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ANALYSIS & COMMENTARY

Eliminating Health And Health Care Disparities Among The Growing Population Of People With Disabilities

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ABSTRACT Fifty-four million people in the United States are now living with disabilities. That number will grow substantially in the next thirty years, as the "baby-boom" generation ages and many of today's children and young adults mature and experience complications related to overweight and obesity. This reality poses a major challenge to the health care and policy communities. People with disabilities confront disadvantages from social and environmental determinants of health, including lower educational levels, lower incomes, and higher unemployment, than people without disabilities. Those with disabilities are also much more likely to report being in fair or poor health; to use tobacco; to forgo physical activity; and to be overweight or obese. People with disabilities also experience health care disparities, such as lower rates of screening and more difficulty accessing services, compared to people without disabilities. Eliminating these multifaceted disadvantages among people with disabilities should be a critical national priority.

President George H.W. Bush signed the Americans with Disabilities Act on July 26, 1990, declaring it another "Independence Day" and exhorting Americans to "let the shameful wall of exclusion finally come tumbling down."[1(p140)] More than two decades later, Census Bureau data about Americans with disabilities tell a discouraging story.[2]

In 2010 fifty-four million Americans had disabilities, representing about 19 percent of the civilian, noninstitutionalized population.[2] Rates of disability rose with increasing age: 5 percent among children ages 5–17, 10 percent among adults ages 18–64, and 38 percent among those age 65 or older. Women had slightly higher rates of disability than men (12.4 percent versus 11.7 percent).

Beyond basic demographics, other 2010 census figures were troubling.[2] Only 46 percent of Americans ages 18–64 with any disability were employed, compared to 84 percent of nondisabled Americans in that age group. The poverty rate for people ages 25–64 with severe disabilities was 27 percent, compared to 12 percent for people with disabilities that were not severe and 9 percent for people without disabilities. Among Americans age twenty-five or older, 28 percent of those with disabilities had less than a high school education, compared to 12 percent of people without disabilities. Other data showed that disability prevalence was higher among blacks, American Indians, and Alaska Natives than in other racial or ethnic groups.[3]

In 1990 the Americans with Disabilities Act recognized people with disabilities as a population meriting federal civil rights protections. Yet in the two decades since its passage, people with disabilities remain disadvantaged, including in their health and health care.[4,5]

Concerns include, first, the physical environment: inaccessible housing,[6,7] and communities that are only marginally "livable" for people with disabilities.[8,9] Persistent, stigmatizing social attitudes[10,11] also affect the health and well-being of these Americans. Compounding the difficulties for those in need of health care are persistent barriers throughout the system caused by inaccessible equipment and facilities; the lack of training of health care professionals to understand and address the needs of people with disabilities; inadequate communication modalities, such as the failure to provide Braille or large-print materials for people with vision deficits or employ sign language interpreters for hearing-impaired people; and other factors.

This article examines disparities in health and health care services among people with disabilities. Because of space constraints, I focus on general medical and preventive care, despite the fact that there are also serious concerns relating to long-term and supportive care for this population. I begin by defining *disability* and underscoring the diversity of this population. Then I describe health and health care disparities experiences by people with disabilities.

At the outset, two critical observations deserve emphasis. First, as the Institute of Medicine noted in *The Future of Disability in America*, the number of people living with disabilities in the United States will grow substantially in the next thirty years, primarily because of an aging population that will develop disabilities.[12] At the other end of the life span, rising numbers of children and youth are living with disabilities because of higher rates of survival among babies born with very low birthweight and other complex trends, such as growing rates of autism spectrum disorders and childhood asthma.[12] Trends linked to obesity in children and young adults suggest that disability numbers might also increase during middle age.[13] Thus, in a few decades a sizable fraction of the US population will probably have one or more disabilities.

Second, as explained below, the US health care system is not currently structured to care effectively for people with disabilities. Here, the word *structure* reflects concepts articulated by Avedis Donabedian in his enduring three-part framework—the structure-process-outcome triad—for assessing health care quality.[14] Donabedian's conception of *structure* was expansive, encompassing not only equipment and physical settings but also the characteristics and training of care providers, organizational policies, and how the "financing and delivery of health services are organized, both formally and informally"[14(p81)]—all critical attributes in caring for people with disabilities.

