

# Health Disparities and People with Disabilities

JOAN F. PETERS, JD. MPH

he COVID-19 pandemic has brought much needed attention to avoidable health disparities that long predate the pandemic. This overdue examination of disparities needs to include health disparities that exist between people with disabilities and non-disabled people, which are even more pronounced among racial and ethnic minorities with disabilities. At this moment of seeking to remedy disparities throughout society, health care providers can take a number of steps to aid the work of closing the gaps of equitable care for people with disabilities.

Not only should the work to end disparities include thoughtful focus on people with disabilities, it must involve them in meaningful ways from the start. It is crucial that individuals with disabilities be included in any discussion or plan to reduce health disparities. "Unless you pay attention to people with disabilities from the outset in rethinking solutions, you're going to perpetuate the long-standing disparities among people with disabilities, including those who are racial and ethnic minorities," said Barbara (Bobbi) Linn, a long-time disability activist. Linn, who has a speech impairment and motor disabilities as a result of cerebral palsy, has a master's degree in rehabilitation counseling. In 1985, she established Bronx Independent Living Services, which is part of a national network of Independent Living Centers that are resource and advocacy centers run by and for people with disabilities.

A substantial number of residents in the United States have a disability. The term disability encompasses a broad group of conditions that include mobility, sensory, communication, mental health and cognitive issues. The number of Americans living with a disability varies depending on the definition of disability; according to

the Census Bureau there are at least 40.7 million Americans with a disability, including children, or 12.7% of the population, living in the community outside of institutions. An estimated 2.1 million more people with disabilities live in institutional care facilities. Approximately one in nine working age adults has a disability. The percentage of adults in the U.S. living with disabilities varies by race and ethnicity. Approximately one in four Black adults has a disability compared to one in five whites and one in six Hispanics.

People with disabilities are sometimes presumed to be in poor health, but health status is in fact separate from disability. However, there are significant differences in health status between people with disabilities and their nondisabled peers. People with disabilities are four times as likely to report their health as fair or poor than people with no disabilities.<sup>5</sup>

Avoidable differences in health outcomes between groups of people that are not due to underlying medical conditions and that are linked to a history of social, economic or environmental disadvantages are termed health disparities. Health disparities have typically been discussed in the context of racial and socioeconomic status.

HEALTH PROGRESS www.chausa.org SPRING 2021 41



In the last decade or so, there have been increasing calls to recognize people with disabilities as a group affected by health disparities. "If you are going to point out health disparities, then you've got to point them out for people with disabilities, too," said Joe Bravo, the recently retired executive director of Westchester Independent Living Center. Bravo began using a wheelchair after a spinal cord injury at age 12.

While comprehensive research is limited, data show that people with disabilities do experience preventable health disparities.<sup>8</sup> To highlight three:

- **Obesity.** Adults with disabilities are more likely to be obese (40%) than adults without disabilities (28%).9
- **Diabetes.** About 1 in 6 people with disabilities (16.7%) has been diagnosed with diabetes, compared to 1 in 14 people without disabilities (7.4%).<sup>10</sup>
- **Smoking.** Adults with disabilities are more likely to smoke (23.1 %) than adults without disabilities (12.3 %).<sup>11</sup>

It is important to note that among people with disabilities, members of some racial and ethnic minority groups often show even greater disparities.<sup>12</sup>

Many of the health challenges experienced by people with disabilities are preventable given a multi-pronged approach with improved access to medical care, health promotion and disease prevention, and social circumstances. Reducing these avoidable health disparities will lead to better health outcomes for people with disabilities and lower health care expenditures. Given the

number of Americans with disabilities, reducing health disparities can have a significant social and economic impact.

# THE SOCIAL DETERMINANTS OF HEALTH

While some aspects of health, such as biology and genetics, are not modifiable, about 80% to 90% of the modifiable health factors are behavioral and social. In the general population, only about 10% to 20% of these modifiable health factors are related to medical care.

