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Editorial

Public Health Goals for Persons With Disabilities: Looking Ahead to 2020

Lisa I. Iezzoni, MD, MSc

Institute for Health Policy, Massachusetts General Hospital, and Department of Medicine, Harvard Medical School, Boston, MA 02114, USA

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Federal public health officials and interested communities nationwide have mobilized again for the decennial initiative to set goals for the nation's health. Ten years ago, *Healthy People 2010*—which delineated public health priorities for 2000 through 2010—cautioned that “as a potentially underserved group, people with disabilities would be expected to experience disadvantages in health and well-being compared with the general population” [1]. Five years later, the U.S. Surgeon General issued a *Call to Action*, reporting that some people with disabilities still lacked equal access to health care [2]. Significant gaps in data sources relating to individuals with disabilities complicate efforts to track what has changed in the past decade [3,4]. Nonetheless, few would dispute that persons with disabilities continue to face substantial risks to their health and well-being.

The Office of Disease Prevention and Health Promotion (ODPHP) in the Centers for Disease Control and Prevention (CDC) is leading the Healthy People 2020 initiative. They want the public's help in setting and achieving public health goals and objectives for the nation. Their Web site (www.healthypeople.gov) seeks public comment, and ODPHP has held hearings around the country to obtain local views. A 13-member advisory committee, the Secretary's Advisory Committee on National Health Promotion and Disease Prevention Objectives for 2020, has urged policymakers to focus on the social and environmental determinants of health in devising strategies to improve the public's health [5].

My question here is simple. What should we tell ODPHP and other public health leaders about the health risks—including the personal, social, economic, and environmental determinants of health—confronting U.S. residents with disabilities?

Determinants of Health

From 40 to 54 million persons in the United States have disabilities. They face the same risks of developing preventable acute and chronic health conditions as do other people. Disabilities are diverse, but many are caused by serious medical conditions that leave persons with a narrow margin of health. Thus, depending on their underlying health conditions, some individuals with disabilities might have higher risks than other people of developing certain preventable health problems.

Rates of disabilities vary across demographic subgroups within the U.S. population. Disability rates rise with increasing age: 6% among persons ages 5 to 15 years; 7% for ages 16 to 20; 13% for ages 21 to 64; 30% for ages 65 to 74; and 53% for ages 75 and older [6]. Across the population aged 5 and older, females (16%) have slightly higher rates of disabilities than do males (14%). Among adults in different racial and ethnic groups, American Indian or Alaskan Native populations report the highest disability rates (30%), compared with 21% for black persons, 20% for white persons, 17% for Hispanic individuals and for Native Hawaiian and other Pacific Islanders, and 12% for Asians [7].

Many persons with disabilities confront sociodemographic disadvantages and have other attributes that heighten

Corresponding author: 50 Staniford Street, Room 901B. Fax: (617) 724-4738.

E-mail address: liezzoni@partners.org

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their risks for preventable health problems. Compared with nondisabled individuals, persons with disabilities are much more likely to have the following [8]¹:

- *Lower levels of education.* Among adults with disabilities, 30% have less than a high school education, compared with 17% among those without disabilities [8].
- *Lower rates of employment.* In June 2008, the Current Population Survey, which tracks employment figures, added questions about disability, and the U.S. Bureau of Labor Statistics began publishing these figures with the January 2009 unemployment report. In that month, unemployment rates were 13% among persons with disabilities, compared with 8% among individuals with no disability; the percentage of the population in the labor force was 23% for persons with disabilities compared with 71% of nondisabled adults [9].
- *Higher rates of poverty.* Twenty-five percent of working-age adults with disabilities live in poverty compared with 9% of other working-age adults [9].
- *Problems finding safe, accessible, and affordable housing.* For example, 20% of persons with major difficulties walking have trouble using the bathrooms in their homes because of physical barriers [10]. A study of 14 federally funded public housing facilities in the Kansas City area found that 14% to 29% did not comply with various federal disability access regulations [11]. A survey of Los Angeles County residents with disabilities found that 25% need home modifications but do not have them [12].
- *Higher rates of depression, anxiety, strong fears, and stress.* For example, 34% of persons with major difficulties walking report being frequently depressed or anxious, compared with 3% among those without disabilities [8].
- *Higher likelihood of being victims of crimes or domestic violence.* The U.S. Department of Justice acknowledges that domestic violence statistics for this population are hard to acquire. Persons with certain types of disabilities may be unable to file reports; others who are abused physically and psychologically by caregivers fear losing essential assistance with activities of daily living [13].
- *Higher rates of being overweight and obese.* For example, 27% of adults with major physical and sensory impairments are obese, compared with 19% among those without major impairments [8].
- *Higher rates of tobacco use.* For example, 47% of adults with major difficulties walking use tobacco, compared with 26% of nondisabled adults [8].

