

COMPOUNDED DISPARITIES: Health Equity at the Intersection of Disability, Race, and Ethnicity

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Section 1

Framing and Introduction

Anyone can become disabled in a flash. Furthermore, across the life span, almost all persons live with disability at some time, especially in their later years. Thus, according to the World Health Organization (WHO), disability is “a continuum, relevant to the lives of all people to different degrees and at different times in their lives,” virtually a “universal phenomenon” and a “natural feature of the human condition.”¹ As the Institute of Medicine stated:

If one considers people who now have disabilities..., people who are likely to develop disabilities in the future, and people who are or will be affected by the disabilities of family members or others close to them, then disability affects today or will affect tomorrow the lives of most Americans. Clearly, disability is not a minority issue.²

Disabilities are diverse although they share one common feature: persons with disability perform basic human functions—such as hearing, seeing, speaking, moving, thinking, and emoting—differently than do other persons.³ Since early times, human societies have struggled with defining disability and determining whether individuals are disabled.⁴ Wherever people gathered to share resources, some individuals could not fully perform their expected social roles or equally contribute to communal wealth because of sensory, physical, cognitive, or mental health impairments. To

survive, these people needed help, which many societies provided. In the 19th century, new diagnostic instruments—including the stethoscope, ophthalmoscope, spirometer, and x-rays—accorded medicine an aura of scientific objectivity with the presumption that physicians could now diagnose disorders without relying on “subjective” reports from individuals. These technologies cemented the role of physicians in identifying and presumably treating disability. By the late 1800s, the “medical model” of disability dominated thinking:

The *medical model* views disability as a problem of the person, directly caused by disease, trauma, or other health condition, which requires medical care provided in the form of individual treatment by professionals. Management of the disability is aimed at cure or the individual's adjustment and behavior change. Medical care is viewed as the main issue, and at the political level the principal response is that of modifying or reforming health care policy.⁵

Two presumptions support the medical model. First, doctors know what is best for their patients. Second, guided by their physicians, persons should strive individually to overcome impairments. However, if these impairments are not cured, persons must accept their limitations and adapt, preferably resolutely and cheerfully, to reduced circumstances.

By the late 1960s, views of disability started changing radically. An emerging new paradigm held that environmental factors—physical barriers, negative societal attitudes, and inadequate public policies—that fail to accommodate difference cause disability. These barriers isolate persons with

disability, excluding them from participating fully in community life. This is the “social model” of disability, and is defined so:

The *social model* of disability...sees the issue mainly as a socially created problem, and basically as a matter of the full integration of individuals into society. Disability is not an attribute of an individual but rather a complex collection of conditions, many of which are created by the social environment. Hence the management of the problem requires social action, and it is a collective responsibility of society at large to make the environmental modifications necessary for the full participation of people with disabilities in all areas of social life. The issue is therefore an attitudinal or ideological one requiring social change, which at the political level becomes a question of human rights. For this model disability is a political issue.⁵

The *International Classification of Functioning, Disability, and Health* (ICF) developed by WHO merges the medical and social models of disability in its classification scheme.⁵ By linking biological, individual, and social perspectives, ICF explicitly recognizes that external forces—including physical environments, social structures, governmental policies, and societal attitudes—contribute to or mitigate disability. Changing societal views of disability must therefore start by putting the medical model “into its proper perspective. If each person or close family member will someday experience disability, finding solutions should not be an individual lonely struggle.”⁶

In the health context, where the medical model can be seen as holding particular sway, there is a profound need to educate all stakeholders about people with disabilities, and not only “disability as a medical condition.” The passage of critical laws and the provision of appropriate needed services and supports are direct measures intended to give people with disabilities the tools they need to survive in the community. But these measures will not, in themselves, transform a system that fails to recognize the presence of inequality and discrimination in the documented health disparities and unequal access experienced by people with disabilities.

We cannot move forward into a demographic analysis of how race and ethnicity intersect with disability or a discussion of supports and legal protections for people with disabilities until we recognize how deeply every socioeconomic characteristic associated with disability is assumed to be a natural and direct consequence of disability: disability equals poor health, poor health equals inability to work, inability to work equals poverty, and poverty in turn explains lack of housing, food insecurity, limited educational opportunities, and health disparities, all factors that inevitably lead back to disability.

Much of the paper that follows focuses on the multiple needs of people at the intersections of race/ethnicity and disability, from identification and data collection to addressing the existence of compound barriers that cause and exacerbate health disparities. For this group at the intersections, even if work on racial and ethnic health disparities progressed quickly and ideally, it would *not* necessarily lead to better treatment and access, recognition, and reduced disparities because the disability component of their lives will still function as an overt or assumed justification for unequal results. In addition, just as disability health disparities cannot be accurately characterized as a

“minority” issue for the individual to address, a similar point, albeit for somewhat different reasons, can be made concerning racial and ethnic groups that are traditionally conceived of as “minorities.” Such groups are projected to become the majority-minority in the United States by 2044. While the non-Hispanic white (alone) population will still be the largest single race/ethnicity, no race or ethnic group is projected to have greater than a 50% share of the nation’s total. The nation’s even more diverse child population is expected to reach the majority-minority cross-over point even sooner in 2020.⁷ “Minority” populations will become the plural majority, but people with disabilities who lie within this plural majority could easily continue to be an invisible group facing compound barriers within the overlay of their own racial or ethnic culture.

Ultimately, the goal is to increase health equity and improve health outcomes for people with disabilities, particularly those who live at the intersections with diverse race, ethnicity, and language characteristics. As will be outlined, the covert biases and discrimination against this population will require working together to unearth and redress the many false assumptions about disability, race, and ethnicity that underlie the way we deliver health care, the historical development of our public health systems, and our disregard for the health disparities experienced by some groups as a natural consequence of being in the group, rather than an inequity that needs to be addressed through multiple approaches.

Our work and research below concludes that the first problem is a genuine dearth of information and data at the intersection of disability and race/ethnicity, and other personal characteristic as well. Second, the barriers are complex and exist across many stakeholders and players from individual

providers to the highest policy levels. The solutions need to equally operate on multiple levels to address embedded systemic structural and attitudinal discrimination as well as encourage practical ongoing change through such hands-on solutions as training of providers and incentivizing innovative projects around care coordination best practices. Third, there is a need for disability “care coordination” that extends far beyond the individual level. The multiplicity of disability laws, policies, and financing incentives, layered on top of the highly complex U.S. health care system, means that major players can work at cross-purposes. Even within a single federal agency, such as the Centers for Medicare and Medicaid Services (CMS), there is insufficient coordination to ensure appropriate delivery of equal health care to people with disabilities across all races and ethnicities. Time and time again, various entities, including the Institute of Medicine, have called for systemic action,^{2,8} but coordinated leadership is still lacking.

This paper begins with a framing of disability, moves through a demographic analysis of who people with disabilities are, and then discusses the range of socioeconomic barriers, as well as the health-specific barriers experienced by people with disabilities at the intersection of race and ethnic health disparities. These specific barriers include attitudes about ethnicity/race and disability, health literacy practice and research, and compound barriers. A summary of federal disability laws and their mandates in the area of health care, including the shortcomings of law as the main driver for addressing health disparities, follows. We conclude with an overview of various supports and services for people with disabilities in terms of health care access, care coordination and delivery, and accessible care delivery. Specific recommendations are made within each main section; they are summarized together in Section 7. Please note that throughout the paper, we have attempted to minimize complexity and maximize consistency in our race and

ethnic terminology as much as possible by adopting the U.S. Census categories used in 2014:
African American/Black, non-Hispanic white, and Hispanic or Latino (of any race).

Section 2

Demographic Analysis of the Population of People with Disabilities

Several national, population-based data sources provide data on disability status. Estimates of disability prevalence vary somewhat between data sources. One of the data sources that has provided the most detail about disability for the most years is the National Health Interview Survey (NHIS), conducted by the National Center for Health Statistics (NCHS) within the Centers for Disease Control and Prevention (CDC). NHIS data have been an important source of information about the population of people with disabilities overall. Analyses on the distribution of disability across racial and ethnic groups have been more limited. In this section, we provide an overview of the entire disability population based on NHIS data, and summarize the available information about types and extent of disability by race and ethnicity.

Disability Prevalence in the Adult Population

Altman and Bernstein combined 5 years of NHIS data (2001–2005) to describe the composition of the overall disability population and highlight important health and health care gaps between people with and without disabilities.⁹ The resulting report is also important in establishing a framework for categorizing the continuum of disability into sets of *basic action difficulties* and *complex activity limitations*. Basic action difficulties are limitations or difficulties in movement

or sensory, cognitive, or emotional functioning. Complex activity limitations are restrictions in the ability to participate fully in social role activities, such as working, maintaining a household, engaging in social activities, or self-care tasks.⁹

Altman and Bernstein reported that 29.5% of the adult population had a basic action difficulty. That proportion included 21.7% with movement difficulty, 13.1% with sensory difficulty, 2.8% with cognitive difficulty, and 3.1% with emotional difficulty. A total of 14.3% of adults had a complex activity limitation, including 4.1% with self-care limitation, 6.9% with social activity limitation, and 11.6% with work limitation. Both types of disability increased with age and were more common among women than men. People of lower socioeconomic status (lower education, unemployed, lower income) were markedly overrepresented in the basic actions difficulty population, and even more so in the population of people with complex activity limitations.⁹

Iezzoni, Kurtz, and Rao examined trends in disability prevalence over time, using NHIS data from 1998 through 2011.¹⁰ They applied Altman and Bernstein's algorithms for identifying each disability type, with the addition of restricting the definitions to individuals with chronic limitations (those lasting 3 months or longer). In 2011, 26.5% of the adult population had at least one type of disability, an increase of 3.9 percentage points from 1998. About one-quarter (25.4%) of adults in 2011 had one or more basic action difficulties. The most common type was movement difficulty (23.3%), followed by sensory difficulty (7.4%), cognitive difficulty (3.3%), and emotional difficulty (2.7%). A total of 14.1% had a complex activity limitation, including 4.6% with self-care limitations, 8.1% with social limitations, and 11.4% with work limitations.¹⁰ Increases since 1998 were apparent for all disability types, although the increase in prevalence of

sensory disabilities was not significant after adjusting for population changes over time in race/ethnicity, age, and body mass index. Across all time periods, disability was significantly associated with poor education, poverty, and unemployment.

Extent and Types of Disability by Race and Ethnicity Among Adults

Altman and Bernstein showed that African Americans/blacks and non-Hispanic whites were overrepresented in the complex activity limitation category, and Hispanics or Latinos and Asians were underrepresented, relative to their proportions in the population of people without disabilities.⁹ Among adults with complex activity limitations, 75.9% were non-Hispanic white, 13.4% were African American/black, 7.8% were Hispanic or Latino, and 0.9% were Asian. In comparison, among adults with no disability, 70.3% were non-Hispanic white, 11.2% were African American/black, 13.2% were Hispanic or Latino, and 2.6% were Asian. Even with multiple years of pooled data, sample sizes were too small to provide reliable estimates for American Indian/Alaska Native and multiracial populations.⁹

Prevalence of complex activity limitations by race and ethnicity (for non-Hispanic whites, African Americans/blacks, and Hispanics or Latino) was examined further by Ward and Schiller.¹¹ They found that African-American/black adults were the group most likely to have complex activity limitations, followed by non-Hispanic whites, and then Hispanics or Latinos; prevalence estimates for complex activity limitation were 17.5%, 15.5%, and 10.0%, respectively for these racial/ethnic groups. Prevalence of complex activity limitation was higher in some Hispanic or Latino subgroups than in others: complex limitations were reported by

17.9% of Puerto Ricans, 12.8% of Cuban Americans, 8.9% of Mexican Americans, 6.2% of individuals from Central or South America, and 15.8% of other Hispanics or Latinos. In each race and ethnicity group, complex activity limitations were more common among women than men and among older adults compared to younger adults.¹¹ Iezzoni and colleagues found that African Americans/blacks had higher odds of any disability when adjusting for age and sex, but the difference between African Americans/blacks and whites was attenuated when controlling for education, employment, and poverty.¹⁰

Statistics on certain types of disabilities among adults age 18 and up have been reported in consistent categories by NCHS from 2002 onward. These disability types include physical difficulty, trouble hearing, and trouble seeing. The annual summary statistics reported by NCHS for these disability categories include distributions by race and ethnicity. The cut points for determining physical difficulty and hearing trouble differ from those used by Altman and Bernstein.⁹ The physical difficulty criteria are more stringent, and the hearing trouble criteria are less stringent. Respondents are categorized as having physical difficulty only if they indicate that one or more of the movement difficulty items is very difficult or impossible for them to do.^{12,13} Respondents who indicate they have any level of trouble hearing (even a little) or are deaf are classified as having hearing trouble.^{12,13}

Across time, age-adjusted statistics for adults show a consistent pattern of more prevalent physical disability among African American/black, American Indian/Alaska Native (AIAN), Native Hawaiian and other Pacific Islander (NHPI), and multiracial respondents. On the other hand, relatively few Asians report physical disability. Physical disability prevalence among

Hispanic or Latino respondents is similar to the prevalence among non-Hispanic whites. Figure 1 shows physical disability prevalence for each race/ethnicity group at 4-year intervals, 2002–2014.