Social, economic and political resources and structures, called the social determinants of health, have substantial influence on health outcomes. The social determinants of health are defined as the "conditions in the environments where people are born, live, learn, work, play, worship and age that affect a wide range of health, functioning, and quality-of-life outcomes and risks." Addressing social determinants of health is critical for improving health and reducing long-standing disparities for people with disabilities.

These modifiable factors can be organized into six broad, often intertwined categories.

- Economic stability, including income, employment, debt and medical bills.
- Education, including literacy, higher education and vocational training.
- Neighborhood and built environment, including housing, transportation, walkability and safety.
- Food, including hunger and access to healthy food
- Community and social context, including family, friends, social interaction, support systems, community engagement and discrimination.
- Health care, including health coverage, provider availability and cultural competency.<sup>16</sup>

Many of the health challenges experienced by people with disabilities are preventable given a multi-pronged approach with improved access to medical care, health promotion and disease prevention, and social circumstances.

"When you're talking about people with disabilities, it's hard to separate the social determinants of health from each other," said Linn. "If you need to use accessible transportation, it affects everything — your ability to get to work, go to the grocery store, get out to see your friends. Discrimination is everywhere — in employment, education — not just in the community."

In addition to discriminatory attitudes, people with disabilities can face physical and/or communication barriers.

Greater income correlates with better health.<sup>17</sup> However, the poverty rate for working age adults

42 SPRING 2021 www.chausa.org HEALTH PROGRESS



with disabilities is more than twice the rate of adults with no disability (28% compared with 13%). In 2019, before the pandemic began to affect the U.S. economy, just 33% of people with disabilities of working age were in the labor force, compared with 77% of people without disabilities. People with disabilities are less likely to have a high school education. 20

Laws, including the Americans with Disabilities Act (ADA), mandate accessibility and prohibit discrimination against people with disabilities among covered entities. Yet clearly discrimination against people with disabilities persists. "Are people with disabilities being hired for jobs? No, that's one of those things that hasn't occurred after the ADA. We thought discrimination would be over. No, it isn't," reflected Bravo.

And employment necessitates reliable transportation. People with disabilities who do not drive and need accessible transit often face difficulties. "A lot of rural areas don't have much in the way of accessible transportation. While New York City has a big paratransit system, there are many problems with it, like having to reserve all rides at least one day in advance, which makes doing anything without advance planning impossible," said Linn.

Food, too, is an issue that cuts across multiple determinants: economic stability, neighborhoods, and community and social context. The CDC gives the example of people who lack access to grocery stores with healthy foods and who are then are less likely to have good nutrition. That raises their risk of health conditions like heart disease, diabetes and obesity, all of which can lower life expectancy. <sup>21</sup>

Disability is one of the strongest factors for food insecurity based on economic reasons.<sup>22</sup> But disability can add another layer of practical complications. A 31-year-old professional who became quadriplegic after a spinal cord injury at age 14 cited his own experience of difficulty simply getting into stores because of locked cart corrals in front of grocery stores. He said, "Non-disabled people can just swing around them, but if you are in a wheelchair, you definitely can't get past that door."

Once inside, stores can present other problems. The man, who did not want his name used in order to protect his privacy, described his experiences, "A lot of store owners don't know about disability, and even if they do, they're not trained on how to deal with people with physical, mental or emotional disabilities. With supermarkets, a ton of their items are on higher shelves. You're going to need somebody to help you if you're in a wheelchair or can't see. Sometimes the employee doesn't want to get their reacher. You don't want to make a big deal of these things, but some store owners just don't realize people with disabilities are human."