Defining 'Disability'

Human societies have long grappled with the question of how to define *disability*.[15] Wherever ancient peoples congregated to share resources, some individuals could not contribute to communal wealth because physical sensory, mental health, or cognitive impairments prevented them from hunting, gathering, or fulfilling expected social roles. People with functional limitations needed help from others simply to survive. As pressures mounted on shared societal coffers, determining whether specific individuals deserved assistance became important. Because people can feign physical and mental deficits, detecting deception has driven determinations of disability for many centuries.[16]

Starting in the nineteenth century, new tools—beginning with the stethoscope, microscope, ophthalmoscope, spirometer, and radiograph—allowed physicians to determine with apparent objectivity whether patients' functional limitations had legitimate biological or physiological roots.[16] By the late 1800s the "medical model" of disability was entrenched, positing health conditions as the cause of, and cure as the solution for, functional deficits. This perspective produced two expectations: First, guided by their physicians, patients must strive to overcome functional limitations through their own efforts; and second, medical solutions are best. If, however, cure is impossible, then the medical model required patients to "cheerfully and unself-consciously" make their own "good adjustment" to loss and deficiencies.[17]

By the second half of the twentieth century, attitudes had changed. Catalyzed by the confluent forces of the independent living movement, civil rights campaigns for racial minorities and women, and self-help consumerism, a disability rights movement emerged.[1,18] In the 1970s a new paradigm asserted that "problems lie not within the persons with disabilities but in the environment that fails to accommodate persons with disabilities and in the negative attitude of people without disabilities."[19(p26)] Disability is "imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society."[20(p22)] This "social" model sees the issue as "an attitudinal or ideological one requiring social change, which at the political level becomes a question of human rights."[21(p20)]

The *International Classification of Functioning, Disability, and Health* of the World Health Organization (WHO) melds the medical and social models in defining *disability*, thus producing a coherent view of health.[21] This classification explicitly recognizes the contribution of external forces—the physical, social, and attitudinal environ-

People with disabilities are particularly susceptible to receiving substandard health care.

ments—in causing or eliminating disability among people with functional impairments.

In addition, the classification includes participation in daily and community life as explicit components of health, thus shifting the focus from prevention or cure to maximizing functioning and well-being. By presenting disability as a continuum, the WHO treats disability as relevant "to the lives of all people to different degrees and at different times in their lives."[22(p82)] The Institute of Medicine recommended adopting the WHO's conceptual framework in all US efforts to monitor and measure population disability, albeit acknowledging that further work must refine and strengthen the nomenclature, and that no single definition of *disability* can serve all societal needs.[12]

People With Disabilities: A Diverse Population

More than twenty years ago, the diversity among the multiple constituencies of the disability civil rights movement impeded that movement's coalescence.[1] People who were blind did not necessarily identify with people paralyzed by spinal cord injury, children with developmental disabilities, or elderly people with dementia—and vice versa. Even the deaf community was divided between people who were born hearing and became deaf in late or middle age, often never learning sign language (people also called "hard of hearing") and the culturally Deaf—people who spoke sign language because they were born deaf or deafened early in childhood, before learning spoken language. Ultimately, advocates for these diverse groups found much common ground, but doing so was challenging.

Even today, certain accommodations for people with one type of impairment can disadvantage those with another type. For example, gently sloped curb cuts with smooth pavement are best for the users of mobility aids such as wheelchairs, but they do not adequately warn blind pedestrians walking with white canes that they are about to enter active roadways. Raised "truncated domes" provide textured, detectable warning surfaces for those blind pedestrians but are difficult for some users of canes, walkers, and wheelchairs to navigate.

According to 2001–05 National Health Interview Survey data, 21.7 percent of civilian, noninstitutionalized US adults reported movement difficulties (problems with walking, standing, kneeling or bending, reaching overhead, or using hands or fingers); 13.1 percent reported difficulties seeing or hearing; 3.1 percent reported emotional difficulties (extended periods of feeling very sad, nervous, restless, hopeless, or worthless or feeling that "everything was an effort"); and 2.8 percent reported cognitive difficulties (problems remembering or confusion).[23(p76)] Many people report more than one type of difficulty.

Depending on their conditions, Americans with disabilities have diverse health care needs that require different interventions and accommodations. Certain fixed or constant conditions, such as congenital blindness or deafness, do not typically require explicit medical interventions, although they shape communication accommodation needs.

Other sensory and physical disabilities arise from medical conditions that progress or change over time, sometimes influenced by clinical interventions and patients' own behavior. Some people actively and continually manage their own bodily needs; in such cases, patients often know more than their clinicians about how best to handle basic clinical concerns. Patients' lifestyles—for example, tobacco use, exercise, and diet—can also affect the progression of impairments.