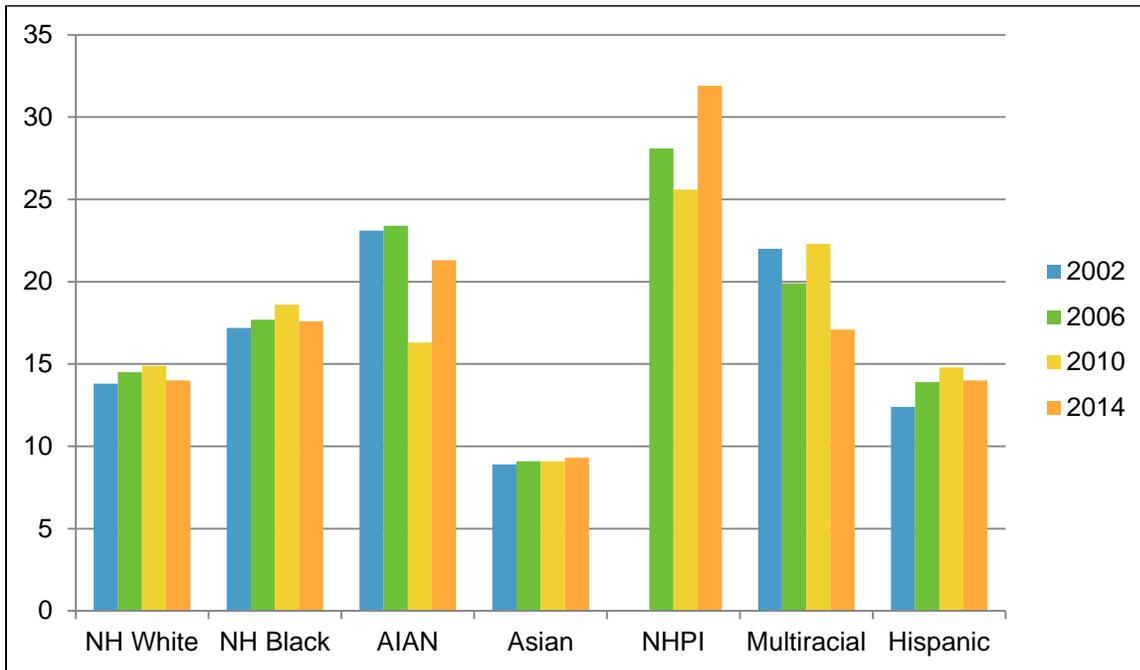


FIGURE 1 Physical disability by race/ethnicity 2002–2014.

NOTE: Changes in sampling methodology mean that data from different years are not necessarily directly comparable.

SOURCE: Adapted from data in Lethbridge-Çejku et al., 2004;¹³ Pleis and Lethbridge-Çejku, 2007;¹⁴ Schiller and Lucas, 2012;¹⁵ Blackwell and Lucas, 2015.¹²

Hearing trouble is likewise especially high among American Indian/Alaska Native and multiracial respondents and low among Asians. However, it is also relatively low among African Americans/blacks and Hispanics or Latinos, and moderately common among non-Hispanic whites, as shown in Figure 2.

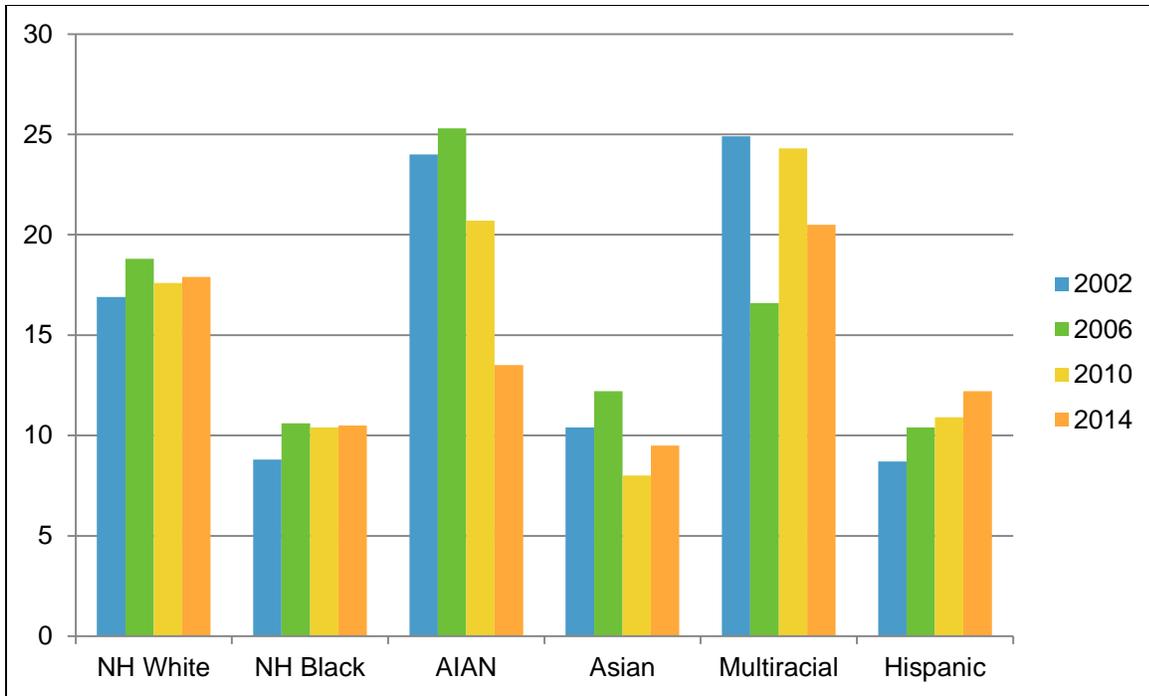


FIGURE 2 Hearing trouble by race/ethnicity 2002–2014.

NOTE: Changes in sampling methodology and a revision to the hearing question mean that data from different years are not necessarily directly comparable.) NH = non-Hispanic.

SOURCE: Adapted from data in Lethbridge-Çejku, et al., 2004;¹³ Pleis and Lethbridge-Çejku, 2007;¹⁴ Schiller and Lucas, 2012;¹⁵ Blackwell and Lucas, 2015.¹²

Distribution of vision trouble across racial and ethnic groups is more similar to the patterns seen for physical disability. Vision trouble is most common among African Americans/blacks, American Indian/Alaska Natives, and multiracial individuals and least common among Asians, and Hispanics or Latinos are fairly similar to non-Hispanic whites (see Figure 3).

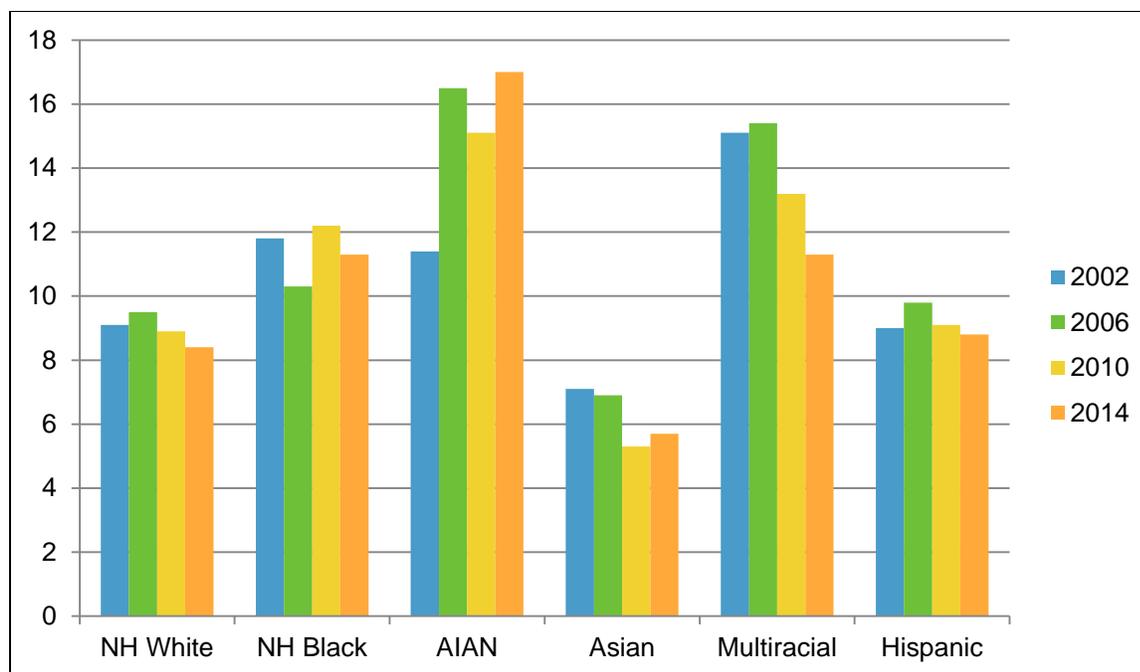


FIGURE 3 Vision trouble by race/ethnicity 2002–2014.

NOTE: NH = non-Hispanic

SOURCE: Adapted from data in Lethbridge-Çejku, et al., 2004;¹³ Pleis and Lethbridge-Çejku, 2007;¹⁴ Schiller and Lucas, 2012;¹⁵ Blackwell and Lucas, 2015.¹²

Data on the specific characteristics of people with disabilities in each racial and ethnic group have not been comprehensively reported. However, racial differences in physical disability prevalence have been observed in relation to age and sex. Holmes and colleagues reported that, among NHIS respondents age 50 and older, African Americans/blacks in each 10-year age group were significantly more likely to have physical limitations than non-Hispanic whites in the same age group.¹⁶ In fact, the prevalence of physical disability for African Americans/blacks in any given age group was similar to the prevalence for non-Hispanic whites who were 10 years older. In each age and race group, women were more likely than men to have one or more physical limitations. Differences between men and women in prevalence of physical disability widened with age.¹⁶ It should be noted that some people with disabilities in underserved racial and ethnic groups are marginalized in additional ways due to sexual identity or orientation, rural residence,

or other characteristics. Data on these multiple intersecting axes of disparity are potentially available through NHIS and other population-based surveys, but no analyses of such data have been published as yet. Small cell sizes for specific subpopulations in a single survey year would necessitate pooling multiple years of data to obtain sufficient sample sizes to provide stable estimates.

In addition to physical, vision, and hearing disabilities, other major categories of disability include intellectual disability and mental health or psychiatric disability (also known as mental illness). Intellectual disability originates before the age of 18 years and is characterized by significant limitations in both intellectual functioning and adaptive behavior.¹⁷ It is estimated to affect approximately 1% of the U.S. population.¹⁸ However, prevalence of intellectual disability varies by race, with African Americans/blacks substantially overrepresented in the population of adults with intellectual disability.¹⁹

Prevalence estimates of mental illness are available from the National Survey on Drug Use and Health, conducted by the Substance Abuse and Mental Health Services Administration (SAMHSA). In 2014, an estimated 18.1% of the U.S. adult population had any mental illness, and 4.2% had serious mental illness.²⁰ Prevalence of any mental illness is higher among women (21.8%) than men (14.1%). Mental illness also varies by age, and is less common among older adults (age 18–25 years: 20.1%, age 26–49 years: 20.4%, age 50+: 15.4%). Racial variations are apparent as well. Among non-Hispanic whites, 19.2% have any mental illness. In comparison, mental illness is somewhat less common among Hispanics or Latinos, African Americans/blacks, and Asians (15.6%, 16.3%, and 13.1%, respectively), but it is more common among NHPI,

AIAN, and people of two or more races (22.3%, 21.2%, and 27.1% respectively). Patterns are similar for serious mental illness, varying by gender (female: 5.0%, male: 3.1%), age (18–25 years: 4.8%, 26–49 years: 4.9%, 50+: 3.1%), and race (non-Hispanic white: 4.4%; Hispanic or Latino: 3.5%; African American/black: 3.1%; Asian: 2.4%; NHPI: 2.9%; AIAN: 4.0%; two or more races: 8.9%).²⁰ The high prevalence of mental illness among people of two or more races is striking, with the proportion of serious mental illness in this group more than twice as high as for non-Hispanic whites.

Many people experience more than one type of disability. In particular, mental health conditions are much more common among people with other types of disabilities than among people with no disabilities. According to 2014 data from the Behavioral Risk Factor Surveillance System, 45.0% of adults with mobility limitations and 39.1% of adults with vision limitations have had depression at some point in their lives, compared to 11.1% of adults with no disability.²¹ Further examination is needed of racial/ethnic variations in combinations of multiple types of disabilities.

