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# Persons With Disabilities as an Unrecognized Health Disparity Population

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Disability is an emerging field within public health; people with significant disabilities account for more than 12% of the US population. Disparity status for this group would allow federal and state governments to actively work to reduce inequities. We summarize the evidence and recommend that observed differences are sufficient to meet the criteria for health disparities: population-level differences in health outcomes that are related to a history of wide-ranging disadvantages, which are avoidable and not primarily caused by the underlying disability. We recommend future research and policy directions to address health inequities for individuals with disabilities; these include improved access to health care and human services, increased data to support decision-making, strengthened health and human services workforce capacity, explicit inclusion of disability in public health programs, and increased emergency preparedness. (*Am J Public Health*. 2015;105:S198–S206. doi:10.2105/AJPH.2014.302182)

People with disabilities have largely been unrecognized as a population for public health attention, but recent efforts have made the poor health of this population visible.<sup>1</sup> Adults with disabilities are 4 times more likely to report their health to be fair or poor than people with no disabilities (40.3% vs 9.9%).<sup>2</sup> The core mission of public health, which is to improve the health of all populations,<sup>3,4</sup> is increasingly framed in terms of health disparities or health inequities. Across the multiple definitions of health disparities and inequities,<sup>5–8</sup> there is general agreement that health disparities refer to differences in health outcomes at the population level, that these differences are linked to a history of social, economic, or environmental disadvantages, and that these differences are regarded as avoidable.

The World Health Organization (WHO) differentiates avoidable and unjust health inequities from the broader category of health inequalities, which include both inequities and unavoidable differences. Comparable terms in the United States are health disparities, which refer to avoidable and unjust differentials, and health differences, which refer to avoidable and unavoidable causes. Within a disability context, determining disparities is complex, in that it requires considering which observed differences in health status are avoidable, and

which may be unavoidable because they relate directly to the underlying health condition that led to the disability. In this article, we summarize the available evidence on health differences and disparities and recommend that people with disabilities be considered a health disparity population.

Race/ethnic health differences are recognized as inequities in health care and health outcomes, leading to recent concerted federal efforts to reduce these disparities.<sup>9</sup> Similar recognition, however, has been lacking for disability-related health differences. Without such recognition and active measures to improve their health, people with disabilities are likely to be at risk for increasingly disparate health outcomes. As a consequence, public health will carry an unnecessary burden in poor health and high health care costs. We examine whether the disability population experiences health disparities by:

1. defining this population,
2. describing its history of discrimination and exclusion,
3. documenting the population-level differences in health outcomes,
4. demonstrating that at least some of these differences are preventable, and
5. recommending public health actions to reduce disability-related disparities.

## PEOPLE WITH DISABILITIES

Some people are born with a disabling condition (e.g., Down syndrome) or demonstrate a condition early in life (e.g., autism, bipolar disorder), whereas others acquire disabilities through injury (e.g., spinal cord injury) or a chronic condition (e.g., limb loss because of diabetes), and still others develop a disability in later stages of life (e.g., dementia, age-related mobility disability). The health needs of people with disabilities vary with the type of limitation (e.g., mobility or cognitive) and by the condition underlying the disability (e.g., spina bifida, Down syndrome). For some, such as people who acquire disability through injury, the nature of their disability can be differentiated more readily from their health status. For others, their health status may directly lead to their disability (e.g., diabetes leading to limb loss and vision loss). Race/ethnicity, age, language, sex or gender, poverty, and low education can compound the impact of disability, leading to even poorer health and quality of life.<sup>10,11</sup> People with disabilities are a diverse group who share the experience of living with significant limitations in functioning and, as a result, often experience exclusion from full participation in their communities.

In 2001, the WHO published a framework that integrated previous models of disability. This framework, the International Classification of Functioning Disability and Health (ICF) for adults (2001) and for children and youth (2007),<sup>12,13</sup> has been adopted internationally and is useful for many public health purposes. In the ICF framework, disability is used as an umbrella term to include bodily impairments, activity limitations, or participation restrictions that relate to a health condition. These limitations, which interact with personal and contextual factors of the environment, result in disability. That is, a disability results from the interaction of having a condition-based limitation and experiencing barriers in the environment. The environment includes not only the

physical environment, but also social factors like culture, attitudes, economics, and policies that shape our life experiences. Environmental factors significantly affect health-related and functional outcomes, and can foster or impede good health and a high quality of life.