In terms of community and social context, people's relationships and interactions with family, friends and community members can have a major impact on their health and well-being. One noteworthy component of this determinant is "social capital," an important marker of social cohesion that has significant ramifications for health.<sup>23</sup>

Social capital deals with shared group resources. Simply getting information allows for greater independence and participation in the community. The young man who struggled with grocery stores noted that he didn't know he could become employed without losing his eligibility for government benefits immediately. (The program allows benefits to phase out.) He only found out because, "I was in a circle of friends who also had spinal cord injuries who were advocates themselves. They all taught me 'you can work and still get services you need. You just need to sign up for this particular government program.' No one else was telling me that."

# REDUCING BARRIERS TO CARE

People with disabilities encounter substantial barriers to health care. They are less likely to access the level of medical care needed to maintain health. While a slightly higher percentage of people with disabilities have insurance coverage than people without disabilities, adults with disabilities are 2.5 times more likely to report skipping or delaying health care because of cost.<sup>24</sup>

One reason that people with disabilities forgo needed medical care may be that it simply costs more to have a disability. They may be paying for unreimbursed medical and pharmaceutical care, accessible transportation, specialized equipment or assistive technologies, as well as caregivers. They may thus have less money to spend on copays, deductibles, etc.

HEALTH PROGRESS www.chausa.org SPRING 2021 43

Apart from financial concerns, the process of actually accessing care brings on particular physical, attitudinal and communication challenges. A 2009 report found that the ADA has had limited impact on how health care is delivered for people with disabilities.<sup>25</sup> It noted significant architectural and programmatic accessibility barriers still remain, and health care providers continue

to lack awareness about steps they are required to take to ensure that patients with disabilities have access to appropriate, culturally competent care. It cited "the absence of professional training on disability competency issues for health care practitioners is one of the most significant barriers that prevent people with disability of the professional training one of the most significant barriers that prevent people with disability of the professional training one of the most significant barriers that prevent people with disability of the professional training on the professional training of the professional train

abilities from receiving appropriate and effective care"

In other words, the existence of services does not guarantee that people with disabilities will be able to use them. <sup>26</sup> One woman in her 50s who uses a wheelchair cited the lack of training among those responsible for transferring her from her wheelchair to equipment in her doctor's office such that she had to bring people with her to help her. She called the experiences "discouraging and alienating," and they have caused her to delay care when possible. She expressed her frustration that health care facilities "aren't designed for sick people." This woman also wanted to remain anonymous to protect her privacy.

People with disabilities can attest that communication and provider attitudes directly impact the quality of care. Before Linn went into surgery a few years ago, she tried to explain to the anesthesiologist that she was concerned how the anesthesia would interact with her other medications. She said the anesthesiologist just walked away from her mid-sentence. While the surgery was successful, Linn wondered whether someone without a speech impairment would have received a different reaction.

While these experiences are anecdotal, they illustrate ways that health care systems often do not meet the needs of people with disabilities.

# **MOVING AHEAD**

Social determinants typically have been seen separately from clinical care. However, even before

COVID, some facilities had started screening for social determinant factors and giving people with disabilities referrals to community resources to meet non-medical needs.<sup>27</sup>

COVID has highlighted the need for clinical and non-clinical systems to work more closely together. But in making the necessary changes to the systems that affect the health of people with

People with disabilities must be able to have meaningful input. Because people experience very different disabilities, multiple disabilities should be represented.

disabilities, the legal protections for them and their particular needs must be kept in mind to prevent existing health disparities being perpetuated.

While many components of the social determinants are beyond the scope of the health care system, providers can take specific steps that lead to improvements in the lives of people with disabilities and that can in the long term reduce health disparities. In addition to compliance with the ADA, employee training on how to work better with people with disabilities is needed.28 Employers' diversity and inclusion commitments should include people with disabilities as well as racial and ethnic minorities. Moreover, true change requires involving people with disabilities on a more fundamental level. People with disabilities "need to be in people's consciousnesses. We have to be part of the conversation on priorities. Otherwise, our concerns won't be addressed," said Bravo.