Disability Among Children

Although disability is less common among children, racial/ethnic differences in disability prevalence are already apparent prior to age 18. Houtrow and colleagues analyzed 2001–2011 NHIS data on disability among children ages 0–17.²² Compared to non-Hispanic whites, disability was more prevalent among African American/black children in most years of data, and less prevalent among Hispanic or Latino children and a combined group of “multiple race or

other” children. Over time, disability prevalence increased by 13.4–22.9% for non-Hispanic whites, African Americans/blacks, and Hispanics or Latinos. Hispanics or Latinos started with the lowest prevalence of disability (49.7 cases per 1,000 children in 2001–2002 data) and showed the largest increase in disability over time. Despite the large increase, Hispanics or Latinos still had a relatively low disability prevalence (61.1 cases per 1,000) by 2010–2011. Conversely, African Americans/blacks started with the highest disability prevalence (82.2 cases per 1,000) and also ended the decade with the highest prevalence (93.5 cases per 1,000), but the percent increase over time was smaller in this group. Houtrow and colleagues noted the majority of the increase in disability was attributable to greater prevalence of neurodevelopmental and mental health conditions in more recent years of data. The greatest increase in these conditions was seen among children under the age of 6, suggesting that an increase in early diagnosis has driven the increase in reported prevalence.²² The increase was seen across racial and ethnic groups, but it was particularly prevalent for children from more advantaged families who may have greater resources for seeking diagnoses and services for their children. This represents a divergence from historical patterns in which disability increased at similar rates for children in all socioeconomic strata and was consistently more common among children from lower-income families. Currently, childhood disability is still more prevalent at lower-income levels, but the findings of Houtrow and colleagues suggest that pattern may be beginning to shift.²²

Recommendations

- 1. Mandate the collection of disability data that, at a minimum, captures functional impairment status.**

Major health surveillance instruments and much health equity work still lack disability identifiers altogether. For example, CMS administrative data sets (including state Medicaid data) do not include standard disability identifiers, and the National Health Equity Index is being developed without disability identifiers. We strongly recommend that the American Community Survey set of six disability questions or a validated equivalent set such as the Washington Short Set of questions on disability be established as a *minimum* requirement across all federally conducted data sources. These questions should also be adopted within surveillance of access to state and local programs that receive federal funds. At the same time, the incorporation of additional data elements concerning the complexity and duration of disability should be encouraged.

2. Collect disability information on a consistent and ongoing basis.

Analysis of smaller disability subgroups requires pooling multiple years of data in order to obtain sufficient sample sizes. Thus, it is crucial that a consistent and detailed set of disability identifiers be collected annually to allow such pooling. Moreover, consistent data across multiple years are needed to allow tracking of trends over time. Our current knowledge of the characteristics of the disability population and associated disparities would be much more limited without the multiyear analyses that have been conducted thus far. Our capacity, as a field, to develop deeper knowledge going forward requires the continued ability to conduct detailed multiyear analyses pertaining to disability,

particularly if we seek to better understand how disability intersects with other demographic and social characteristics.

3. Maintain and expand sources of detailed information concerning disability.

Surveys such as the NHIS, the Medical Expenditure Panel Survey, and the Survey of Income and Program Participation have historically gathered substantial detail about disability, and those detailed data have been very important for understanding the makeup of the disability population and the disparities faced by subsets of that population. Revisions to these surveys should expand, not reduce, the disability data collected to enable analyses that fully examine the characteristics of the population of people with disabilities (including type, complexity, and duration of disability) and how disability intersects with other characteristics such as race and ethnicity.

Section 3

Disabilities, Social Determinants, and Health Disparities

Whereas public health previously considered “disability” primarily as a negative health outcome, more recently disability is regarded as a *demographic characteristic* that describes the individual. As such, disability can be used in ways similar to other demographic characteristics such as age, race and ethnicity, or sexual orientation in understanding relationships with health and well-being. Disability is distributed across racial and ethnic communities, but, as seen above, it is not distributed equally across groups. Distribution of disability varies by type of limitation, but it is generally more prevalent in African American/black and AIAN communities, and less prevalent in Asian and white communities.

Determinants of health and well-being generally influence people with disabilities in the same ways as the general population. People with disabilities may experience additional challenges depending on the nature of the disability and the underlying condition contributing to the disability. The social determinants of health perspective of *Healthy People 2020*²³ serves as a useful framework for considering the challenges to well-being. We focus specifically on the social factors of education, economic stability, social and community context, neighborhood and built environment, and health care access. In doing so, we present data from nationally representative samples of children and adults where those data are readily available.



FIGURE 4 Healthy People 2020 approach to social determinants of health.
 SOURCE: Office of Disease Prevention and Health Promotion, 2016.²³

Education

Just over 40 years ago, the first federal legislation (PL 94-142) was passed to specifically guarantee eligible children with disabilities a free and appropriate public education. The Individuals with Disabilities Education Act (IDEA) of 1975 reflects recognition of the importance of educational experiences, including early intervention, in promoting optimal development in infants, children, and youth with disabilities. Educational services and reporting are federally mandated and provided through federal, state, and local funding: Part C for children birth through age 2; Part B for children 3–21 years. Earlier legislation, in the form of Section 504

of the Rehabilitation Act of 1973 (PL 93-112), also applies to public schools because they receive federal financial assistance. Section 504 is less detailed but applies more broadly to all students with disabilities, and it gives them access to related services and accommodations even if they do not qualify for special education services under IDEA. Prior to Section 504 and IDEA, children with disabilities could be and were excluded from public education in many states and school districts.

Primary and Secondary Education

About 6.4 million children, or about 13% of children enrolled in public schools, received special education services in 2012–2013,²⁴ most for specific learning disabilities or speech and language impairments. However, the eligibility, quantity, and quality of services varies substantially across geographic regions of the country and school districts, and parents report numerous challenges in accessing appropriate services for their children. Youth with disabilities are more likely to be described by their parents as less engaged with school, where engagement refers to caring about doing well at school and completing all homework. Students with disabilities are less likely to graduate from high school within 4 years compared to all students (63.1% vs 82.3%),²⁵ and adults with disabilities are more likely to report never having graduated from high school than adults without disabilities (13% vs 9.5%).²⁶ Youth with disabilities are overrepresented in juvenile detention facilities, with one national survey indicating 33% of incarcerated youth having some type of disability.²⁷ Greater likelihood of incarceration, and decreased likelihood of adequate educational programming in the facilities contribute to what is termed the “school to prison” pipeline.²⁸

Postsecondary Education

We have less information about postsecondary education enrollment by persons with disabilities. Although publicly supported institutions for postsecondary education are required to provide support for students with disabilities, these services vary widely across institutions. Data collection is sparse and inconsistent on postsecondary enrollment of students with disabilities.²⁹ Given the importance of postsecondary education for employment and future income, better data are needed on enrollment and completion of students with disabilities.

Economic Stability

Poverty

Living in poverty means living with greater parental and family stress, greater hunger and food insecurity, more housing instability, less likelihood to access health services with associated costs, and fewer opportunities to participate in sports, recreation, cultural events such as music and art, and other social activities. Children of diverse race/ethnicity and children with disabilities are much more likely to be living in families who are at or below the federal poverty level. Much higher rates of poverty are reported for children who are African American/black (65%), American Indian (62%), and Hispanic or Latino (62%).³⁰ Across race/ethnicity groups, the rate of children with disabilities living in poverty is substantially higher than children without disabilities (34% vs 24%).³¹ As adults, people with disabilities are twice as likely to live in

poverty compared to nondisabled adults, this difference is particularly evident in working age adults (28% vs 13%; see Table 1). Disability eligibility for some services such as Medicaid are income restricted, effectively requiring people to remain in poverty in order to retain these services.

Employment

Employment is an important gateway to a sense of purpose and identity, increased income, social networks, and access to training and other resources (e.g., the Internet). Adults with disabilities are much less likely to be employed than adults without disabilities (34% vs 75%). Across all types of disabilities, working age adults are less than half as likely to be employed as adults without disabilities. Lower rates of employment are particularly notable among adults with cognitive and with ambulatory disabilities where less than one-quarter of adults with these types of disabilities are employed. Rates of unemployment—that is, persons who are capable of working but do not have employment—is also twice the rate of persons without disabilities (15% vs 8.7%).

Food Insecurity

Disability is one of the strongest risk factors for food insecurity. Food insecurity refers to being without reliable access to adequate affordable, nutritious food.³² In 2009–2010, one-third of households with a working-age adult who was unable to work because of disability were food insecure, and one-quarter of households were food insecure when the working-age adult's

disability did not prevent them from working. This compares with 12% of households without a working-age adult with disability who were food insecure. Not only are persons with disabilities more likely to experience food insecurity, they are more likely to experience more severe food insecurity that is reflected in patterns of disrupted eating and reduced food intake. These challenges are further compounded by the reality that healthy food shopping and preparation may be more difficult for persons with mobility, cognitive, or visual disabilities.³²

Housing

Inadequate and unaffordable housing is an important health indicator for both people of color and people with disabilities,³³ increasing their risk of housing insecurity and homelessness.³⁴ Poor health outcomes are associated with substantial disparities in housing, lack of housing mobility, and housing discrimination.³⁵ People with disabilities are more likely to live in substandard housing that present health hazards such as pests, physical damage, or rodent infestations than those who do not have disabilities, even controlling for income.³⁶ The national housing shortage and rapidly rising housing costs drastically and differentially affects nonelderly adults with disabilities living solely on Supplemental Security Income (SSI). In 2014, the national average rent for a one-bedroom apartment was 104% of monthly SSI disability payments, with rents exceeding 150% in 15 housing areas.³⁷ An estimated 84,000 people with serious mental illness, substance use disorder, post-traumatic stress disorder (PTSD), developmental and cognitive impairments, and other disabilities were chronically homeless in 2014.³⁷ Among people who were homeless in 2015, 16.5% were Hispanic or Latino and 35.5% were African American/black.³⁸ Some people with disabilities require accessible housing, which

is in short supply and most likely available in newer and more expensive housing. The cost of modifying a home for accessibility is prohibitive for many low-income people with disabilities.³⁶ Low-income housing has experienced almost no growth during the past 2 decades, contributing to it being extremely limited with long waiting lists, and a very limited number of accessible units. Lack of affordable, accessible housing is one of the biggest barriers people face who are living in costly nursing homes or other institutions and who want to move to the community.³⁹

Social and Community Context

Social Cohesion

Unlike characteristics of race, ethnicity, and language that are typically shared with other members of one's family and community, a person with disabilities may be the only person in their family or social group to experience these limitations. This typically results in the person with disabilities not having easy access to a community of peers as a child, adolescent, and adult. Families of children with disabilities often report feeling isolated from their communities and extended families. Centers for independent living and disability self-advocacy organizations are invaluable in providing the opportunity for developing friendships and a sense of community for some people with disabilities. Children with emotional, developmental, or behavioral conditions are almost twice as likely to not be engaged in organized after-school activities.⁴⁰ For adults with disabilities, social isolation is reflected in their being less likely to socialize frequently with family and friends, and much less likely to go out to restaurants to eat. People with severe

disabilities (32%) are much less likely than are people with slight (55%) or moderate disabilities (66%) to report they eat in restaurants at least twice a month (NOD, 2010).⁴¹

Discrimination

The United States has a long history of discrimination against people with disabilities, most notably in institutionalization of many people with severe disabilities. Numerous legislative bills have been passed to address the discrimination and segregation that people with disabilities have experienced. The Americans with Disabilities Act of 1990 was intended to reduce discrimination, and the ADA definition of disability is “a person who has a physical or mental impairment that substantially limits one or more major life activities, a person who has a history or record of such an impairment, or a person *who is perceived by others* as having such an impairment” [italics added]. Yet people with disabilities continue to report discrimination as a major barrier in their lives. For example, a significant minority of people with disabilities (43%) report that they have encountered some form of job discrimination in their life.⁴¹

Incarceration

Based on data from the Department of Justice (DOJ) survey in 2011–2012, about 3 in 10 state and federal prisoners and 4 in 10 of local jail prisoners report having at least one disability. The most common type of disability reported was cognitive disability, which was also associated with high rates of serious psychological distress. Non-Hispanic white (37%) and prisoners of two or more races (42%) were more likely to report a disability than African American/black

prisoners (26%).⁴² Recent attention to the circumstances of incarcerated persons with disabilities highlights complaints that (1) prisoners are routinely denied attention to their mental or physical needs, (2) inmates receive inequitable access to facilities programs and activities, and (3) there is a lack of effective communication for inmates with hearing or vision loss.⁴²

Neighborhood and Built Environment

Safety

Families of children with disabilities and special health care needs are as likely to live in safe communities or neighborhoods as families whose children do not have special needs.⁴⁰ However, crimes against people with disabilities was more than twice that of persons without disabilities in 2013 (36 per 1,000 vs 14 per 1,000), with people with multiple disabilities representing 51% of the victims. Crimes included rape or sexual assault, robberies, aggravated assaults, and simple assaults. The rates of violent crime against persons with disabilities who were white (38 per 1,000) or African American/black (31 per 1,000) was higher than for other races (15 per 1,000).⁴³

Transportation

Transportation is often essential for access to services, employment, recreation, and engagement in community. Yet people with disabilities are more than twice as likely to report that transportation was a significant barrier for them (34% vs 16%).⁴¹ A 2003 study by the U.S.