The ICF model is the most accepted model of disability in public health,<sup>14</sup> but its adoption in the United States has been slow. This may be because the ICF is based on a model of social participation, and not on the medical model that is still predominant in the United States. Use of the ICF would require coding changes to billing and administrative systems that may not seem justified because of difficulties in applying ICF qualifiers in real-world situations, such as the clinical environment, and because of a lack of practical tools for its use. To address the latter problem, the WHO recently endorsed and released “How to Use the ICF: A Practical Manual for the ICF.”<sup>15</sup> Two further developments are encouraging and may result in future adoption and adaptation of the ICF framework by different US federal agencies. First, on January 2, 2013, the US Social Security Administration, under federal register docket no. SSA-2012-007, published a notice to solicit collaboration from the public and federal agencies to evaluate the ICF for use by the Social Security Administration to assess disability and to capture data related to functioning.<sup>16</sup> Second, on January 1, 2013, clinicians and administrators began a 6-month pilot test of Medicare’s mandated claims-based functional data collection. These new requirements apply to physical therapy, occupational therapy, and speech language pathology outpatient therapy services provided in any setting. This mandated functional status reporting system has associations with the ICF; general categories of functional impairment (G codes) that therapists can use to meet Centers for Medicaid and Medicare requirements are based on the ICF taxonomy and represent aspects of functioning addressed in rehabilitation therapies.<sup>17</sup>

### Defining Disability for Public Health Surveillance

Disability has been defined differently across federal agencies, national data systems, and international frameworks. For example, in 2003, there were no fewer than 67 US federal statutory definitions of disability.<sup>18</sup> Definitions

that determine eligibility for services and supports, such as Social Security Disability Insurance and Supplemental Security Income, are understandably restrictive to limit the number of beneficiaries, whereas others that guarantee protection of rights, such as in the Americans with Disabilities Act, are deliberately inclusive to provide antidiscriminatory protection to a broad group of people. Definition differences also reflect an evolution in our understanding of disability and its relationship to health, the relative value society has placed on people with disabilities, and how program eligibility or legal protections have been addressed. Studies have drawn on data that used different definitions and referred to different segments of this population. Lack of comparability across studies has been a major obstacle to developing a solid body of evidence on the health status, health differences, and the health disparities of this population.<sup>19</sup>

For the first time in 2000, the US Department of Health and Human Services (HHS) blueprint for the nation, *Healthy People*, included a specific chapter on goals and objectives for the disability population.<sup>20</sup> The first disability objective in *Healthy People 2010* called for use of a standardized set of questions to identify people with disabilities in surveys. This was not achieved by 2010 and was continued as a disability objective in *Healthy People 2020*.<sup>4</sup> With passage of the Affordable Care Act (ACA) in 2010, Section 4302 required data collection standards be used for race/ethnicity, sex, primary language, and disability status. This *Healthy People* objective was achieved in October 2011 when HHS established data standards for defining disability in public health surveys.<sup>21</sup> These standard questions across the life span ask about

1. deafness or serious difficulty in hearing (all ages);
2. blindness or serious difficulty in seeing (all ages);
3. serious difficulty in concentrating, remembering, or making decisions because of a physical, mental, or emotional condition (5 years or older);
4. serious difficulty walking or climbing stairs (5 years or older);
5. difficulty dressing or bathing (5 years or older); and

6. difficulty doing errands alone (e.g., visiting a doctor’s office or shopping) because of a physical, mental, or emotional condition (15 years or older).

An affirmative response to any of these questions is considered a disability.