In addition, interviews with individuals with disabilities find they can be unaware of their health risks and need for screening and preventive services. Some persons describe so-called “magical thinking”—the belief that because they already have one significant impairment, it is unlikely that more can go wrong with their health [8]. They therefore do not seek or receive routine screening services, such as those recommended by the U.S. Preventive Services Task Force (USPSTF).

Thus, individuals with disabilities experience high rates of disadvantages relating to the personal, social, economic, and environmental determinants of health that have been recognized by the Secretary’s Advisory Committee on National Health Promotion and Disease Prevention Objectives for 2020 [5]. These disadvantages heighten the risks that persons with disabilities will not achieve the national health goal envisioned by the Committee, of living long and healthy lives. Not surprisingly, surveys find that adults reporting disabilities are 30% more likely than nondisabled respondents to report being in fair or poor health [7]. These health disparities are particularly marked for certain population subgroups: for example, 33% more black respondents with disabilities than black respondents without disabilities report fair or poor health, as do 38% more disabled American Indian/Alaskan Natives than their nondisabled counterparts.

Barriers to Public Health and Health Promotion Services

Persons with disabilities face several major externally imposed barriers to accessing health care services and public health interventions.

Discriminatory and Stigmatizing Societal Attitudes

Despite significant gains in civil rights and greater participation in daily community life, persons with disabilities continue to confront discriminatory and stigmatizing attitudes. These attitudes may possibly extend to health care settings. For instance [8]:

- Smokers with major difficulties walking are 20% less likely than other smokers to be asked about their smoking histories by their physicians during routine annual check-ups. However, scientific evidence suggests that when physicians ask about patients’ smoking histories, even this simple act can encourage attempts to quit smoking. Some persons with walking difficulties may have limited lung capacity, increasing their risks of respiratory infections and other pulmonary complications. Ceasing smoking is therefore critical in this population.
- Women of child-bearing age with major difficulties walking are 70% less likely than other women to be asked about contraception during routine physician

¹The statistics listed come from various national health surveys and may not represent the exact circumstances in 2009.

office visits. However, if these women are sexually active, they face risks of unintended pregnancy. They may also have heightened risks of complications (such as deep vein thrombosis) from hormonal contraceptives or have trouble with manual dexterity, making barrier contraceptives less feasible. Therefore, safely and effectively preventing unintended pregnancy can require consultation with their physicians.

Stigmatizing attitudes could contribute to these findings. For instance, physicians may choose not to discuss smoking with disabled patients under the distorted belief that smoking brings consolation to otherwise unhappy lives. Physicians may not discuss contraception with disabled women under another erroneous belief that they are not sexually active and at risk of unintended pregnancy. In a survey of Los Angeles County residents with sensory or physical disabilities, 13% reported being treated unfairly at their health care provider's office because of their disability; 18% of persons reporting severe disabilities described unfair treatment [12].

One particularly worrisome issue involves distribution of scarce resources during public health emergencies, such as provision of mechanical ventilators during a pandemic influenza outbreak. While the U.S. Department of Health and Human Services (DHHS) acknowledges that such shortages will likely occur in the event of an influenza epidemic, DHHS has offered little guidance on how to allocate scarce resources. Other groups have provided recommendations for distributing ventilators and other scarce resources, some categorically excluding individuals with disabilities [14]. It is critical to conduct an open and transparent debate with the public and government officials about allocation guidelines before a pandemic public health emergency occurs.

Physical Access Barriers

Little systematic information is available about the accessibility of health care facilities. A survey of Los Angeles County residents with physical or sensory disabilities found that 22% had difficulty accessing their health care provider's office; non-Hispanic black respondents and persons with severe disabilities reported the highest rates of physical barriers (33% and 31%, respectively) [12]. Plentiful anecdotal reports suggest that basic equipment required for routine health and screening services is frequently physically inaccessible, including weight scales, examination tables, and mammography and other radiology equipment.

Many factors may explain lower rates of screening and preventive service use among persons with disabilities, including competing health demands and patient preferences. Nonetheless, equipment inaccessibility likely contributes to lower levels of service use among persons with disabilities as suggested by the following examples [12]:

- Persons who cannot stand to be weighed report not knowing their weight. Some with spinal cord injuries

(SCI) joke about weighing the same as the day they were injured because they have not been weighed since. Women with SCI who become pregnant describe being weighed during prenatal care visits on laundry or freight scales in hospital basements or loading docks [8].