Department of Transportation identified about 560,000 people with disabilities who reported never leaving their home because of transportation problems.⁴⁴

Health Services

Access to Health Care

Access to health care includes timely access to quality primary and specialty care, and, for some, access to durable medical equipment (DME). Adults with disabilities are less likely to have private or employer-funded health insurance and more likely to be insured through Medicaid and Medicare,⁴⁵ but they are about as likely not to be insured at all as people without disabilities (16.8 to 18.6% vs 18.9%).⁹ From 2001 to 2005, people with emotional difficulties were most often to report being uninsured (28%).⁹ Despite comparable rates of health insurance coverage, adults with disabilities are two to three times more likely to report having not accessed needed health care in the previous year owing to cost.⁴⁶ Children with special health needs are more than twice as likely as their nondisabled peers to report unmet health care needs (12% vs 5%). Adults with disabilities are also more than twice as likely to report unmet mental health needs (7% vs 3%). In terms of preventive services, women with disabilities in 2008 were less likely to be current with their Pap test (79% vs 83%) and mammogram (72% vs 78%).⁴⁷

Health Outcomes

People with disabilities have much poorer health outcomes, with many of these poor outcomes believed to be preventable. Obesity rates are 58% and 38% higher among adults and youth with disabilities than their nondisabled peers.⁴⁸ The annual number of new cases of diabetes is almost three times as high among adults with disabilities relative to adults without disabilities (19.1 per 1,000 vs 6.8 per 1,000). Disability status is a high risk factor for early onset cardiovascular disease, with rates of 12% vs 3.4% among 18 to 44 year olds with and without disabilities.²⁶ Adults with disabilities are also much more likely to experience cardiovascular disease during young adulthood as well as older years. See Figure 5 and Figure 6 for additional examples.

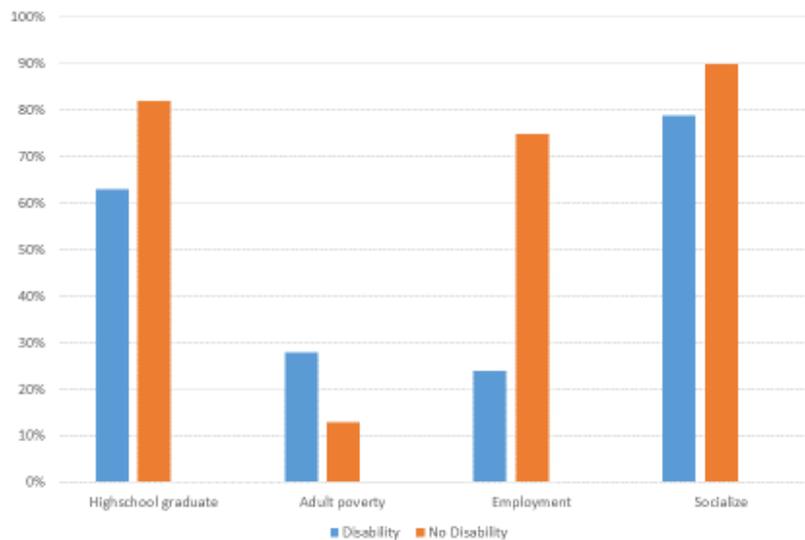


FIGURE 5 Disparities in select social determinants of health for people with and without disabilities

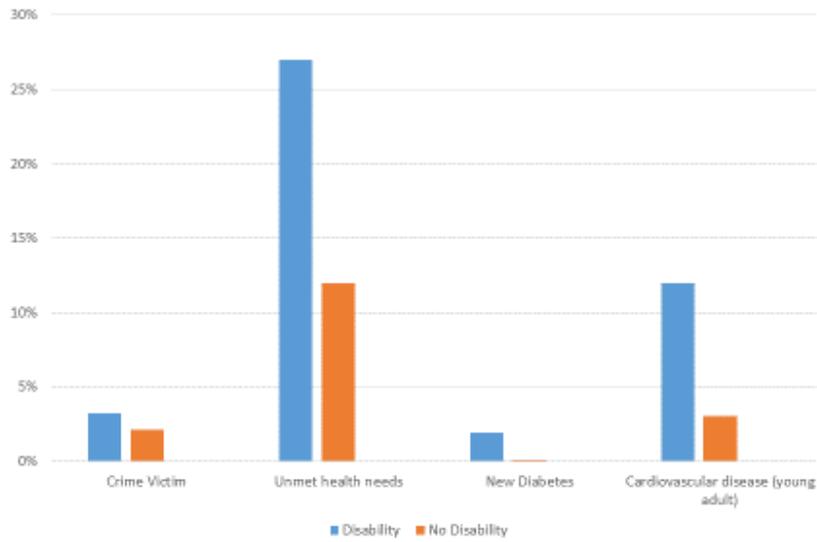


FIGURE 6 Disparities in select health outcomes for people with and without disabilities.

Additional information and data sources on disparities in social determinants and health outcomes is presented in Table 1.

TABLE 1 Disparities for Persons with Disabilities Based on the Social Determinants of Health and Well-Being

Social Determinant	Challenge Area	Data Source and Year	Data (child/adult with disability vs no disability)
Education	School engagement	NSCH 2011/12	Never/rarely/sometimes engaged in school—33.2% vs 15.3%
	High school graduation	NCES 2013-14 BRFSS 2010	Graduate high school in 4 years—63% vs 82% Less than high school education—13% vs 10%
	Enrollment in higher education	No reliable data source	
Economic Stability	Poverty	ACS 2014	Living in poverty— Children (under 5): 34% vs 24% Children (5–17): 33% vs 12% Adults (18–64): 28% vs 13%

Social Determinant	Challenge Area	Data Source and Year	Data (child/adult with disability vs no disability)
			Adults (over 65): 13% vs 8%
	Employment (18–64)	ACS 20141	Employment— All disabilities: 34% vs 75% Hearing disabilities: 51% Vision disabilities: 40% Cognitive disabilities: 24% Ambulatory disabilities: 24%
	Unemployment	CPS 2011	Able to work but unemployed— 15% vs 9%
	Food insecurity	ERS 2009–2010	Not working due to disability: 34% Other reported disability: 25% No disability: 12%
	Housing stability	Priced out in 2014 NOD 2010	Rent for 1 bedroom unit averaged 104% of SSI monthly income Home ownership— 59% vs 67%
Social and Community Context	Organized activity outside of school	NSCH 2011–2012	No organized activity outside of school— Overall CSHCN: 22% vs 19% (Youth with emotional, developmental, or behavioral conditions 31%)
	Social cohesion	NOD 2010	Socialize with friends, family, or neighbors at least twice a month— 79% vs 90%
	Civic participation	NOD 2010	Internet access— 54% vs 85% Voted in last presidential election— 59% vs 59%
	Discrimination and segregation	NOD 2010	Encountered job discrimination in lifetime— 43% (no comparator)
	Incarceration	DOJ 2011–2012	3 in 10 state and federal prisoners have a disability; 4 in 10 jail prisoners
Neighborhood and Built Environment	Safety	NSCH 2011–2012	Children live in safe community or neighborhood— 86% vs 87%

Social Determinant	Challenge Area	Data Source and Year	Data (child/adult with disability vs no disability)
	Crime and violence	NCVS 2007	Victim of violent crime (per 1,000 persons)— 32.4 vs 21.3
	Transportation	NOD 2010	Inadequate transportation— 34% vs 16%
Health Services	Access to health care	NSCH 2011–2012	Children with unmet need in past year—12% vs 5%
	Access to health care	BRFSS 2010	Adults with unmet need in past year due to cost—27% vs 12%
	Access to mental health care	NOD 2010	Adults with unmet mental health need in past year—7% vs 3%
	Access to primary care	BRFSS 2010	Preventive care: Current with mammogram— 71% vs 77% Current with Pap test— 78% vs 82%
	Obesity—adult	BRFSS 2008	Adults: 36% with disability, 23% without disability
	Obesity—child/youth	NHANES 2003–2008	Ages 2–17: 22% with disability, 16% without disability
	Diabetes	NHIS 2008–2010	Annual number of new cases (per 1,000 persons)—19.1 vs 6.8
	Cardiovascular disease	NHIS 2009–2011	18–44 years—12% vs 3% 45–64 years—28% vs 10%

NOTES: ACS = American Community Survey; BRFSS = Behavior Risk Factor Surveillance System; CPS = Current Population Survey; DOJ = Department of Justice; ERS = Economic Research Service, U.S. Department of Agriculture; 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; NCES = National Center for Education Statistics; NSCH = National Survey of Children’s Health.

Recommendations

- 1. Recognize disability within public and private systems as a population that experiences disparities in health and social determinants.** The data clearly support recognizing people with disabilities as a health disparity population. The disparities in

social determinants of health such as education, economic stability, social and community contexts, and access to health services contribute to these disparities in health outcomes. As done by the Centers for Medicare and Medicaid Services, other federal and state agencies should formally recognize people with disabilities as a health disparity population and include them in policies, programs, and practices intended to reduce health disparities.

2. **Explicitly include disability in health equity research and programs.** Disability status should be routinely included in all research and programs that address health equity.

3. **Health and social service programs should examine participants by disability and race/ethnic diversity to best meet their needs.** To meet participant needs and to document effectiveness of services, health and social service programs need to know the disability status and the type of disability of their program participants. This information should influence program planning and be included in reports.

Section 4

Health Specific Barriers for People with Disabilities

SECTION 4A:

ATTITUDES ABOUT RACE, ETHNICITY, AND DISABILITY

Race and Ethnicity

The United States racial legacy and history of racial inequalities is deeply woven in American culture. The misconception that African Americans/blacks are inferior to whites^{49,50} is a pervasive and dangerous ideology that negatively affects a number of domains across the life span. The African American/black experience within the United States has been shaped by slavery, segregation, discrimination, and racism. Racial bias and discrimination has contributed to severe differences in life outcomes between whites and racial and ethnic groups other than non-Hispanic whites. Racial and ethnic health disparities are substantial, well documented, and persistent.⁵¹⁻⁵⁵

The Hispanic experience in American society differs from the African American/black experience in that the Hispanic population has grown dramatically in recent decades, and is culturally diverse reflecting different histories and language than white Americans.⁵⁶ In addition, concerns about illegal immigration affect the attitudes of whites toward Hispanics or Latinos.

Undocumented immigrants are blamed for taking jobs away from Americans, suppressing wages, contributing to higher unemployment, and imposing a fiscal burden on other tax payers.⁵⁶ It is likely that negative attitudes toward undocumented immigrants extend toward Hispanics or Latinos in general. Thus explicit and implicit bias toward Hispanics or Latinos may be compounded by a perception of foreignness.⁵⁷ Stereotypes and negative attitudes toward Hispanic-Americans are pervasive in the United States and reinforced by news and entertainment media messaging.⁵⁸

African Americans/blacks and Hispanics or Latinos experience barriers to routine care at a higher rate than their white counterparts.⁵⁹⁻⁶² Moreover, these groups report less access to preventive services,^{63,64} poorer health outcomes,⁶⁵ and decreased likelihood of having a usual source of care.⁶⁶ A 2002 written report by the Institute of Medicine found African Americans experienced poorer quality of care, had more unmet health needs, and were less likely to access a primary care provider and to be referred for specialty care. Disparities were also noted in rates of access to and use of health care services. Health disparities among Hispanics or Latinos vary significantly by English fluency.⁶⁷ In a national sample of insured, nonelderly adults, English-speaking Hispanic or Latino patients used health care services much less than similar non-Hispanic white patients. Spanish-speaking Hispanic or Latino patients were significantly less likely than non-Hispanic white patients to have had a physician visit, visit with a mental health provider, influenza vaccination, or mammogram.

There are several philosophies surrounding this trend including provider bias, perception, and prejudice.⁶⁸⁻⁷² Moreover, authors found that physician stereotyping, bias, and clinical bias play a

role in health care disparities across racial and ethnic groups. Much of this bias may result from unconscious beliefs through a mechanism known as implicit bias. Such unconscious mechanisms can include emotional responses such as increased amygdala activation when viewing African American/black faces.^{73,74} Implicit bias and resulting prejudicial attitudes have been seen in nursing students,⁷⁵ medical students and residents,⁷⁶ practicing nurses,³⁹ and doctors.⁷⁷⁻⁸⁰ This implicit bias is associated with race-based disparities in treatment, including emergency situations,⁷⁹ health care communication,⁸¹ and especially in pain management.⁷⁹ Through these treatment disparities, implicit bias is believed to contribute to racial disparities in overall health.⁸⁰

Adverse stereotypes about diverse racial and ethnic groups by health care providers can negatively affect health outcomes and contribute to health disparities. Studies indicate that physician stereotyping can negatively affect how doctors engage with patients from diverse racial groups. Moreover, a patient's race directly affects a providers' beliefs and expectations of the patient.^{69,82-85} A number of studies have found that during clinical interactions with African American/black patients physicians provide less information, spend less time, are more verbally aggressive, and less supportive.^{69,86-91} Providers feel that African Americans/blacks are less cooperative and less likely to comply with medical treatment.^{69,70}

Disability

Negative attitudes toward and assumptions about disabilities have an adverse effect on the health and quality of health care for people with disabilities. The perception of disability clearly elicits

pity, compassion, and desires to be helpful, but it also elicits distinctly negative reactions such as disgust and anxiety, and manifests in attitudes and judgments such as the tendency to blame individuals for their disabling conditions and the tendency to avoid contact with people who have disabilities.⁹² Disability bias has been reported to be moderate to strong. In fact, bias against people with disabilities was among the strongest implicit and explicit responses. These negative attitudes were evident across genders, ethnicities, age groups, and political orientations and even among participants who themselves had disabilities.^{93,94} Health care providers are not protected from prevalent social attitudes and biases. In fact, they are drawn to the profession and trained to restore their patients to full health.⁹⁵ Unfortunately, this mindset proves challenging when confronted with a patient who has a permanent disability. Health care providers may feel frustrated or defeated at the outset because public health has already failed to prevent or heal the disability.⁹⁶ Negative attitudes have been reported by medical students,^{97,98} nursing students,⁹⁹ other health professional students,⁹⁹ physicians,¹⁰⁰ and nurses.¹⁰¹

Attitudinal bias¹⁰² among health care professionals¹⁰³ against people with mental health conditions may play a greater role in access, treatment, and quality of health care. Health care providers are likely to hold stereotypical beliefs about people with mental health conditions, and this bias may be a barrier to obtaining quality care even for conditions unrelated to mental health. Legitimate health complaints by patients with a history of mental health disorders are often assigned little credibility as health care staff attribute all complaints of distress to the mental condition.¹⁰⁴

Health care providers face barriers to effective communication and providing quality health care

to diverse populations. One fundamental barrier is the perception that the patient differs in significant, meaningful, and somewhat undefined ways from other patients and from the provider. This scenario is prevalent when caring for patients from different ethnic or racial backgrounds and when caring for patients with disabilities.¹⁰⁵ In a study to develop a Disability Attitudes in Health Care scale, Chadd and Pangilinan (2011)¹⁰⁶ found that regardless of year or clinical experience, medical students and residents viewed patients with disabilities more negatively and as different than able-bodied patients. This finding reflects a perception that it is more difficult or less appealing to provide health care to such a patient. The assumption of difference is the basis for other beliefs and attitudes that are detrimental to patient care.