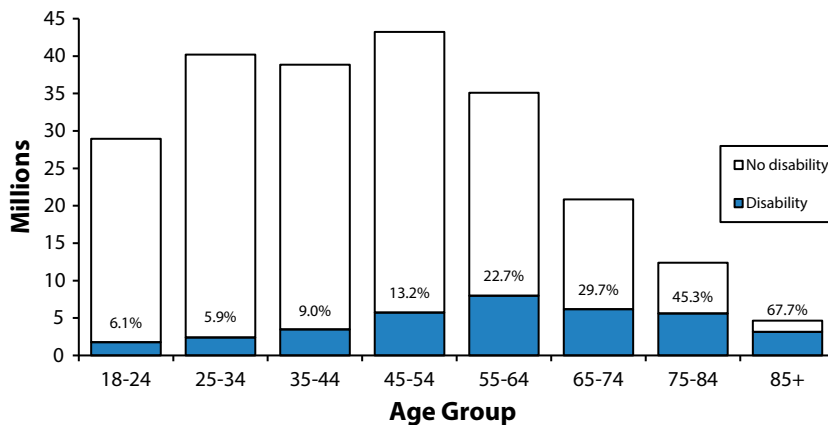
Because surveys have counted disability in different ways, prevalence estimates in public health surveys have ranged from 12% to 30%.<sup>2,22</sup> Although sampling and data collection methods have varied, these differences in prevalence estimates relate primarily to how disability is defined and what level of severity qualifies for disability status. The recently established HHS standards for data collection specify “seriously limited,” which results in approximately 12.5% of the general US adult population being considered disabled. Other data sets that measure mild-to-moderate limitations include substantially larger portions of the population.<sup>2</sup> Among people who report serious limitations, 46% report mobility disability, 39% report problem-solving or concentration limitations, 26% report hearing, and 21% report vision, with 43% reporting more than 1 limitation.<sup>23</sup>

### Disability Across the Life Course

A life course perspective recognizes that health trajectories are particularly affected at certain times in life: (1) health status results from the cumulative impact of experiences in the past and the present, (2) the environment affects the capacity to be healthy and function effectively in society, and (3) health disparities reflect inequities that go beyond genetics and personal choice.<sup>24</sup> For children and youths, the term “special health care needs” is used more frequently in public health than “disability,” and includes many children who experience functional limitations. Children with special health care needs have been defined as

those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.<sup>25(p138)</sup>

When youths with disabilities or special health care needs transition from pediatric care into adult service systems, they and their families often encounter major barriers with health systems that are unprepared to provide



**FIGURE 1—Weighted population estimate of adults with disabilities and adults without disabilities by age group: National Health Interview Survey, United States, 2010.**

adequate health care for their complex needs.<sup>26</sup>

The cumulative impact of experiences over the life course result in prevalence rates of disability as a proportion of the population that increase with age. Figure 1 is based on the new HHS standards, and demonstrates that by age 85 years and older, two thirds of Americans report functional limitations. In the overall population, however, the majority of people with disabilities are younger than 65 years, and one third are ages 44 to 65 years, which are the prime years for contributing to the workforce.<sup>23</sup>

## HISTORIC DISADVANTAGE FOR PEOPLE WITH DISABILITIES

Disadvantages for people with disabilities are documented by a long history of legislation and legal rulings to address discrimination and exclusion. Dating back to the mid-19th century, common practice in the United States and some European countries was to institutionalize children and adults with significant disabilities. Life in these institutions was often far from idyllic, and by the mid-20th century, media exposure of the dire life circumstances in institutions galvanized calls for their closure.<sup>27</sup> Involuntary sterilization of women with disabilities in institutions was reflected in the eugenics movement. Following a 1927 Supreme Court ruling, the state's power to conduct forced sterilization was upheld

(*Buck v Bell*), and was legal until recently in almost half of the US states.<sup>28,29</sup> Beginning in the 1960s and 1970s, advocates concertedly pressed for de-institutionalization so that children with disabilities could be raised by their families, and adults could participate in their communities with needed services and supports.

Federal legislation and programs have led the development of services and supports. Title V of the Social Security Act was passed in 1935 and provided resources to all states for services to children with crippling or handicapping conditions. Today, one third of the Title V Maternal and Child Health Block Grant to states must be spent on children with special health care needs.<sup>30</sup> Clinical demonstration programs authorized by Congress in 1957 rapidly expanded to become the Health Services and Resources Administration's interdisciplinary training programs for pediatric care of children with disabilities. In the subsequent decades, health care professionals who trained through these programs transformed health care for children and youths with neurodevelopmental and other disabilities. Similar training is not available for the care of young and older adults with disabilities.<sup>31</sup> The dilemma of adolescent transition illustrates the growing pressure on our national health care and public health systems to adequately address the existing and future health needs of people with disabilities across their life course. Problems in accessing community-based, quality, and appropriate health care in a timely way have been

lamented for decades; these problems were recently summarized.<sup>32</sup>

In 1963, Congress established the Administration on Developmental Disabilities (now Administration on Intellectual and Developmental Disabilities) state-based networks of university-based teaching and research centers, state councils for grass-roots mobilization, and civil rights protection and advocacy centers. This network of programs serves as a model internationally for collaboration at the state and national levels to improve all facets of the lives of people with developmental disabilities.