Regardless of their specific conditions, however, people with disabilities are particularly susceptible to receiving substandard health care. Those with complex medical needs often slip through the fault lines crisscrossing health care delivery systems, especially poorly integrated specialized services.[24]

Disparities In Health

People with disabilities are much more likely than the nondisabled to report being in fair or poor health. According to 2001–05 National Health Interview Survey data, only 3.4 percent of adults without disabilities reported fair or poor health, compared with 30.6 percent of those with difficulty seeing or hearing, 37.9 percent of those reporting movement difficulties, 51.8 percent of people with emotional difficul-

ties, and 63.8 percent of those with cognitive difficulties.[23]

Among people reporting movement difficulties, 77.2 percent of those experiencing the most severe type of movement difficulty reported fair or poor health, compared with 14.8 percent of those experiencing the least severe movement difficulty. According to data from an earlier National Health Interview Survey, 34 percent of people with major difficulties walking reported being frequently depressed or anxious, compared with 3 percent of those without disabilities.[9]

Data from the Centers for Disease Control and Prevention's 2004–06 Behavioral Risk Factor Surveillance System surveys showed disparities in reports of fair or poor health by racial and ethnic subgroups of people with and without disabilities.[3] For example, Asians with disabilities were 16.8 percentage points more likely to report fair or poor health than were nondisabled Asians. In contrast, among people identifying themselves as American Indians or Native Americans, those with disabilities were 37.9 percentage points more likely to report fair or poor health than were those without disabilities. Among adults with a disability, reports of fair or poor health were highest among Hispanics (55.2 percent) and American Indians and Alaska Natives (50.5 percent) and lowest among Asians (24.9 percent).

The 2001–05 National Health Interview Survey data also indicated that people with disabilities had higher rates of risk factors for worsening overall health and developing conditions such as heart disease and certain cancers.[23] For instance, disabled people ages 18–44 were more likely than their nondisabled peers to be obese (28.4 percent versus 17.8 percent), to smoke cigarettes (37.5 percent versus 22.4 percent), and to be physically inactive during leisure time (47.7 percent versus 32.8 percent).

Similarly, people with disabilities ages 45–64 were more likely than their nondisabled counterparts to be obese (36.2 percent versus 21.5 percent), to smoke cigarettes (27.8 percent versus 19.5 percent), and to be physically inactive (79.2 percent versus 65.9 percent).

These data do not adjust for the social and environmental factors—such as poverty and other socioeconomic disadvantages—that could contribute to differences in rates between disabled and nondisabled people. Nonetheless, factors specific to certain disabilities might account for some of the differences.

For instance, after publishing a paper showing higher overweight and obesity rates among people with disabilities,[25] my coauthors and I received communications from readers with disabilities. A deaf woman described being afraid to jog in her neighborhood because she could not hear traffic sounds or the steps of other people, including possible assailants, running after her. People with mobility difficulties reported that gyms and health clubs did not have accessible equipment.

Physicians may be less likely to address risky health behavior if a patient has a disability.

One troubling possibility is that physicians are less likely to address risky health behavior if a patient has a disability. Using National Health Interview Survey data, my colleagues and I found that smokers who had major difficulties walking were 20 percent less likely than other smokers to be asked about their smoking histories by their physicians during annual checkups.[26] Anecdotal reports suggest that some physicians choose not to discuss smoking with disabled patients under the distorted belief that smoking brings consolation to otherwise unhappy lives. However, some people with walking difficulties have limited lung capacity, which increases their risks of respiratory infections. Therefore, ceasing smoking is critical in this population.

Disparities In Health Care

In 2000 the federal government's *Healthy People 2010* report 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."[27(p6-3)] The report cited common misconceptions about people with disabilities that contribute to disparities in the services they receive, especially an "underemphasis on health promotion and disease prevention activities."[27(p6-3)] Other federal reports, including the Agency for Healthcare Research and Quality's annual *National Healthcare Disparities Report*, have documented these disparities, focusing primarily on screening and preventive services.[28–30]

Repeated studies using national and state survey data have shown findings such as those in Exhibit 1, demonstrating much lower rates of screening mammography and Pap tests among

women with disabilities than among those without.[23] Also using national survey data, the 2010 Agency for Healthcare Research and Quality disparities report highlighted other access and quality problems disproportionately affecting people with disabilities (Exhibit 2).[30]

Beyond survey data, little information is available to explore disparities among people with disabilities. Medicare and Medicaid claims files, used frequently to investigate disparities in service use for racial and ethnic minorities, do not contain indicators of current disability. To investigate patients' experiences with breast and non-small-cell lung cancer, we used data from the National Cancer Institute's Surveillance, Epidemiology, and End Results cancer registries, merged with Medicare claims for people under age sixty-five who qualified for Medicare because of disability entitlement—that is, they had received Social Security Disability Insurance for two years. We found disparities in treatment and outcomes for both cancers.