A second barrier to quality care that reflects an attitudinal bias is the inability assumption. People without disabilities tend to underestimate the abilities of people with disabilities, assuming lower levels of cognitive ability, independence, and interest in improving and maintaining current function. Robey and colleagues (2006)¹² found that even caregivers of adults with disabilities had infantilizing implicit attitudes toward people with disabilities. With the assumption that the patient is extremely limited, the next logical and inaccurate assumption made by health care providers is that patients with disabilities are incapable of contributing to their own health care or health care plan and decisions. The health care provider acts with benevolence on behalf of the disabled patient and, while they have the patient's best interests in mind, they are also likely to hold inaccurate assumptions and biases that limit the quality of health care.

A third assumption that reflects a negative bias and that directly affects health care is that quality of life is severely compromised by disability.¹⁰⁶ When asked to imagine their life after acquiring

a paralyzing injury, health care providers estimated their life would be barely worth living. In fact only 18% of emergency care providers including emergency nurses, technicians, residents, and attending physicians imagined they would be glad to be alive after sustaining a spinal cord injury. This is in stark contrast to the 92% of spinal cord injury survivors who reported having a good quality of life.¹⁰⁷ This misconception directly affects patient care by limiting the type, scope, and aggressiveness of treatment options considered. One study found that 71% of pediatric residents questioned the aggressive treatment of children with severe disabilities,¹⁰⁸ and only 22% of emergency care providers reported they would want to be treated with “everything possible to ensure survival” after a severe spinal cord injury.¹⁰⁷ Drainoni and colleagues (2006)¹⁰⁹ reported a case of a woman with intellectual disability and advanced breast cancer requiring surgery. Her physician determined that surgical intervention was not warranted due to her already low quality of life (owing to her disability). She died within a year.

Impact of Attitudes on Health Care

Something curious was happening in the emergency room. Eight patients had come in within minutes of each other. Almost instantly, the junior resident, two interns and a medical student signed up for all of them—except for one. Half an hour passed, then an hour. As the senior resident doctor at the time, I supervised the others as they tended to the middle-aged man with chest pain, the elderly woman with a broken wrist and the teenage girl with a sore throat.

New patients kept coming in, and they, too, were seen quickly. Still, there was that one patient everyone seemed to avoid, a man in his 20s with back pain. I watched as the medical student picked up his chart, then placed it back on the

rack. Nurses, too, weren't going to his room. Finally, I assigned a team to care for him. “We drew the short straw here,” I overheard the nurse say. The resident sighed. “I already ordered labs and an X-ray. It's going to take too long to examine him, so let's just get this started.”

What was different about this patient? Was it a dangerous, contagious disease? A mental health problem marked by a violent streak? A history of weekly drunken visits to the ER? No. All he had was a wheelchair.

—Wen, 2014 NPR shots¹⁷

Attitudes about disability negatively affect the quality of medical care, especially in communication, diagnostic overshadowing, and providing quality age-appropriate care.

Communication

Health care provider attitudes profoundly affect communication, health literacy, and ultimately the health of their patients with disabilities. One alarming example appears in the area of patient communication. Breakdowns in communication are reported across disability types.^{110–113}

Patients with disabilities complain that physicians do not spend enough time to communicate effectively.^{110,112–117} Deaf patients often complain about difficulty understanding their health care provider. They report providers speaking too quickly and using unfamiliar vocabulary. Although the use of an ASL interpreter has been associated with significantly higher use of preventative care including colonoscopy, flu shot, and cholesterol screening among deaf people,¹¹⁸ interpreter services are not always provided even when requested by the patient.^{114–116,119} In qualitative

studies of health care experiences, focus group participants with disabilities described negative experiences in the health care system creating a loss of trust in health care providers and even fear of certain health providers and settings.^{109,115} As noted in the *World Report on Disability*,¹²⁰ negative experiences with the health care system, such as experiencing disrespect, insensitivity, and devaluation, may lead people with disabilities to eschew seeking care and rely upon self-diagnosis and treatment.

Diagnostic Overshadowing

Physicians lack the expertise and skills to distinguish clinical concerns arising from disability from those related to other health conditions. Often the apparent disability “overshadows” the clinical concern during the health care visit. This limited knowledge and understanding of disability deleteriously affects quality of care, contributing to delays in diagnosis and treatment, unsafe care, and inequities in care.^{121–126}

Quality Age-Appropriate Care

As previously mentioned, people with disabilities may be regarded as childlike¹²⁷ and asexual.^{128–130} This assumption may contribute to the finding that women with disabilities undergo colon cancer screening at similar rates as their nondisabled peers, but experience disparities in breast cancer and cervical cancer screening.^{131–133} The sexual health of women with intellectual disabilities is particularly neglected¹³⁴ in terms of screening for breast^{135–137} and cervical cancer.¹³⁷

Impact of Attitudes on Public Health

The stated mission of public health activities is to prevent mortality, morbidity, and disability. Attention has only recently turned to the health of people who are living with a disability that is not “prevented.”⁹⁶ The fact that disability is largely absent from public health training and practice leaves public health unprepared to address the health needs of this vulnerable population. Particularly detrimental are the effects on how public health issues are prioritized and researched.

Prioritizing Measures: DALYs

The Disability Adjusted Life Years (DALYs) was developed in an effort to objectively quantify the effects of disease, health behaviors, and health interventions in order to set priorities and allocate public health resources. DALYs estimates disease burden by combining estimates of premature mortality (life years lost) and estimates of years of healthy life lost to disability.^{138,139} Use of DALYs requires complex calculations that combine premature mortality estimates for a health behavior, intervention, or disease with disability estimates, which are modified with disability and age multipliers.¹⁴⁰ DALY measures are commonly used by U.S. researchers and government bodies.¹⁴¹

This measure is problematic for two reasons. First, the premise of this instrument is that a disabled person’s life is less valuable and thus less cost-effective than the life of an able-bodied person.^{140,142} The conception of the DALYs may have been based on the faulty

assumption that disability necessarily lowers quality of life. A second concern with the DALYs is the method by which disability weights are determined. People without disabilities establish disability weights by comparing the “utility” and “quality of life” for people with different disabilities.^{140,143} As previously stated, people without disabilities grossly underestimate quality of life for people with disabilities.^{106,144–147} Krahn and colleagues (2014)¹⁴⁸ proposed that journals, the CDC, and NIH adopt policies to use Health-Adjusted Life Years instead of DALY measures in research and publications. We strongly support this proposal.

The Invisibility of Disability in Epidemiological and Clinical Trials Research

Clinical trials and other public health research routinely exclude participants with disabilities or comorbid conditions in the interest of recruiting a homogenous sample to maximize the odds of measuring an effect.¹⁴⁹ However, excluding people with comorbidities from this research leads to the creation of an evidence base that is not representative of the general population.¹⁵⁰ Some comorbidities excluded in studies are held by a plurality or majority of the target population for the treatment being studied.¹⁵¹ These evidence-based interventions, then, may have unexpected or deleterious effects on the many patients who differ from the homogenous participant group.^{152,153}

The National Institutes of Health (NIH) Revitalization Act of 1993 ensured the inclusion of women and of diverse racial groups when it required reporting of racial and gender makeup of participants in NIH-funded clinical trials. Similar reporting requirements for disability characteristics of clinical trial samples would be a logical step towards equity. Some journals are

adopting standards for reporting racial/ethnic characteristics of study samples.¹⁵⁴ Greater adoption of these policies would also be expected to increase equity, as would journals' adoption of policies for reporting disability characteristics of study samples.

Attitudes at the Intersection of Race, Ethnicity, and Disability

Although attitudinal research has been conducted separately for disadvantaged racial, ethnic, and disability groups, much less attention has been paid to people with disabilities in disadvantaged racial and ethnic groups. (Section 4B will discuss the related point that little research attention has been paid to the racial, ethnic, and cultural distinctions among people with disabilities.)

Promising Practices: Disability Competence for Public Health and Health Care Providers

Two surgeons general reports,^{155,156} one Institute of Medicine Report (2007),² the National Council on Disability Report (2009),¹²⁸ and the WHO World Report on Disability (2011)¹²⁰ all recommended that we, as a society, improve knowledge, skills, and attitudes of health care providers to improve the care and health of people with disabilities.¹⁵⁷ Although the Liaison Committee for Medical Education (LCME) emphasizes the value of diversity and providing culturally competent care in its accreditation standards,¹⁵⁸ there is no requirement to include disability in the training of future physicians in the United States. Likewise, disability content is lacking in nursing training programs.¹⁵⁹ Similarly, most public health training programs do not include curriculum on people with disabilities and methods for including them in core public

health efforts. The fact that any student learns about caring for patients with disabilities is thanks to individual champions within medical, nursing, and public health programs.

We believe that accreditation standards for health care training programs should be expanded to address the health needs of the 20% of the population with disabilities.¹⁶⁰ A health care workforce with appropriate training on the care of patients with disabilities would begin to improve health care for this underserved population.

Including disability training as one aspect of cultural competence would mitigate many current concerns including persistent societal stigma toward people with disabilities that infiltrate patient–provider interactions. These biases contribute to misconceptions and erroneous assumptions that compromise patient care, contributing to delays in diagnosis and treatment, unsafe care, and inequities in care.¹²⁰

Appropriately training future health care providers to care for patients with disabilities could prevent the aforementioned and other problems.^{161,162} Introducing concepts from WHO’s International Classification of Functioning⁵ would help students appreciate the social and societal aspects of disability in addition to the medical model of care. This perspective will enhance the provider’s ability to recognize disability, identify contributors to disability including social and environmental factors, communicate effectively with patients who have disabilities, and understand where disability fits into individuals’ lives, values, preferences, and expectations about their health and future—all essential foundations for patient-centered care.^{97,162–164} In fact, disability training of health care students has been shown to improve

attitudes.¹⁶⁵⁻¹⁶⁷ Similarly, addressing disability in public health training programs would expand workforce skills and practice to ultimately enable public health professionals to successfully develop programs and activities that include people with disabilities.

Competencies have been recently drafted for public health¹⁶⁸ and outlined for health care providers. The Alliance for Disability in Health Care Education is currently drafting a set of disability competencies for health care providers. These competencies are undergoing an evaluation process prior to publication in 2018.¹⁶⁹ Curricular elements that include patients with disabilities would support the fundamental goals of cultural competence, diversity, and meeting the needs of underserved and vulnerable populations. By implementing a health care curriculum that increases sensitivity to people with disabilities and also provides core concepts and key aspects about people with disabilities and health care issues, medical, nursing, public health and other undergraduate and graduate programs can improve trainees' confidence and comfort in caring for patients with disabilities, while replacing negative assumptions and stereotypes with an open frame of mind that is prepared to ask questions and listen to the needs and preferences of their patients.¹⁷⁰

Recommendations

- 1. Disability competence must address several topical components.** Subject matter content should include at a minimum such topics as disability sensitivity and stereotypes, physical and programmatic accessibility required by law, and clinical expertise.

2. Disability competence must be required at multiple levels and across disciplines.

Training on disability competence should be provided at the preservice, professional licensure, and continuing education levels, and as a component of ongoing accreditation.

Disability training must be directed at primary care and all health care professionals, including mental health, dental, and rehabilitation/habilitation practitioners. It should also include public health and human services practitioners and researchers, as well as policy makers within federal and state departments of health, human services, and public health.

SECTION 4B:

**HEALTH LITERACY IN THE CONTEXT OF
DISABILITY, DISPARITY, AND HEALTH EQUITY**

Defining Health Literacy

During the past 20 years, we have witnessed the conceptualization and practice of health literacy as well as the conduct of related research grow exponentially. The extant literature includes thousands of peer-reviewed articles, studies, tools, measurements, evidence-based practices, and interventions specifically designed to enhance health literacy among individuals and populations.¹⁷¹⁻¹⁷⁵ A selected review of this literature reveals that: (1) definitions of health literacy continue to evolve; and (2) policy makers, researchers, practitioners, and other stakeholders have yet to reach consensus on a shared understanding and definition of health literacy.

