabilities in institutional care. Environmental objectives outlined in this chapter call for (*a*) increasing access to assistive devices and technology for people with disabilities, (*b*) increasing access to health and wellness programs, and (*c*) reducing environmental barriers to societal participation. The final objective calls for the existence of disability and health pro-

grams in all states and territories by the end of the decade and provides the setting for the actions to fulfill the Healthy People agenda.

EMERGING OPPORTUNITIES

The Healthy People 2010 agenda has provided the impetus for alliances to improve the health of people with disabilities. A workshop was convened in 2001 with 80 participants, including 37 from nongovernmental disability-related organizations, 25 disability researchers and policy makers from universities, as well as representatives of state and federal disability-related agencies. The outcome of this exercise was a volume outlining current and envisioned programs and policies for the coming decade.[12] The growing partnership among disability advocates, university researchers, and state and federal disability program staff members provides the core relationships from which creative and productive leadership for the future is emerging.

Explicit in the workgroup reports is the need for expansion of current data efforts. Most important to this process is the development and implementation of a set of items to identify people with disabilities for use in surveys. This effort is currently finding expression in the inclusion of a two-question set in the current Behavioral Risk Factor Surveillance Survey in all states. A recent *Morbidity and Mortality Weekly Report* article presented data on rates of disability from 11 states and the District of Columbia.[13] CDC's consultation with Statistics Canada and Eurostat, which have already developed "global indicators" for disability status, and the United Nations Statistical Division provide optimism that this objective is feasible and will soon produce a standardized disability status indicator so that comparisons of health characteristics can be made between people identified with disabilities and those without. With disability status as a descriptor, health disparities can be identified for the more than 100 objectives in Healthy People 2010 that take disability into account. Interventions targeting people with disabilities may then be justified. Currently, state data indicate that people with disabilities smoke more, are more often overweight, and exercise less than people not identified as having disabilities.[14]

The ICF has also been used to frame the assessment of activity limitation/participation domains using 1994–1995 data from the National Health Interview Survey–Disability Supplement (NHIS-D) (unpublished data, Fedeyko and Lollar). Forty-two questions were used to generate analyses for eight basic activity limitation/participation domains for people ages 5 and older.

A second data issue is how to assess environmental factors affecting the health and well-being of people with disabilities. Projects to develop psychometrically valid instruments for measuring the impact of environmental factors have been completed by several researchers. The instruments include an environmental measure for use in surveys, a second for use in clinical services, and a third focusing on children's environments.[15–17] As more tools are developed that can be used to code various dimensions outlined in the ICF, public health practitioners will have a firm data foundation for policy and intervention. Whiteneck's surveillance tool has been used as a model for developing items to be included in the Healthy People 2010 supplement of the NHIS to assess environmental barriers, the need for and use of assistive technology, and the accessibility of health facilities.

An important component needed to further public health efforts on behalf of people with disabilities, and encouraged in the workgroup reports,[12] is increased training of public health professionals in disability and health issues. Tanehaus et al. published the results of a survey of schools of public health regarding disability curricula.[18] The authors recommend the inclusion of dedicated courses addressing disability issues as well as integration of disability issues across the public health curriculum. To that end, the Boston University School of Public Health is developing a handbook on public health and disability for use across curricular areas, and Oregon Health Sciences University is developing a disability and public health course. From these activities, a set of distance learning modules will be developed by the CDC in conjunction with its university partners for use by state and local public health professionals.

Another key to improving the health of people with disabilities is the commitment and investment of state and local public health departments. Strong state public health and disability programs have developed in Rhode Island, North Carolina, Massachusetts, and Iowa, for example. Rhode Island has recently published its first report, the *Rhode Island Disability Chartbook,*[19] reporting Behavioral Risk Factor Surveillance System data. The report provides the foundation for collaboration with other public health programs in the state by highlighting disparities or health characteristics requiring attention. Likewise, the North Carolina Office on Disability and Health has published two monographs designed to remove barriers to health care for people with disabilities—one addressing barriers in

health care professionals' offices and another providing strategies to promote accessible communication.[20,21] The Massachusetts Department of Public Health has instituted a plan to educate contractors about making their offices and facilities accessible to people with disabilities. Iowa has included in its state Healthy People plan a section specifically addressing the health of Iowans with disabilities. As more state public health departments include people with disabilities in their planning, the need for attention to the health of people with disabilities nationally will move higher on the agenda. As public health professionals, university researchers, and policy makers act in conjunction with community advocacy groups, the health of people with disabilities will improve.

CONCLUSION

Disability has been described as "the nation's largest public health problem,"[22] affecting as many as 54 million Americans.[23] Although this rapidly increasing population[24] defines an "epidemic of survival," it also defines the possibilities for public health.

Disability and public health have historically been separated by problems related to focus, definition, and misperceptions. Encouraging trends are, however, emerging in public health that consider the health of people with disabilities as a priority. WHO provides a foundation through the ICF, Healthy People 2010 establishes a vision, and numerous state public health departments are creating the opportunities for implementation of that vision in the community. The history of public health highlights its response to new challenges to improve the health of the country. People with disabilities are the next natural group to be included.

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