A free and appropriate public education in the United States was only guaranteed to children with disabilities with the passage of the Education of All Handicapped Children Act of 1974 (subsequently Individuals with Disabilities Education Act). Section 504 of the Rehabilitation Act of 1973 was the beginning of substantive federal legislation protecting persons with disabilities from discrimination and promoting opportunities for independence and self-determination. This was followed in 1990 with the Americans with Disabilities Act (ADA), the world's first comprehensive legislation on the declaration of equality for people with disabilities.<sup>33</sup> Protection from discrimination in employment, programs, and services provided by public entities (including transportation), public accommodations, and telecommunications was provided by the ADA as passed in 1990 and amended in 2008.<sup>34</sup>

Opportunities and supports for independent living in the community have progressed notably over the past several decades. The Independent Living movement mobilized disability advocates in pressing for support to live independently in the community. However, many people with significant disabilities who were not living with their families were still cared for in institutional settings at the discretion of the state. It required a Supreme Court ruling, the *Olmstead* decision of 1999, to uphold the right for a person with disabilities to live in the most integrated setting. That ruling held that unjustified institutionalization constitutes discrimination.<sup>35</sup> In response, states have expanded efforts to develop alternative ways of funding and providing community-based services and supports.<sup>36</sup> This history of discrimination and institutionalization has contributed to the health differences observed today.

**TABLE 1—Population Differences Between People With and Without Disabilities on Health Indicators of Health Care Access, Health Behaviors, Health Status, and Social Determinants of Health: United States**

Health Indicator	People With Disabilities (%)	People Without Disabilities (%)	Data Source
<b>Health care access</b>			
In past year, needed to see doctor but did not because of cost <sup>a</sup>	27.0	12.1	BRFSS 2010
Women current with mammogram <sup>a</sup>	70.7	76.6	BRFSS 2010
Women current with Pap test <sup>a</sup>	78.3	82.3	BRFSS 2010
<b>Health behaviors</b>			
Adults who engage in no leisure-time physical activity <sup>a</sup>	54.2	32.2	NHIS 2008
Children and adolescents considered obese (aged 2–17 y) <sup>b</sup>	21.1	15.2	NHANES 1999–2010
Adults who are obese <sup>a,b</sup>	44.6	34.2	NHANES 2009–2010
Adults who smoke (100 cigarettes in lifetime and currently smoke) <sup>a</sup>	28.8	18.0	NHIS 2010
Annual no. of new cases of diagnosed diabetes (per 1000 persons) <sup>a</sup>	19.1	6.8	NHIS 2008–2010
<b>Adults with cardiovascular disease</b>			
18–44 y	12.4	3.4	NHIS 2009–2011
45–64 y	27.7	9.7	
Victim of violent crime (per 1000 persons) <sup>a</sup>	32.4	21.3	NCVS 2007
Adults reporting sufficient social and emotional support <sup>a</sup>	70.0	83.1	BRFSS 2010
<b>Social determinants of health</b>			
Adult (> 16 y) unemployment	15.0	8.7	CPS 2011
Adult (> 16 y) employment	17.8	63.6	CPS 2011
Adults with < high school education	13	9.5	BRFSS 2010
Internet access	54	85	NOD 2010
Household income < \$15 000	34	15	NOD 2010
Inadequate transportation	34	16	NOD 2010

Note. BRFSS = Behavior Risk Factor Surveillance System; CPS = Current Population Survey; NCVS = National Crime Victimization Survey; NHANES = National Health and Nutrition Examination Survey; NHIS = National Health Interview Survey; NOD = National Organization on Disabilities Survey of Americans with Disabilities; Pap test = Papanicolaou test. All differences reported are statistically significant. Most of these data were drawn from the HP2020 Data Indicators Warehouse<sup>40</sup> additional sources used for mammograms and Pap tests,<sup>41</sup> and violence.<sup>42</sup>

<sup>a</sup>Age-adjusted.