An array of definitions of health literacy are prevalent in the health care literature. Nutbeam defined “health literacy as the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand, and use information in ways which promote and maintain good health.”¹⁷⁶ In 2000, the U.S. Department of Health and Human Services defined health literacy as the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.¹⁷⁷ In 2004, with the issuance of the Institute of Medicine (IOM) study, this focus began to shift from viewing health literacy solely in the domain of the individual to include the skill of health care professionals and the capacity of health care systems as well as other entities that provide health information. The IOM concluded:

Health literacy is a shared function of social and individual factors. Individuals’ health literacy skills and capacities are mediated by their education, culture, and language. Equally important are the communication and assessment skills of the people with whom individuals interact regarding health, as well as the ability of the media, the marketplace, and government agencies to provide health information in a manner appropriate to the audience (p. 32).¹⁷⁵

Lastly, the work of Rima Rudd and colleagues brings us full circle. Rudd pushes us to reenvision and redefine health literacy from a completely different lens. There are two primary assertions from her work. First, she asserts that major responsibility for health literacy should rest in the design and implementation of health care that removes systemic barriers to the communication of health information and that facilitates access to, and the meaningful engagement of people in,

such processes. Second, she posits that it is essential to recognize the broader sociocultural contexts in which health literacy is experienced. She postulates that in order to optimize health and well-being, health information must be adapted to the everyday lives of people and the everyday occurrences in the communities in which they live. According to Rudd, and commensurate with these insights, health literacy is the capacity of professionals and health institutions to provide access to information and support the active engagement of people.¹⁷¹

The health literacy definitions presented thus far could be interpreted as only applying to a person's physical health as none specifically address mental or behavioral health. The supplement to the first *Surgeon General's Report on Mental Health* cited evidence that chronic physical illness is recognized as a risk factor for mental illness when risk is considered for individuals.¹⁷⁸ Subsequent studies documented this finding. Currently there is a movement for integrative care—coordinating and providing behavioral health care in primary care settings; however, there is still a lack of recognition of the need for such integration in many health care systems and practices. A substantial number of individuals who have disabilities and chronic illness may also experience comorbidity of depression or other mental health disorders.

Therefore it would be an oversight if we failed to include a definition of mental health literacy.

The following definition of mental health literacy is offered to raise awareness of the need to address mental health in the conceptualization of health literacy and in related research and interventions. The Canadian Mental Health Alliance defines mental health literacy as the “knowledge, beliefs, and abilities that enable the recognition, management, or prevention of mental health problems. Enhanced mental health literacy is thought to confer a range of

benefits—prevention, early recognition and intervention, and reduction of stigma associated with mental illness.”¹⁷⁹

Why is defining health literacy so important? The definition provides the foundation for the necessary values, policies, structures, and practices of health literacy from the combined interests and needs of individuals, families, communities, and health care system professionals and systems. A universally shared understanding and framework will increase the view that “the capacity for effective social, political, and individual action is reflected in the recognition of health literacy as an asset rather than a goal.”¹⁷¹ Based on this definition and conceptualization, we can deduce that implementing theoretical and practical approaches to health literacy, that are linked to sociopolitical and cultural contexts in local communities, both align with the promotion of health equity and have the greatest potential to reduce the burden of health disparities across diverse population groups.

Health Literacy Through the Lens of Disability, Culture, and Language

In 2003, the CDC stated that limited health literacy affects adults across all racial and ethnic groups, and that cultural and linguistic competence should be adhered to in policy and practice in initiatives to address disparities.¹⁸⁰ Most recent U.S. Census data indicate that in 2014 just under 30% of the population belongs to racial and ethnic groups other than white alone,¹⁸¹ and the foreign-born population was placed at 42 million people or approximately 13% of the population.⁷ In 2014 over 21% of the U.S. population over 5 years of age speaks a language other than English at home.¹⁸² Among these 4.5% reside in limited-English-speaking households

where no member of the household 14 years of age or older (1) speaks only English, or (2) speaks a non-English language and speaks English very well.¹⁸³ As measured by the Program for the International Assessment of Adult Competencies (PIAAC), the proportion of people ages 16 to 64 living in the United States demonstrated disparity in health literacy by race, ethnicity, and employment status. A total of 16% of unemployed whites, 34% of African Americans/blacks, and 36% of Hispanics or Latinos scored at or below level 1 on the PIAAC between 2012 and 2014.²⁴ The diverse population of people with disabilities living in the United States is accounted for in these demographic data. However, with few exceptions, the extant literature is almost devoid of health literacy frameworks and interventions that are responsive to the racial, ethnic, cultural, and linguistic diversity among peoples residing in the United States, its territories, and in tribal communities.^{184,185}

The previously presented definitions of health literacy are conceptualized in a manner in which they could be inclusive of disability, yet current practice indicates otherwise. While evidence is beginning to emerge, there is a paucity of research and intervention literature that specifically examines health literacy within the context of people with disability in general, and those with developmental and intellectual disability in particular.^{184,185} This literature tends to address people with disabilities as a homogenous group, distinguishing only the nature of the disability by physical, sensory, cognitive, and mental illness categorizations. Moreover, this literature neither acknowledges nor addresses the intersection of disability, race, and ethnicity and their implications for health literacy interventions. The systematic exclusion of people with disabilities from many of the current health literacy research efforts, and the failure of studies to address

their myriad cultural and linguistic differences,⁵⁷ are contributing factors in the ongoing health disparities and health inequity among this population.

Historical and current practices in research often do not integrate people across the broad disability spectrum in studies that are conducted with the general population—those without disabilities—including studies focused on health literacy and targeted interventions. Some studies and reports attribute this exclusion to the lack of knowledge and disability competence within the general research community, including implicit bias, stereotyping, and unfounded beliefs about the competency of people with intellectual and developmental disabilities and mental illness.^{128,185–187} This separate or parallel worldview that permeates research must be challenged by people with disabilities, their families, and allies to confront the inequities inherent within this nation’s health research enterprises. Ensuring the integration of people with disabilities in public health research will also require political will and changes in public policy that will challenge the underlying causes of such inequity among health care professionals and systems.

The current body of knowledge about health literacy and disability is still in the early stages of development. The few published studies focus on the following five issues:

1. Defining and advocating the issues;
2. Describing what health literacy means for people with specific disabilities;
3. Proposing models and frameworks that best address the capacities of people across disability groups, including those with intellectual and developmental disabilities;

4. Identifying potential areas for analysis to examine issues empirically; and
5. Assessing the health literacy of families and others who support people with disabilities to perform essential functions.^{184,185,188,189}

Convergence of Cultural Contexts in Health Literacy and Disability: A Framework for Research and Practice

Those within the research, practice, and public health community are recognizing the role of culture in health literacy. Guidance, tools, and other resources have been disseminated focusing on health literacy and culture, culture diversity, and cultural and linguistic competence. Those organizations contributing to this knowledge include but are not limited to the Centers for Disease Control and Prevention, Health Resources and Services Administration, Centers for Medicare and Medicaid Services, Agency for Healthcare Research and Quality, Office of Disease Prevention and Health Promotion, and other medical, health, behavioral health, and public health professional associations.^{190–194} These resources articulate and promote the integration of culture, cultural and linguistic competence, and health literacy as integral to rather than separate aspects of care. The next sections list relevant statements from selected federal government agencies.

Organization Statement on Health Literacy and Culture, Office of Disease Prevention and Health Promotion, HHS

Health literacy is a complex phenomenon that involves skills, knowledge, and the expectations that health professionals have of the public's interest in and understanding of health information

and services. Health information and services are often unfamiliar, complicated, and technical, even for people with higher levels of education. People of all ages, races, incomes, and education levels—not just people with limited reading skills or people for whom English is a second language—are affected by limited health literacy. According to research from the U.S. Department of Education, only 12% of English-speaking adults in the United States have proficient health literacy skills. The effect of limited health literacy disproportionately affects lower socioeconomic and minority groups. (p. 2)

Health literacy is influenced by the language we speak; our ability to communicate clearly and listen carefully; and our age, socioeconomic status, cultural background, past experiences, cognitive abilities, and mental health. (p. 5)

Culture affects how people communicate, understand, and respond to health information. Cultural and linguistic competency of health professionals can contribute to health literacy.

Health care professionals have their own culture and language. Many adopt the “culture of medicine” and the language of their specialty as a result of their training and work environment. This can affect how health professionals communicate with the public.

For many individuals with limited English proficiency (LEP), the inability to communicate in English is the primary barrier to accessing health information and services. Health information for people with LEP needs to be communicated plainly in their primary language, using words and examples that make the information understandable.

Recognizing that culture plays an important role in communication helps us better understand health literacy. For people from different cultural backgrounds, health literacy is affected by belief systems, communication styles, and understanding and response to health information. Even though culture is only one part of health literacy, it is a very important piece of the complicated topic of health literacy.

While the previously described public health guidance statements delineate the need to respond to cultural differences, only one includes disability (i.e., cognitive abilities and mental health) in the conceptualization of health literacy and culture. Concordantly, much of the health literacy interventions, practices, and resources excluded people with disabilities as a cultural group when they were developed. Johnson, Minogue, and Hopkins (2014)¹⁹⁵ argue for the inclusion of persons with intellectual disabilities and that they should be advocates in all aspects of research and health care involving their own outcomes—a rare occurrence for this population of people with disabilities.¹⁹⁵ The current state of the evidence on health literacy prompts the question: evidence based for whom? Regrettably the answer points to the inequities that continue to have an adverse impact on the diverse population of individuals who experience an array of congenital and acquired disabilities across the life span.

Figure 7 depicts the multiple dimensions of culture and how they converge in the context of health literacy within the context of the diverse population of people with disabilities and their

families. Each of the six circles represents cultural contexts and their implications for health literacy.

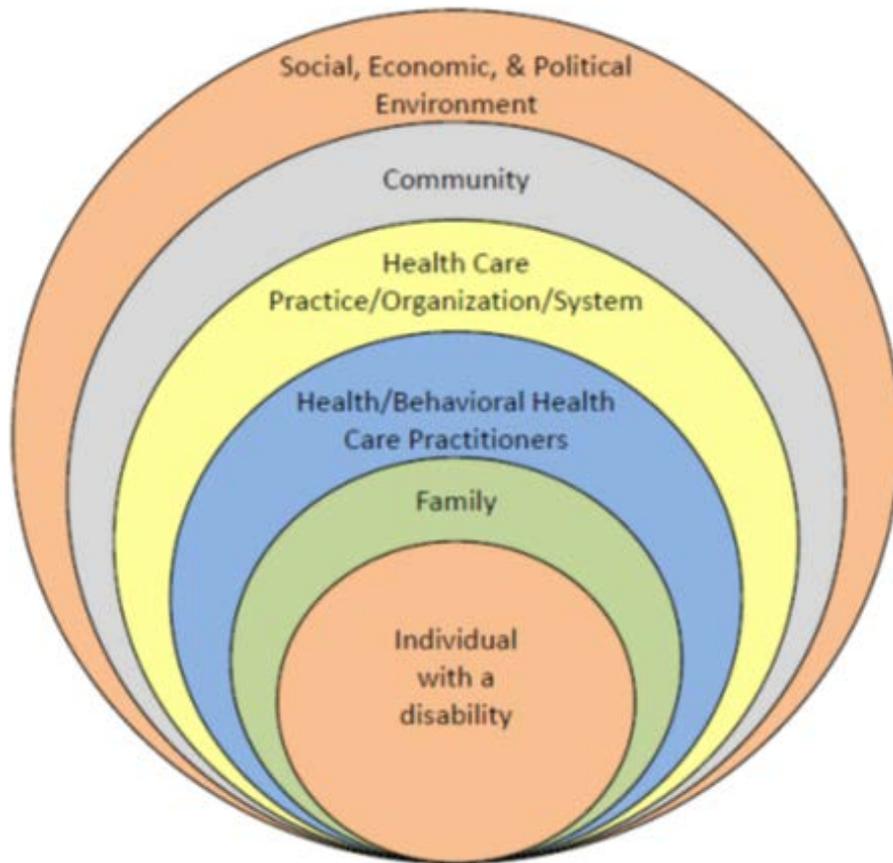


FIGURE 7 Convergence of cultural contexts in health literacy: A focus on disability.

Individual with a Disability

Cultural factors that influence diversity among individuals and groups include and are not limited to race, ethnicity, nationality, age, gender, gender identity or expression, sexual orientation, socioeconomic status, education, languages spoken, military service/veteran status, religiosity, and spirituality. Disability is only one of multiple cultural identities. It is essential to

recognize and respond to the myriad within group differences among people with disabilities and their lived experience.

Implications for health literacy. The type and extent of disability (sensory, cognitive, physical, mental health) will affect health literacy. Martensson and colleagues found that the published literature fostered

a complex understanding of health literacy, acknowledging the broadness of skills in interaction with the social and cultural contexts, means that an individual's health literacy may fluctuate from one day to another according to the context (p. 151).¹⁸⁹

This finding is commensurate with Rudd's theory of health literacy that emphasizes understanding its relevance and practice in everyday life situations.

Family

The family of an individual with a disability represents a social unit where disability may or may not be a shared identity among its members. The family has culturally defined values, beliefs, and practices that govern everyday life including how members relate to each other internally and interact with external society. There may or may not be consensus on cultural beliefs about what it means to have a disability and the expected behaviors of the family member with a

disability. Families may be defined by legal statute, by lineage, and by choice. The previously stated factors that influence diversity among individuals and groups apply to families.