People with disabilities should be invited to sit on advisory groups, boards, panels, policy committees and related groups within health care systems as well as in external initiatives with which health care providers and administrators are involved. People with disabilities must be able to have meaningful input. Because people experience very different disabilities, multiple disabilities should be represented. These opportunities need to be truly disability-friendly, taking place in physically accessible locations, with written materials available in multiple formats, including simplified information for people with cogni-

44 SPRING 2021 www.chausa.org HEALTH PROGRESS

tive impairments or limited English proficiency; American Sign Language Interpreters should be available as needed.

In terms of physical accessibility, designs for facilities and spaces should be reviewed by people with disabilities before plans are approved. People living with a disability can see problems with apparently "ADA-compliant" projects that nondisabled people may not think of. Including people with disabilities in the planning process can prevent costly remedial measures later on. Here too, it is important to involve people representing various disabilities. A person with a mobility disability may be focused on wheelchair accessibility, while a low vision person may emphasize signage. Moreover, the ADA is a floor not a ceiling. One frustrated women with a mobility disability described arriving at health care facility that had only the legal minimum of handicapped parking spaces, which were both in use, leaving her unable to use one for her appointment.

In addition to an organization's own patient base, there are many local resources for finding people who could give valuable input about disability access and use. Independent living centers, the cross-disability resource and advocacy centers for people with disabilities, are located in every state. Many national disability organizations have local chapters. While the concerns of older people do not always overlap with those of people with disabilities, area agencies on aging also can be a resource. By developing working relationships with a range of community partners and resources, providers can help break down the silos of information and better meet the needs of patients with disabilities.

Most immediately, COVID vaccination outreach efforts should be inclusive of people with disabilities. Information should be accessible in a range of formats. Vaccines should be administered in physically accessible locations by staff sensitive to and knowledgeable about people with disabilities.

# CONCLUSION

Improving the health of people with disabilities may require a change in mindset. Bravo said, "Attitudes have gotten better, but I don't think people see us as equals. And they still feel sorry for us." For true health equity and the reduction of avoidable health conditions, people with disabilities

must be included in rethinking the social determinants of health.

**JOAN F. PETERS** lives in Brooklyn, New York, and writes on disability, chronic illness and public health issues.

### **NOTES**

- 1. "Anniversary of Americans With Disabilities Act: July 26, 2019," U.S. Census Bureau, accessed January 18, 2021, https://www.census.gov/newsroom/facts-forfeatures/2019/disabilities-act.html.
- 2. "Understanding Disability Statistics, ADA National Network, accessed February 10, 2021, https://adata.org/factsheet/understanding-disability-statistics.
- 3. Nanette Goodman et al., *Financial Inequality: Disability, Race and Poverty in America*, National Disability Institute, 2017, https://www.nationaldisabilityinstitute.org/wp-content/uploads/2019/02/disability-race-poverty-in-america.pdf.
- 4. "Adults with Disabilities: Ethnicity and Race," Centers for Disease Control, last reviewed September 16, 2020, https://www.cdc.gov/ncbddd/disabilityandhealth/materials/infographic-disabilities-ethnicity-race.html.
  5. Gloria L. Krahn et al., "Persons with Disabilities as an Unrecognized Health Disparity Population," *American Journal of Public Health* 105, no. S2 (April 1, 2015): S198-S206, https://doi.org/10.2105/AJPH.2014.302182.
  6. Krahn et al., "Persons with Disabilities."
- 7. Krahn et al., "Persons with Disabilities."
- 8. Charles Drum et al., Health Disparities Chart Book on Disability and Racial and Ethnic Status In the United States (Durham, NH: University of New Hampshire Institute on Disability, 2011), https://iod.unh.edu/projects/health-disparities-project/health-disparities-chart-book.
- 9. S. Paul et al., Annual Disability Statistics Compendium: 2020 (Durham, NH: University of New Hampshire, Institute on Disability, 2020), Table 11.3, https://disability compendium.org/sites/default/files/user-uploads/ Events/2021\_release\_year/Final%20Accessibility%20 Compendium%202020%20PDF\_2.1.2020reduced.pdf. 10. "Disability and Diabetes Prevention," Centers for Disease Control, reviewed November 16, 2020, https://www.cdc.gov/ncbddd/disabilityandhealth/features/ disability-and-diabetes-prevention.html.
- 11. Paul et al., Compendium, Table 11.2
- 12. Rachel N. Blick et al., "The Double Burden: Health Disparities Among People of Color Living with Disabilities," Ohio Disability and Health Program (2015), accessed