<sup>b</sup>Obesity defined as a body mass index of  $\geq 30$  kg/m<sup>2</sup>.

## DOCUMENTING POPULATION DIFFERENCES IN HEALTH OUTCOMES

As a group, people with disabilities fare far worse than their nondisabled counterparts across a broad range of health indicators<sup>37–39</sup> and social determinants of health. Table 1<sup>40–43</sup> presents a number of population indicators that are drawn primarily from the Data Indicators Warehouse for *Healthy People 2020*,<sup>40</sup> where goals of a 10% population-level change are often regarded as aspirational. Although the gaps in individual indicators may not be dramatic, their cumulative effects are. Adults with disabilities are 2.5 times more likely to report skipping or delaying health care because of cost.<sup>2,44</sup> Because people with some disabilities require more health care for management of

their disabling conditions or increased risk of some chronic conditions, measurement of failure or delay in receiving needed care is important rather than comparing receipt of care. At the same time, women with mobility limitations are less likely to be current in mammograms and Pap tests.

People with disabilities consistently report higher rates of obesity, lack of physical activity, and smoking.<sup>2,45</sup> Some also have higher rates of newly diagnosed cases of diabetes, and their percentages of cardiovascular disease are 3 to 4 times higher.<sup>46,47</sup> Although they have higher rates of chronic diseases than the general population, adults with disabilities are significantly less likely to receive preventive care.<sup>48,49</sup> As an illustration, people with cognitive limitations are up to 5 times more likely to have diabetes than the general population<sup>47</sup>

while potentially receiving less adequate management care.<sup>44,50</sup> Inclusion of people with disabilities is critically important as agencies coordinate efforts<sup>51</sup> to prevent and manage chronic diseases and conditions like diabetes, cardiovascular disease, and hypertension.

Injury is known to be a leading cause of disability, but what is less well recognized is the heightened risk of injury (both unintentional injury and violence) among children and adults who already have a disability. Disability status is as great or greater a risk for unintentional injury than age, sex or gender, race, or education.<sup>52–54</sup> People with disabilities are 1.5 times more likely to be victims of nonfatal violent crimes than people with no disability, and more than twice as likely to report rape or sexual assault compared with people without a disability.<sup>42</sup> Women are victimized more often

than men, and people with cognitive disabilities have the highest rates of violent victimization.<sup>42</sup> Both men and women with disabilities are at significantly increased risk for intimate partner violence.<sup>55</sup> Mental distress such as depression or anxiety is a common concern for people with disabilities who are also less likely to report receiving adequate social and emotional support.<sup>56,57</sup>

### Inequalities in Preparedness and Health Insurance

Emergency preparedness is a safety issue of special concern for this population. There is inadequate data collection on emergency planning for people with disabilities, but what is available indicates this is an especially vulnerable time for this population. For example, during Hurricane Katrina, 38% of people who did not evacuate to safety had a mobility disability or were a care provider for a person with a disability.<sup>58</sup>

Rates of insurance coverage are generally comparable between disability and nondisability populations,<sup>2,45</sup> but the nature of coverage differs. Approximately 75% of people without disabilities have private health insurance, but fewer than 50% of people with complex limitations (severe disabilities) are privately insured.<sup>2</sup> Furthermore, although public insurance provides coverage for many people with disabilities, it does not cover all people, and the greatest gaps are felt by people with emotional disabilities; 28% are uninsured.<sup>2</sup> Even with insurance, people with disabilities are much more likely (16% vs 5.8%) to miss getting needed care because of cost.<sup>44</sup>

### Inequalities in Health Determinants

A social determinants approach to health explicitly recognizes the importance of the social environment, individual behaviors, and health services in addition to biology and genetics.<sup>4</sup> On virtually all measures of social determinants, adults with disabilities fare poorly. The current experience of living with a disability is associated with more likelihood of not having a high school education (13% vs 9.5%) and much less likelihood for employment (21% vs 59%),<sup>40</sup> less access to the Internet (54% vs 85%), much more likelihood of having an annual household income less

than \$15 000 (34% vs 15%), and inadequate transportation (34% vs 16%).<sup>43</sup>

People who have systematically experienced the economic and social disadvantages of poverty and discrimination face greater obstacles to optimal health.<sup>9</sup> These experiences of disadvantage, discrimination, and difficulties in accessing health care and health promotion services contribute to unhealthier lifestyle behaviors and poorer mental health, creating a cycle of more chronic conditions, poorer health, and increasing functional limitations.