Implications for health literacy. There is growing interest in the idea that health literacy should be understood as context-bound and changing competencies located not in individuals but in relationships and within social networks.¹⁸⁵ It is imperative for health care and social services professionals to understand the cultural context of the family and support the health literacy of its members, including the person with a disability, in a manner that the family prefers and needs at different phases across the life span. Effective health literacy approaches will integrate culturally and linguistically competent practices. Tools, resources, and evidence-based practices that define the role of family in supporting the health literacy of people with disabilities across racial, ethnic, and cultural groups are yet to be developed.

Health and Behavioral Health Practitioners

Practitioners bring their cultures of origin, the culture of the discipline or specialty in which they are trained, and the culture of the practices, organizations, and systems in which they work to health literacy. It is important that practitioners acknowledge culture by doing two things:

1. Recognize and accept cultural differences in health beliefs, family roles, expectations of health professionals—without judgement.
2. Demonstrate a valuing of these differences in the manner of communication and shared health care decision making.¹⁹⁶

It is recommended that practitioners also reflect on their own cultural belief systems, including the culture of health and medicine, and how these professional cultures influence their interactions with individuals with disabilities and their families.

Implications for health literacy. Practitioners will need to integrate cultural, linguistic, and health literacy considerations in the care provided to people with disabilities and their families. This may require practitioners to pursue formal and informal opportunities to learn from people with disabilities and their families, as well as professional development. Basic topics may include the role of culture in health, health and health care disparities among people with disabilities, and adapting health literacy practices for diverse populations with disabilities. Some practitioners may need to address explicit and implicit biases about people with disabilities.

Health Care Practices, Organizations, and Systems

It is essential that the multiple dimensions of culture within a practice, organizational, or system setting are acknowledged and recognized. Leaders in such settings should articulate values for and implement practice models across all components of the organization or system that is responsive to the cultural and linguistic diversity of individuals and communities served. This will require revisiting policies, structures, processes, and procedures to determine the extent to which the organization or system has the capacity to provide care and related services and supports to a diverse population of people with disabilities and their families.

Implications for health literacy. Organizations and systems need to prepare and support staff, at all levels, to communicate with and to interact effectively with each other and with individuals who experience disabilities and their families seeking and receiving care. This may involve revisiting how health literacy is understood and implemented and ensuring the necessary infrastructure to address the health literacy preferences and needs of all populations, including those with disabilities across racial, ethnic, and cultural groups.

Community

Community means different things to different people, and it is defined differently in the literature for different purposes. Community can be defined as a complex network of people, institutions, shared interests, locality, and a sense of psychological belonging. Community is a social network of culturally diverse individuals and families. Any given community has its own cultural identity or multiple cultural identities that may remain constant or evolve over time. There is frequent reference in the literature to the “disability community.” It is unclear if people with disabilities identify with this homogeneous designation or embrace other understandings of what community means to them. Inequities exist within many communities that adversely affect the health and well-being of its members.

Implications for health literacy. The National Action Plan to Improve Health Literacy and other research indicate that low or limited health literacy is more prevalent among people with low income and minorities—minorities in this instance referring to individuals from racial and ethnic groups other than non-Hispanic white. Another body of research documents health

disparities among people with disabilities and associate these disparities, to some extent, with low health literacy. There is a need to engage communities to discover their understanding, preferences, and needs related to health literacy and the sociocultural contexts in which health literacy can be applied in their everyday lives. The experiences of the community of people with disabilities and their families is essential to the discovery process and health interventions that are effective for all.

Social, Economic, and Political Environment

The social, economic, and political climates within local communities, states, tribal nations, and the country influence cultural expectations about health and well-being. Cultural differences in how health prevention and health promotion messages are received and acted upon by the U.S. population in general, and the population of people with disabilities in particular, vary significantly. The economy, political dynamics, and social movements affect the extent to which public health initiatives are sustained and measured over time. Goode and colleagues put forth the rationale that “a complex array of factors may contribute to the lack of interest and poor integration, including public policy and funding that has not prioritized disability research, the still common view of disability as a medical condition rather than a population group, and the lower value placed on the lives of people with disabilities relative to those without disabilities” (page S6).⁵² This rationale applies to the conduct of health literacy research and interventions.

Implications for health literacy. While there are concerted public health efforts to increase the health literacy of the U.S. population, individuals with disabilities have not been well integrated.

It will be necessary to change the culture of public health policy, interventions, research, and practice to stop the exclusion of people with disabilities in health prevention and health promotion designed to benefit all residents of the U.S., its territories, and tribal nations.

Summary

The current health literacy research initiatives, body of knowledge, and interventions have not been inclusive of people with disabilities. While definitions and conceptualizations of health literacy hold this promise, many within public health and the health research community continue to segregate people with disabilities from the general population of people without disabilities. Public health policy, supported by research findings, describe the importance of health literacy for the health and well-being of individuals, populations, and the communities in which they live. Yet these same public health policies and practices, whether intentional or unintentional, contribute to the well-documented health disparities and inequities among people with disabilities. Braveman and Gruskin (2003)¹⁹⁷ define health equity as “the absence of systematic disparities in health (or in the major social determinants of health) between social groups who have different levels of underlying social advantage/disadvantage—that is, different positions in a social hierarchy” (p. 254).¹⁹⁷ These researchers further assert that health inequities put groups of people who are already socially disadvantaged at further disadvantage with respect to their health based solely on their group membership. Research has proven that people with disabilities remain at a distinct disadvantage with respect to their health including the lack of evidence-based interventions that promote health literacy.

There is a critical need to address the biases, stereotypes, and discrimination within health care that adversely affect people with disabilities. It is only when the medical, health, and mental health communities—that do not specialize in disability—accept that “disability is a natural part of the human experience and it does not diminish the right of individuals with developmental disabilities to enjoy the opportunity to live independently, enjoy self-determination, make choices, contribute to society, and experience full integration and inclusion in the economic, political, social, cultural, and educational mainstream of American society”¹⁹⁸ that progress toward addressing health equity can be achieved. While this statement is from the Developmental Disabilities Assistance and Bill of Rights Act, its message spans the boundary of developmental disability and extends to all people with disabilities residing in the United States, its territories, and tribal nations.

Recommendations

- 1. The public and private sector need to promote and fund health literacy research portfolios that are inclusive of individuals with disabilities from diverse racial, ethnic, linguistic, and cultural groups.** Both quantitative and qualitative studies are needed to further define the experiences of people with disabilities across diverse groups and the implication of the sociocultural contexts of their everyday life experiences on health literacy. This will involve researchers’ capacity to identify and measure the multiple cultural identities among people with disabilities, rather than classifying all people with disabilities into homogenous groups or using their race and ethnicity as a proxy for culture.

2. Funders need to require documentation that health literacy research includes principles of cultural, linguistic, and disability competence. Public health policy is needed that encourages the principles and practices of cultural and linguistic competence and health equity intervention research in the conduct of research on health literacy. Such policy needs to be supported by professional development for many within the research community in order to mitigate biases and stereotypes that are barriers to and perpetuate the segregation of people with disabilities in health literacy studies.

SECTION 4C:
**EVIDENCE REGARDING POSSIBLE COMPOUND DISPARITIES FOR PEOPLE
WITH DISABILITIES IN UNDERSERVED RACIAL AND ETHNIC GROUPS**

People with disabilities and people in underserved racial and ethnic groups each experience barriers to health care, as well as disparities in other social determinants of health.^{54,199} Barriers and disparities could be exacerbated for people who belong to both of these marginalized populations. Determining whether compound disparities exist is challenging given that research on health and health care disparities at the intersection of disability and race/ethnicity is very limited. In this section, we summarize the available evidence regarding possible compound disparities for people with disabilities who also belong to underserved racial or ethnic groups.

Data from large population-based studies have found that adults with disabilities in underserved racial and ethnic groups are more likely to report fair to poor health, or that their health has worsened since the past year, compared with people without disabilities in the same racial/ethnic groups and with non-Hispanic whites with disabilities.^{65,200–202} Racial and ethnic differences in health status within the disability population reinforce the fact that at least some of the poor health found among people with disabilities is potentially preventable.

In general, people with disabilities are at least as likely as people without disabilities to have health insurance. However, relative to people without disabilities, those with disabilities are much more likely to have coverage from public sources (primarily Medicaid and Medicare) rather than private insurance. Reliance on publicly funded health insurance is particularly high

for people with disabilities in racial/ethnic groups other than non-Hispanic white.⁶⁵ People with disabilities also have more frequent encounters with health care.^{65,203} However, among working-age adults with disabilities, Hispanics or Latinos and African Americans/blacks have lower use of ambulatory care than non-Hispanic whites.⁶⁵ Moreover, high use of health care does not guarantee that all health care needs are met, or that routine preventive care is received, as detailed in the following paragraphs.

Research indicates that, overall, people with intellectual disabilities are less likely than people without disabilities to receive clinical preventive services as frequently as recommended.²⁰⁴ Studies of racial and ethnic disparities within this population suggest that disparities may be even greater for people with intellectual and developmental disabilities (IDD) who are also members of underserved racial or ethnic groups. For example, Bershadsky and colleagues reported that Hispanics or Latinos and non-Hispanic blacks with IDD were less likely to have received recent preventive care than non-Hispanic whites with IDD.²⁰⁵ In particular, even when controlling for covariates, African Americans/blacks had statistically significantly lower odds of having received a flu vaccine (odds ratio [OR] = 0.68) or visited a dentist in the past year (OR = 0.60).²⁰⁵

Preventive services specific to women are another area in which compound disparities appear to exist. Parish and colleagues found that African-American/black women with intellectual disabilities were significantly and substantially less likely to have received a mammogram compared to white women with intellectual disabilities (51% of African-American/black women had received a mammogram during a 2-year period compared to 76% of white women).²⁰⁶

Racial/ethnic disparities in receipt of screening mammography also have been described among women who are deaf. A study in California found that African Americans/blacks and Hispanics or Latinos in a sample of deaf women were significantly less likely than the white women in the sample to have had a mammogram in the past 2 years (43.5% for African Americans/blacks and Hispanics or Latinos combined vs 69.8% for whites).²⁰⁷ The proportion of each racial/ethnic group who had received a mammogram in the deaf sample was also substantially lower than proportions reported for the same racial/ethnic groups in the general population of women in California, supporting the premise that there are compounded disparities for women who are both deaf and members of an underserved racial or ethnic group.

Two studies have analyzed national, population-based survey data to specifically examine additive and interaction effects of disability status and race/ethnicity regarding health care. Using data from the Medical Expenditure Panel Survey (MEPS), Horner-Johnson and Dobbertin examined delayed and unmet needs for medical care and prescription medications among working age adults (ages 18–64 years).²⁰⁸ When controlling for differences in socioeconomic status and health insurance, adults with disabilities were significantly more likely to report delayed and unmet needs than adults without disabilities. The data suggested possible additive effects for American Indian/Alaska Natives (AIAN) and multiracial individuals with disabilities but, owing to small sample sizes, the confidence intervals for the estimates were wide and the effects were not statistically significant. The authors found one significant interaction between disability and race/ethnicity: the disability-related increase in unmet needs was greater for Hispanics or Latinos than for non-Hispanic whites, even though Hispanics or Latinos overall reported lower levels of unmet need. Additive effects of race/ethnicity and disability status were

more apparent in MEPS data on dental care.²⁰⁹ Working-age adults with disabilities who were African American/black, AIAN, or multiracial had significantly elevated odds of having less than one dental checkup per year on average (ORs of 2.51, 2.99, and 2.43, respectively), compared to the reference group of non-Hispanic whites without disabilities.²⁰⁹ Furthermore, odds ratios for these groups were higher than those for people without disabilities in the same racial groups and for non-Hispanic whites with disabilities.²⁰⁹ Odds of delayed dental care and unmet needs for dental care were also high among AIAN and multiracial people with disabilities, although confidence intervals were quite wide for these groups.²⁰⁹

Racial/ethnic disparities in unmet health care needs are also present for those under the age of 18 years, when children with disabilities are often grouped under the heading of children with special health care needs (CSHCN). In analyses of 1994–1995 data from the National Health Interview Survey on Disability, Newacheck, Hung, and Wright found that CSHCN in underserved racial/ethnic groups were less likely to have health insurance, have a usual source of care, or have used physician services in the past year, and more likely to have been unable to get needed medical care or to have been hospitalized.²¹⁰ More recently, Ozturk and colleagues reported similar patterns among youth with muscular dystrophy.²¹¹ In particular, African American/black youths with muscular dystrophy had lower overall health care use and less use of primary care, therapy, and specialist care, but higher use of hospital and emergency treatment.²¹¹

Efforts to understand specifically how the health care barriers faced by people with disabilities may be compounded by race or ethnicity have been virtually nonexistent. A recent scoping

review found only one published study that was specifically framed by its authors as an examination of barriers to health care access for people with disabilities who are also members of underserved racial or ethnic groups. Nine additional studies had other stated purposes, but included some relevant data on health care access barriers at the intersection of race/ethnicity and disability.²¹² Frequently cited barriers in the reviewed studies included lack of insurance, type of insurance, language barriers, low education level of patients, lack of a usual source of care, patient mistrust of the medical establishment, problems with physician–patient communication, problems with inaccessible and unreliable transportation, lack of clinician knowledge about needed specialty care, poor service coordination, and long wait times for care.²¹² However, in the literature reviewed by Peterson-Besse and colleagues it was unclear how the identified barriers might be experienced differently by people with disabilities who also belong to underserved racial/ethnic groups as opposed to non-Hispanic whites with disabilities, or people without disabilities in other racial/ethnic groups.