HEALTH PROGRESS www.chausa.org SPRING 2021 45

January 4, 2021, https://nisonger.osu.edu/sites/default/files/u4/the\_double\_burden\_health\_disparities\_among\_people\_of\_color\_living\_with\_disabilities.pdf. 13. Drum et al., *Chart Book*.

14. Sanne Magnan, "Social Determinants of Health 101 for Health Care: Five Plus Five," NAM Perspectives Discussion Paper, National Academy of Medicine, 2017, https://doi.org/10.31478/201710c .

15. "Social Determinants of Health," Centers for Disease Control, accessed January 5, 2021, https://health.gov/healthypeople/objectives-and-data/social-determinants-health.

16. Samantha Artiga et al., Beyond Health Care: The Role of Social Determinants in Promoting Health and Health Equity, Kaiser Family Foundation, May 2018, https://www.kff.org/racial-equity-and-health-policy/issue-brief/beyond-health-care-the-role-of-social-determinants-in-promoting-health-and-health-equity/.

17. Blick et al., Double Burden.

18. Silvia Yee et al., Compounded Disparities: Health Equity at the Intersection of Disability, Race, and Ethnicity, Washington, DC: National Academies of Sciences, Engineering, and Medicine (2018), https://dredf.org/wp-content/uploads/2018/01/Compounded-Disparities-Intersection-of-Disabilities-Race-and-Ethnicity.pdf.
19. Gina Livermore et al., "National Disability Employment Awareness Month: Still Important After 75 Years," October 2, 2020, Mathematica, https://www.mathematica.org/commentary/national-disability-employment-awareness-month-still-important-after-75-years.

20. Yee et al., Compounded Disparities.

21. "Access to Foods that Support Healthy Eating Patterns," Centers for Disease Control, accessed January 5, 2021, https://www.healthypeople.gov/2020/topics-objectives/topic/social-determinants-health/interventions-resources/access-to-foods-that-support-healthy-eating-patterns. 22. Yee et al., Compounded Disparities.

23. "Social Cohesion," Centers for Disease Control, Office of Disease Prevention and Health Promotion, accessed March 9, 2021, https://www.healthypeople.gov/2020/topics-objectives/topic/social-determinants-health/interventions-resources/social-cohesion.

24. Krahn et al., "Persons with Disabilities."
25. The Current State of Health Care for People with Disabilities, National Council on Disability, September 30, 2009, https://ncd.gov/publications/2009/sept302009.
26. Deborah J. Edwards, Dikaios Sakellariou, Sally Anstey, "Barriers to, and Facilitators of, Access to Cancer Services and Experiences of Cancer Care for Adults with a Physical Disability: A Mixed Methods Systematic Review," Disability and Health Journal 13, no. 1 (2020): 100844, https://doi.org/10.1016/j.dhjo.2019.100844. 27. Artiga et al., "Beyond Heath Care." See also Yee et al., Compounded Disparities.

28. "Core Competencies on Disability for Health Care Education," Alliance for Disability in Health Care Education, 2019, http://www.adhce.org/.

46 SPRING 2021 www.chausa.org HEALTH PROGRESS

# HEALTH PROGRESS

Reprinted from *Health Progress*, Spring 2021, Vol. 102, No. 2 Copyright © 2021 by The Catholic Health Association of the United States