### DOCUMENTING PREVENTABLE INEQUALITIES

Although differences in health outcomes between people with and without disabilities are substantial, they are often dismissed with the argument that they do not represent true disparities. The arguments frequently fall into 1 of 2 categories: (1) these differences are caused by the condition that led to the disability—"they're disabled, of course their health is poor"—or (2) that the poor health was present first and subsequently led to the functional limitation—"how do you know what came first?" The health differences observed in disability populations are more complexly determined than implied by these arguments. Some portion of observed differences likely are attributable to the condition (causal circularity); the critical concern is that a closer look is needed to identify those differences that are preventable and unjust within this population.

Researchers have used several research design strategies to disentangle these complexities to document the preventability of some differences. One strategy has been to focus on health variables in which the base rates would be expected to be the same across populations regardless of disability status. An example is examination of age-adjusted rates of clinical preventive services, such as mammograms or blood pressure checks, which are procedures that are recommended for all populations. Population research has consistently documented that women with disabilities receive lower rates of clinical preventive services such as mammograms,<sup>59,60</sup> and receive differential treatment of detected cancers.<sup>60,61</sup> These differences are not evident for all clinical preventive services; people with disabilities are

noted to have equivalent or higher rates of immunizations and management of hypertension.<sup>38,45</sup>

The second concern, the causality conundrum, is a challenge to documenting preventable health disparities with cross-sectional data. In the absence of longitudinal data, researchers have implemented alternative methodologies to explore causality. With obesity, for example, researchers have documented that children with disabilities are also at higher risk for obesity than their nondisabled peers, suggesting an early onset of obesity for at least some people with disabilities. Another strategy is to assess health and health behaviors before the age at which disability might result from those behaviors. For example, researchers examining relative smoking rates for people with and without disabilities limited the sample to those younger than 45 years, which is the age before the effects of long-term smoking likely would have resulted in disability.<sup>62</sup> Smoking rates were still substantially higher in young and middle-aged people with disabilities in this study. Another research strategy is to require that disability status be established for a set time before measuring health outcomes. For example, researchers required that disability status be documented (through Supplemental Security Income or Social Security Disability Income eligibility) at least 6 months before cancer diagnosis. Using this requirement, they were able to demonstrate higher cancer rates and more advanced stages of some cancers at time of diagnosis for people with certain disabilities.<sup>63</sup>

We recognize that although some differences likely are related to the underlying condition that led to the disability, others are not. Our primary concern is that inadequate attention and research have gone into determining those differences that are disparities. The ready dismissal of observed health differences in this population could itself be considered unjust.

### PUBLIC HEALTH ACTIONS TO REDUCE HEALTH INEQUALITIES

The available evidence documents that people with disabilities meet all the criteria for a disparity population. They experienced a history of social, economic, and environmental disadvantages in which children and adults

with disabilities were institutionalized and marginalized. They experience documented differences in health outcomes at the population level that relate to higher rates of unmet health care needs, unhealthy lifestyle behaviors, mental health and chronic diseases, and social determinants of poor health. Finally, many of these differences are recognized as avoidable and disproportionately affect this population.

Public health recognition of these needs is reflected in a number of major reports over the past decade. The Office of the Surgeon General issued a report in 2002 that outlined a blueprint for action to improve the health of people with intellectual disabilities.<sup>37</sup> This was followed in 2005 by a Surgeon General's Call to Action to improve the health and wellness of all people with disabilities.<sup>38</sup> In 2007, the Institute of Medicine issued *The Future of Disability in America*, which placed particular emphasis on health, adolescent transition, and technology.<sup>19</sup> The National Council on Disability report of 2009<sup>32</sup> summarized the shortcomings of health care access for people with disabilities. These reports have made strong and consistent recommendations on how to improve health care and to address the inequity experienced by this population.