For early-stage breast cancer, women with disabilities were much less likely than other women to get breast-conserving surgery (adjusted relative risk: 0.80; 95% confidence interval: 0.76, 0.84) rather than mastectomy.[31] When women receive this surgery, they require radiation therapy to have the same disease-free survival as with mastectomy. However, women with disabilities who had breast-conserving surgery were much less likely than other women to receive radiotherapy (adjusted relative risk: 0.85; 95% confidence interval: 0.77, 0.90). Women with disabilities were much more likely to die from breast cancer than were other women (adjusted hazards ratio: 1.31; 95% confidence interval: 1.18, 1.45).[31]

Similarly, for early-stage non-small-cell lung cancer, my colleagues and I found that people with disabilities were significantly less likely than nondisabled people to receive surgery, currently the only definitive treatment for this cancer.[32] People with disabilities were also significantly more likely than those without disabilities to die from their lung cancer. After accounting for demographic and tumor characteristics, controlling for disparities in the use of surgery eliminated the survival discrepancy between disabled and nondisabled patients.

EXHIBIT 1

Rates Of Mammography And Pap Testing Among Women With And Without Different Disabling Conditions

Type of difficulty	Mammography in past 2 years (%)[a]	Pap test in past 3 years (%)[b]
None	74.4	82.5
Movement difficulty (any)	66.4	69.3
Level 1 (least severe)	75.4	79.0
Level 2	69.8	71.6
Level 3	66.3	67.9
Level 4	59.1	60.3
Level 5 (most severe)	54.9	54.2
Seeing or hearing difficulty	62.8	68.8
Emotional difficulty	58.4	72.4
Cognitive difficulty	52.1	58.3

SOURCE Adapted from National Center for Health Statistics data; Note 23 in text. [a]Women age fifty and older. [b]Women age eighteen and older.

EXHIBIT 2

Quality Measures For Which People With Disabilities Report Worse Experiences Than People Without Disabilities

Topic	Description of quality measure
Access	People without a usual source of care who indicated a financial or insurance reason for not having a source of care People who were unable to get or delayed getting needed medical care in the past 12 months: Dental care Prescription medicines People with a usual source of care, excluding hospital emergency departments, that had office hours nights or weekends People with difficulty contacting their usual source of care over the telephone Adults who did not have problems seeing a specialist they needed to see in the past 12 months
Lifestyle modification	Adults with obesity who spent half an hour or more in moderate or vigorous physical activity at least three times a week
Patient safety	Adults age 65 or older who received potentially inappropriate prescription medications in the calendar year
Patient-centeredness	Adults who had a doctor's office or clinic visit in the past 12 months whose: Providers listened carefully to them Providers explained things in a way they could understand Providers showed respect for what they had to say Providers spent enough time with them Rating of health care by adults who had a doctor's office or clinic visit in the past 12 months People with a usual source of care for whom health care providers explained and provided all treatment options

SOURCE Adapted from Agency for Healthcare Research and Quality. 2010 national healthcare disparities report; Note 30 in text. Table 10.8: Measures for which persons with complex activity limitations were worse than persons with neither basic nor complex activity limitations.

Many factors likely explain these disparities in care, probably including patients' preferences for different types of treatments and competing needs resulting from multiple, complex health conditions. Erroneous assumptions and stigmatizing attitudes among clinicians also probably play a role. In a survey of Los Angeles County residents with sensory or physical disabilities, 13 percent reported being treated unfairly at their health care provider's office because of their disability. And 18 percent of those who said that their disabilities were severe reported unfair treatment.[33]

Using National Health Interview Survey data, my colleagues and I found that women of childbearing age with major difficulties walking were 70 percent less likely than other women to be asked about contraception during routine physician office visits.[26] If these women were sexually active, they confronted risks of unintended pregnancy; these women could also have faced heightened risks of complications (such as deep vein thrombosis) from hormonal contraceptives or have trouble with manual dexterity, making barrier contraceptives less feasible. One possible explanation for the finding is that clinicians erroneously assume that women with mobility difficulties are not sexually active.[9]

Inaccessible health care equipment and facilities probably contribute to some disparities in care. The survey of Los Angeles County residents with physical or sensory disabilities found that 22 percent of them had difficulty accessing their health care provider's office, with non-Hispanic black respondents and people with severe disabilities reporting the highest rates of physical barriers (33 percent and 31 percent, respectively).[34] Even if facilities have adaptive and assistive equipment—such as lifts and transfer equipment—this is not necessarily used appropriately.[33]

Interviews with women with disabilities who had developed early-stage breast cancer found that they frequently confronted physical barriers to care, such as inaccessible examining tables, weight scales, infusion chairs, mammography machines, and radiology equipment.[35,36] For example, a woman who is paraplegic reported that the cancer clinic at a major academic medical center she was referred to did not have a weight scale that was accessible by wheelchair. A woman's weight determines certain chemotherapy dosages. To determine her weight, the woman reported that her oncologist lifted her from her wheelchair and stepped onto a scale, holding her in his arms.