- Women with major difficulties walking are 40% less likely than other women to get Pap smears, which are recommended with Grade A evidence by the USPSTF to prevent cervical cancer deaths [15]. Some women with major mobility problems report never having had a Pap smear because they cannot get onto the fixed-height examination table in their physicians' office.
- Women with major difficulties walking are 30% less likely than other women to get mammograms, which are recommended by the USPSTF every 1 to 2 years for women age 40 and older (Grade B evidence). Although wheelchair accessible mammography equipment does exist, many facilities have not yet acquired these machines. Women with major walking difficulties report being unable to obtain adequate images or having such unpleasant initial experiences that they do not return for their periodic screening [8].

Communication Barriers

Inaccessible communication poses barriers for persons who are deaf or hard of hearing, persons who are blind or have low vision, individuals with speech impairments, and persons with cognitive and developmental disabilities. Persons may not receive the information they need to manage their health in formats that they can access or understand. In addition, failures of information transfer during screening or preventive services can compromise clinical procedures. These communication barriers are diverse. Several examples include the following:

- According to the Nutrition Labeling and Education Act 1994 requirements, nutrition labeling on packaged foods can use print as small as 8-point type [16]. Footnotes and caloric conversion information can be as small as 6-point type. Nutritional labels provide critical guidance for consumers concerned about purchasing healthy foods. However, the type size on these labels is too small for persons with low vision to read, and information is not readily available in other formats (e.g., Braille). Although nutritional information on specific products may be available through other sources (e.g., manufacturer Web sites), consumers need information at the time of purchase.
- Women who are deaf or hard of hearing are 20% less likely than other women to obtain mammograms [8]. The reasons for this are unclear, but two factors might contribute. Some persons who are Deaf and use American Sign Language (ASL) as their primary language report that they have little knowledge about routine

preventive health services, such as information frequently provided through Public Service Announcements (PSAs). They do not listen to radio and may watch limited television, needing closed captioning to access auditory television content. If English is their second language, they also may not routinely read magazines or newspapers and see print PSAs. Second, some women who communicate using ASL describe difficult situations in mammography suites. Unless an ASL interpreter accompanies them, they may be unable to follow instructions from the mammography technician, who disappears behind a protective radiation shield when taking the image. Without being able to see the technician, the woman may be unaware of when to hold her breath (to avoid motion artifact while the equipment generates the mammogram image). A simple system of readily visible light cues could rectify this situation (e.g., a red light for holding breath; a green light for breathing normally).

- Ineffective communication between patients and physicians may generate fears and anxieties that are long-lasting, compromising future care. Some persons who are Deaf report physicians being unwilling to hire ASL interpreters for routine office visits, preferring instead to communicate by note-writing. One young woman described being unaware what was going to happen when she had her first Pap smear. The physician failed to explain the procedure (e.g., insertion of the speculum), producing such profound distress that the woman insists she will not return again for subsequent screening [8]. Although the Americans with Disabilities Act requires effective communication during clinical encounters, a Catch-22 confounds this mandate. Physicians are prohibited from charging patients for the costs of the ASL or other sign language interpreters, and interpreter fees often exceed reimbursement for the services. Thus, despite the legal mandate, physicians have a financial disincentive to hire sign language interpreters.

Financial Access Barriers

Although persons with disabilities are more likely than others to have “social safety net” health insurance, some are uninsured. In particular, individuals with disabilities in states with restrictive Medicaid coverage policies have high rates of being uninsured. In the South, for example, 39% of low-income workers reporting disabilities lack health insurance (the nationwide uninsurance figure for this population subgroup is 24%).² Without health insurance coverage, persons may lack access to critical screening and preventive health services.

² These unpublished figures come from our ongoing analyses of the 2000–2005 Medical Expenditure Panel Survey produced by the Agency for Healthcare Research and Quality.

Public Policy Implications

As noted at the outset, public health officials have recognized the barriers experienced by persons with disabilities. Nevertheless, more efforts are needed to eliminate barriers to public health and preventive services faced by persons with disabilities. According to the Institute of Medicine report *The Future of Disability in America*, the number of Americans with disabilities will likely rise substantially in coming decades [17]. Aging “baby boomers” will fuel much of this growth, as this enormous cohort enters age ranges with greatest disease and disability risks. Although rates of some serious limitations among elderly persons have declined, sobering reports warn of higher rates of potentially impairing conditions among children and working age adults. Much of this growing risk relates to preventable health conditions, such as those caused by overweight and obesity. Improving access to health promotion and disease prevention programs for persons with disabilities should be a national public health priority.

Persons with disabilities, clinicians, and researchers should add their voice to the Healthy People 2020 process. But setting goals is only the first step. Attaining those goals—and building effective efforts to address health and health care disparities among persons with disabilities—will require considerable creativity, dogged focus, and intense commitment. Ten years hence, when setting Healthy People 2030 goals, we want to be light years ahead of where we find ourselves today.

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