These recommendations have been reinforced by objectives for people with disabilities in the Healthy People reports. Disability and health is 1 of 42 topic areas in *Healthy People 2020*.<sup>4</sup> The 20 *Healthy People 2020* objectives in disability and health are distributed across 4 areas: systems and policies (3 objectives), barriers to health care (4 objectives), environment (5 objectives), and activities and participation (8 objectives). Without action on these measurable and targeted objectives, health disparities can be expected to continue and possibly increase for people with disabilities.

Health expenditures associated with disabilities, including medical care and long-term services, have been estimated at \$400 billion annually,<sup>64</sup> with 70% of these costs covered through public programs. This represents a significant national expenditure that still results in preventable health gaps. The implications of recognizing individuals with disabilities as a health disparity population are presented in 5 areas:

1. improved access to health care and human services,
2. increased data for decision-making,
3. strengthened health and human services workforce capacity,
4. explicit inclusion in public health programs, and
5. increased preparation for emergencies.

### Access to Health Care and Human Services

The disparities in unmet health care needs of people with disabilities stand as a stark reminder of the work that must be done to improve access to care. Health reform, through the ACA,<sup>65</sup> holds special importance for people with disabilities through a number of key provisions. Denial of coverage because of preexisting conditions will no longer be allowed (ACA §1101 and §2704). Protection through a new patient's bill of rights will no longer allow a lifetime cap on benefits that leave people with disabilities without the care they need when they need it most (ACA §2711). Expansion of the Medicaid program is intended to allow many Americans with disabilities who did not previously qualify for coverage to be insured and stay healthy (ACA §2001). The ACA also authorizes federally conducted or supported surveys and health care and public health programs to collect standard demographic characteristics that include disability status (ACA § 4302).

Despite passage of the ADA more than 20 years ago, health facilities and services often are not fully accessible. National data are not available, but a recent survey of almost 2400 primary care facilities serving Medicaid patients in California noted that fewer than half of facilities were fully architecturally accessible; only 8.4% had accessible examination tables, and less than 4% had accessible weight scales.<sup>66</sup> Furthermore, there are few resources to help people with disabilities know which medical facilities will accommodate their limitations. As a result, many people with disabilities do not receive complete medical examinations because equipment such as weight scales, examining tables, and mammography equipment do not accommodate their disability. In late 2013, the Architectural and Transportation Barriers Compliance Board (Access Board) released much-anticipated standards to define accessibility of medical equipment to be used on a voluntary basis.<sup>67</sup>

Disparities in accessing health care and clinical preventive services can be reduced by implementing the standards for accessible equipment and close monitoring of ADA and ACA compliance. Several measures have been developed recently to assess accessibility of health care facilities,<sup>68-71</sup> but, to date, no requirements have called for the systematic collection of data on accessibility of facilities or medical equipment.

### Data to Drive Policy and Practice

By implementing the standardized disability identifiers across surveys, public health will be able to use existing data sets to compare health outcomes and health differences across multiple data systems, and to disaggregate disability into different functional categories (e.g., vision, hearing, mobility, problem solving or concentration). The resulting advance in scientific capacity and innovation in disabilities research should greatly improve knowledge of health outcomes, causes of health differences and disparities, and effectiveness of interventions. The next important step would be for public health researchers to routinely analyze their data by disability status to determine when disability is important as a demographic characteristic variable for the focus of their study. These data could provide health systems and professionals the much-needed information about where to focus to improve the health of people with disabilities across the life span.

Increasing the amount and coordination of disability research and routinely including people with disabilities in general health research will help close the knowledge gap on effective interventions. The Interagency Committee on Disability Research was established by Congress in 1978 to promote coordination, collaboration, and information sharing among federal agencies and stakeholders on disability and rehabilitation research. In 2011, the Interagency Committee on Disability Research established a Federal Collaboration on Health Disparities Research Workgroup, which can provide critical leadership for active collaboration across agencies in planning health disparities research, including funding, monitoring, and dissemination of findings.