In another example, radiotherapy staff used Velcro straps to keep a woman with cerebral palsy securely on the table, but positioning her arm, which moves uncontrollably, was problematic. "There are all kinds of positioning devices that they could've used," the patient said. "Velcro, Velcro strapping. But they ended up using masking tape every single time"—taping her arm to the table.[35(p715)]

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Looking Toward The Future

Entrenched socioeconomic disadvantages and structural barriers within the health care system are now widely recognized as determinants of health and health care disparities among people with disabilities. In November 2010 the federal government released the current iteration of its decennial initiative, Healthy People 2020. Among its objectives for people with disabilities, Healthy People 2020 includes reducing unemployment, increasing the accessibility of new and retrofitted housing, reducing barriers to participating in community activities, and decreasing barriers in health care facilities.[37]

The barriers within the health care system overall have persisted for more than two decades after the enactment of the Americans with Disabilities Act. Decreasing them may thus require explicit and targeted interventions. People with disabilities have occasionally used lawsuits to address problems in accessing care. On July 26, 2000, ten years to the day after the Americans with Disabilities Act became law, several people with disabilities sued the Kaiser Permanente Health System in California for disability discrimination.[38] Kaiser Permanente settled the lawsuit in April 2001, and since then it has endeavored "to improve access and remove architectural, attitudinal, and other barriers for people with disabilities, to educate and train providers concerning culturally competent care..., and to develop patient-centered best practices and models of care for people with disabilities."[38(p240)]

The act's regulations did not cover medical equipment, posing challenges to organizations such as Kaiser Permanente, which want to im-

prove physical access to their services. The Affordable Care Act of 2010 includes section 510, "Establishment of Standards for Accessible Medical Diagnostic Equipment." This section mandates that the US Architectural and Transportation Barriers Compliance Board, in consultation with the Food and Drug Administration, promulgate within twenty-four months after enactment minimum technical criteria for ensuring the accessibility of medical equipment. Such equipment includes examining tables and chairs, weight scales, mammography equipment, and other radiological testing equipment used in hospitals, physician offices, clinics, and other health care settings. The next steps will be for manufacturers to follow these standards and for health care providers to install accessible equipment.

Other Affordable Care Act provisions also address disability concerns. For example, section 2705 prevents group health plans or health insurers from discriminating against people with disabilities. Section 4302 requires collection of data relating to health care disparities among those people, as well as data on racial and ethnic minorities and other population subgroups. Section 5307 supports the development of curricula to train health care professionals about providing culturally competent care to patients with disabilities.

Conclusion

As the Institute of Medicine has stated, "disability is not a minority issue."[24(p16)] Considering people who now have disabilities, those who will develop disabilities in the future, and those who are or will be affected by disabilities of family members or friends, "disability affects today or will affect tomorrow the lives of most Americans."[24(p16)]

Furthermore, the numbers of people living with disabilities across the life span—from the youngest to the oldest Americans—are growing.[24] Thus, eliminating health and health care disparities among this population should be a critical national priority. ■

NOTES

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In this month's *Health Affairs*, Lisa Iezzoni, a professor of medicine at Harvard Medical School and director of the Mongan Institute for Health Policy at the Massachusetts General Hospital, brings her traditional and rigorous scientist's eye to an issue close to home: the health and health care disparities manifest in the nation's population of disabled people.

"As I would ride around in my wheelchair (which I have used since 1988 because of multiple sclerosis)," she says, "strangers would come up to me and ask questions about wheelchair use or tell me stories about their disabled relatives or friends. I called this my 'rolling focus group,' and I wondered why people were not asking their physicians some of the questions they asked me. When I went to look at the published medical literature, I found remarkably little written about health care experiences of persons with disabilities. So I decided to explore these issues in my own research."

The result was this article, which describes health disparities tied to social and economic determinants among disabled people, as well as care disparities such as lower rates of screening. With the growing population of disabled people, Iezzoni says, eliminating these should be a critical national priority.

In addition to her academic and medical affiliations, Iezzoni is a member of the Institute of Medicine and serves on the editorial boards of *Health Services Research* and the *Disability and Health Journal*. She received the Distinguished Investigator Award from AcademyHealth in 2010.

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