### Strengthened Health and Human Services Workforce Capacity

Every major report addressing the poor health of people with disabilities has called for improvements in training of health care providers about adults with disabilities. The National Council on Disability in its 2009 report noted that, “The absence of professional training on disability competency issues for health care practitioners is one of the most significant barriers preventing people with disabilities from receiving appropriate and effective health care.”<sup>32(p13)</sup> It provides numerous examples of patients’ perception of how their care was inadequate because of professionals’ lack of knowledge or erroneous assumptions. The Institute of Medicine<sup>19</sup> reported that health professionals are poorly prepared to meet the complex medical and psychosocial needs of people with disabilities. However, disability competency is not currently a core curriculum requirement for medical school accreditation or for receipt of federal funding. Furthermore, a 2000 survey of US graduate schools of public health showed that only 13% of programs had a graduate track in disabilities.<sup>72</sup>

Training can be improved at several levels: (1) basic disability awareness for all public health workers and clinical care providers, (2) discipline-specific training on select aspects of disability, and (3) a needed infrastructure for core leadership training of health professionals in disabilities that addresses the full life span. A foundation of knowledge on disability and public health has been emerging,<sup>73,74</sup> which lends itself to training an array of health and public health professionals. *Healthy People 2020* includes a disability and health objective that calls for increasing the number of public health programs with a course on disability.<sup>4</sup> Improved training of health care providers can support earlier identification and intervention for children with disabilities, improved services for youths with disabilities transitioning into the adult care system, and improved health care and health promotion for adults with disabilities. If implemented, these actions could build the foundation for a multitiered process to increase disability awareness in the clinical and public health workforce and develop the needed infrastructure and direction for future development of workforce leadership in disability competence.

### Inclusion of Disabled Persons in Public Health Programs and Services

People with disabilities are often excluded from participation in mainstream public health programs and services. This resulted from many disadvantages, including historic segregation and isolation, explicit exclusion in developing the evidence base for interventions, provider discomfort in working with people with disabilities, and inadvertent exclusion by not recruiting for this population and not accommodating for their vision, hearing, mobility, or cognitive limitations.<sup>75,76</sup>

Inclusion into effective mainstream health practices is a powerful tool for improving the health of people with disabilities. Some federal agencies, notably the National Institute on Disability and Rehabilitation Research (within Department of Education), the Agency for Healthcare Research and Quality, and most recently, the Centers for Disease Control and Prevention, have initiated efforts that promote the explicit inclusion of people with disabilities in research and programs.<sup>77–79</sup> To date, there has not been concerted effort across federal agencies on language or policy for explicitly including disability populations in mainstream programs and research. Such efforts have been undertaken for race/ethnicity disparities as a result of the HHS Action Plan to Reduce Racial and Ethnic Health Disparities.<sup>9</sup> Based on the successes in addressing racial/ethnic disparities, similar actions could lead to the explicit inclusion of people with disabilities.

### Emergency Preparedness to Protect Health and Save Lives

During times of emergency or in disaster situations, people with disabilities are less likely to be evacuated and can be especially vulnerable. Emergency preparedness means planning for the different phases of multiple disaster scenarios that could be natural or man-made. It involves system-level responsiveness that assures that people with disabilities and their support systems are included in all phases of preparedness, evacuation, and recovery within communities, including adaptive strategies for in-place and shelter accommodations on a community-wide scale. It also requires individual-level planning and training in advance of, during, and following events.<sup>80</sup> Coordinated efforts and explicit planning across

HHS agencies could lead to better addressing the needs of people with various limitations.

### SUMMARY

Public health faces a critical opportunity to improve the health of the public and achieve equity in health status for all people—the opportunity and responsibility to promote health equity for people with disabilities. This sizable population has generally been unrecognized as a health disparity population. Importantly, people with disabilities are over-represented in many target populations for public health intervention—from smoking to obesity to injury prevention—yet their presence in these target groups is not recognized nor accommodated. As a group, people with disabilities experience more chronic diseases and conditions, and experience them at earlier ages, making this a critically important population to include to achieve success in health promotion campaigns. Federal and state agencies and national and state public health organizations can recognize people with disabilities as a health disparity population and address these disparities. Proposed actions include improved access to health care and human services, collection and routine use of disability data for decision-making, strengthened health and human services workforce capacity, explicit inclusion of people with disabilities in public health programs, and improved preparation and coordination for emergencies. By decreasing the disparities of people with disabilities, these actions can support public health in improving the health of all people in the United States. ■

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## Contributors

G. L. Krahn was the lead writer; all authors contributed equally to conceptualization and development of this article.

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Human participation protection was not required because human participants were not used specifically for the work reported in this article.

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