Focus groups conducted with adults with disabilities in underserved racial and ethnic groups suggest that these individuals confront all the physical and attitudinal barriers to quality care associated with both race/ethnicity and disability.²¹³ Participants described encountering stereotypes related to their race/ethnicity, as well as physical and attitudinal barriers and lack of necessary clinical knowledge related to their disability. Some participants felt their disability status affected their health care more than their race or ethnicity. For example,

I think the disability, the way they treat you because of disability, overrides your race, and you have racial problems that come in every day, but when you put the disability on it, I think the main focus of the discrimination is the disability.

However, other participants believed they experienced discrimination on both fronts:

I believe that it's a compound thing. It's one thing to be disabled, it's a whole 'nother thing to be a disabled minority.

When you ask questions, especially as a young person, you don't know anything...there's no way you could possibly be that in tune to know what you're talking about, but then, on top of it you have a disability. So you definitely don't know what you're talking about.

Other qualitative studies similarly suggest compounded barriers. Interviews with immigrant families of individuals with developmental disabilities have indicated that issues such as language barriers substantially complicate the typical challenges of coordinating care for a family member with complex health care needs.²¹⁴ African Americans/black and Hispanic or Latino parents of children with developmental disabilities have also reported poorer quality of interactions with health care providers compared to white parents.²¹⁵

In addition to standard preventive care and acute health care services, many people with disabilities rely on long-term services and supports (LTSS) to maintain their health and

maximize functioning. LTSS include various forms of assistance, technology, and other supports to aid people in completing personal care activities (e.g., dressing, bathing), or other tasks such as shopping and meal preparation. Most people prefer to receive LTSS in their own homes or other community-based settings rather than in institutional settings such as nursing homes. In 1999, the U.S. Supreme Court issued a ruling in the case of *Olmstead v. L.C.* (known as the Olmstead decision) stating that people with disabilities have the right to live in the community instead of an institution. The proportion of LTSS provided in institutional settings has been steadily decreasing since then,²¹⁶ However, people with disabilities in underserved racial and ethnic groups experience disparities in this regard as well. The number of Asians, blacks, and Hispanics or Latinos in nursing homes grew between 1999 and 2008 (at a greater rate than the growth of these groups in the general population) even while the overall population of nursing homes declined.²¹⁷ People in underserved racial and ethnic groups, especially African Americans/blacks, continue to be overrepresented in nursing homes.²¹⁸ Moreover, nursing homes with high proportions of African-American/black or Hispanic or Latino residents are more likely to be of poor quality.^{219,220} Thus, people with disabilities and older adults in underserved racial and ethnic groups experience doubly substandard LTSS. (For additional discussion on the Supreme Court's *Olmstead* decision, and factors potentially influencing racial and ethnic disproportionality in nursing home populations, see Sections 5 and 6, respectively.)

Recommendations

Health and health care disparities associated with race and ethnicity have been well documented. Disparities experienced by people with disabilities have not been as widely recognized but have

received increased attention in recent years (see, for example, publication by Krahn and colleagues¹⁹⁹). Attention to how disability-related disparities interact with those associated with race/ethnicity and other axes of inequity is only just beginning. We offer the following recommendations to guide ongoing research and action in this arena:

1. Fully incorporate data on disability status, type, and complexity within public and private systems that monitor and report health-related differences between groups.

Health-related differences can be broadly interpreted as those pertaining to social determinants of health (including health care access and utilization, and availability of community services to support health) in addition to health outcomes (e.g. overall health status, morbidity, mortality). Monitoring these issues obviously requires availability of data that address these topics while also providing sufficient detail about disability status, type, and complexity. It also requires that these data be routinely analyzed and reported. Reports should include comparisons between people with and without disabilities, and address how disparities may differ as disability intersects with other characteristics such as race/ethnicity. Analyzing smaller subgroups will typically necessitate pooling multiple years of data. Thus, data collection should use consistent measures and methods from year to year, to the maximum extent possible.

2. Include disability information in the Electronic Health Record (EHR) Standards and Certification Criteria issued by the Office of the National Coordinator for Health Information Technology. The 2015 standards included many other items related to health and health care disparities, but they did not require collection of information

about disability status. Adding collection of disability data to the standards is crucial for allowing examination and monitoring of health care disparities for this population, as well as the ways in which disability-related disparities intersect with disparities related to membership in other marginalized populations.

- 3. Conduct and encourage research specifically directed at understanding health status and health care experiences of people with disabilities who are also members of other underserved populations.** Much more information is needed about the complex interplay of barriers and supports encountered by people with multiple marginalized identities. We especially recommended community-based participatory approaches that involve members of the study population in designing and conducting the research. Such approaches help ensure that research appropriately addresses the questions that are most relevant. In addition, research with health care providers is needed to better understand the barriers they face to providing high-quality care to diverse people with disabilities, and to learn what supports they would find most helpful.

Section 5

Federal Legislation Related to Disability

SECTION 5A:

SERVICES, SUPPORTS, AND INCLUSION LAWS RELATED TO HEALTH CARE

The United States has enacted disability-specific laws for literally centuries. The subjects of those laws, as well as the manner of their enactment, provide insights into how disability, and people with disabilities, have been viewed over time by lawmakers and the public. Over the past 50 years in particular, the passage of disability-related laws is also a testament to the growing identity, cohesiveness, and political power of the American disability community. The chart below provides a timeline of selected federal laws that relate to the health of people with disability, with health understood as a function of the social determinants of health covered in *Healthy People 2020*.²³ (See Section 3 for an analysis of disability and the social determinants of health.) Table 2 below accompanies and illustrates the overall analysis of legal trends that follows. This general analysis, in turn, provides context to a discussion of specific current federal disability rights laws that have the greatest potential effect on the health of people with disabilities.

TABLE 2 Major Federal Legislation Affecting People with Disabilities^{221–223}

Year	Law
1798	Legislation establishes a federal network of hospitals for the relief of sick and disabled seamen; a forerunner to today's U.S. Public Health Service
1864	U.S. Congress authorizes the Columbia Institution for the Instruction of the Deaf and Dumb and the Blind, the first college in the world established for people with disabilities and now known as Gallaudet University, to confer college degrees
1878	National Quarantine Act transfers quarantine functions from the states to the federal Marine Hospital Service
1891	Immigration legislation gave Marine Hospital Service the responsibility for medical examination of arriving immigrants
1918	Smith-Sears Veterans Vocational Rehabilitation Act (Soldiers' Rehabilitation Act) for returning soldiers with disabilities
1920	Fess-Smith Civilian Vocational Rehabilitation Act creates a vocational rehabilitation program for civilians with disabilities
1921	Creation of the Bureau of Indian Affairs Health Division, forerunner to the Indian Health Service
1935	Social Security Act creates a national insurance system for certain population groups
1941	Act to permit people accompanied by seeing eye dogs to enter government buildings
1943	Rehabilitation Act amended to explicitly provide services to people with mental disabilities
1948	Civil Service Act amended to prohibit discrimination on basis of handicap in classified civil service positions
1950	Social Security Act amended to create a public assistance program for people who are "totally and permanently disabled"
1954	Vocational Rehabilitation Act revised to establish a system of state vocational rehabilitation agencies
1956	Social Security Amendments of 1956 creates the Social Security Disability Insurance (SSDI) program for disabled workers aged 50 to 64
1958	Federal grants to institutions of higher learning to train special education teachers
1962	Public Health Service Act Amendment establishes National Institute of Child Health and Human Development
1963	The Developmental Disabilities Act of 1963 established University Affiliated Facilities (UAFS) to train and expand the number of professionals equipped to meet the needs of persons with developmental disabilities.
1965	Title XVIII and XIX of the Social Security Act establishes Medicare and Medicaid (federally funded health care programs for aged and low-income people with disabilities)
1965	Older Americans Act creates nutritional and social programs administered by HHS' Administration on Aging
1970	Developmental Disabilities Services and Facilities Construction Amendments of 1970 provides federal financial assistance to states for comprehensive services for people with severe disabilities and requires Developmental Disabilities Councils in each state to plan and coordinate activities
1971	Legislation creates grants to support home modifications for veterans with disabilities
1972	Social Security Act of 1972 authorizes the Supplemental Security Income (SSI) program, consolidating federally administered cash benefits for needy individuals and couples who are aged, blind, or have a disability.
1973	*Rehabilitation Act is rewritten with key sections as follows:

Year	Law
	<ul style="list-style-type: none"> • Section 501 protects people with disabilities from employment discrimination by federal agencies • Section 503 protects people with disabilities from employment discrimination from federal contractors above a certain size • Section 504 of the Act protects individuals with disabilities from discrimination in all federally assisted programs and activities
1974	The Housing and Community Development Act of 1974 authorizes funding for removal of architectural barriers and in the construction of public facilities, and requires urban areas to consider the needs of individuals with disabilities.
1975	*The Education for Handicapped Children Act of 1975 (now known as the Individuals with Disabilities Education Act or IDEA)
1975	The Developmental Disabilities Assistance and Bill of Rights Act of 1975 reauthorizes the Developmental Disabilities Services and Facilities Construction Amendments of 1970, and establishes state protection and advocacy systems to protect the rights of individuals with developmental disabilities with additional authorized funding for projects of national significance
1980	The Civil Rights of Institutionalized Persons Act of 1980 (CRIPA) authorizes the federal Department of Justice to protect the rights of individuals who are in the care of state institutions such as jails and prisons, juvenile correctional facilities, public nursing homes, mental health facilities, and institutions for individuals with intellectual disabilities
1981	The Omnibus Budget Reconciliation Act of 1981 authorizes Medicaid to waive certain federal requirements so states can provide personal care and other home and community-based services to individuals who would otherwise receive care in an institutional setting
1986	The Employment Opportunities for Disabled Americans Act permanently authorizes provisions that enable employed people with disabilities to continue receiving SSI and Medicaid when their earnings exceed maximum levels but they cannot afford health care coverage equal to Medicaid
1986	The Education for Handicapped Children Act amended to provide federal financial assistance to states for developing early intervention services for infants and toddlers with disabilities
1986	The Air Carrier Access Act prohibits discrimination in air transportation by domestic and foreign air carriers against qualified individuals with physical or mental impairments, and establishes standards on a wide range of issues including boarding assistance, accessibility features in newly built aircraft, and new or altered airport facilities
1987	Nursing Home Reform Act requires states to conduct Pre-Admission Screening and Resident Review (PASRR) of individuals with disabilities prior to admission to a nursing facility to determine if they actually need nursing facility level of care, and if not, but an individual requires specialized services, the state must provide or arrange for such services in an appropriate setting
1988	* Fair Housing Amendments Act of 1988 expands the Fair Housing Act of 1968 to prohibit discrimination based on disability, expands avenues of administrative enforcement, and establishes design and construction accessibility provisions for certain new multifamily dwellings as a component of nondiscrimination
1990	*Americans with Disabilities Act (ADA) expands the civil rights and nondiscrimination mandate of Section 504 of the Rehabilitation Act to the private sector, and establishes a definition of <i>disability</i> that incorporates the social model of disability
1993	Rehabilitation Act Amendments of 1993 mandate Centers for Independent Living to provide four “independent living core services”: information and referral, independent living skills training, peer support, and individual and systems advocacy
1999	* <i>Olmstead v. L.C.</i> was decided by the Supreme Court, which held that the

Year	Law
	unjustified segregation of persons with disabilities constitutes discrimination under the ADA
2002	The Help America Vote Act of 2002 addresses accessibility in every part of the voting process, including voting machines, provisional ballots, voter registration, and poll worker training
2006	Money Follows the Person Rebalancing Demonstration provides demonstration grants to states to help individuals transition from institutions to community settings, and financially incentivizes states rebalancing of their long-term care systems toward more cost-effective community supports
2006, 2011	Combating Autism Act increases funding to the National Institutes of Health and the Centers for Disease Control and Prevention for education, screening and programs for children with autism and other developmental disabilities
2008	*ADA Amendments Act redefines <i>major life activities</i> and adds interpretive guidance to counterbalance several Supreme Court decisions that had narrowed the application of the ADA, especially in employment
2008	Paul Wellstone and Pete Domenici Mental Health Parity and Addiction Equity Act law requires commercial insurance carriers to set mental health insurance copayments and treatment limits that are equal to those set for physical conditions, and bans higher cost-sharing for mental health or substance abuse disorder benefits.
2008	The Genetic Information Non-Discrimination Act of 2008 (P.L 110-233) will prevent employers and insurance carriers from engaging in discriminatory practices based on an employee or individual's genetic information
2010	*The Affordable Care Act (ACA) of 2010 bans preexisting condition exclusions, eliminates lifetime annual and lifetime caps, establishes 10 categories of Essential Health Benefits, prohibits discrimination on the basis of health status and disability, and expands income eligibility for Medicaid
2014	The Autism Collaboration, Accountability, Research, Education, and Support (CARES) Act of 2014 reauthorizes the Combating Autism Act of 2011 for 5 years and continues research, surveillance, public awareness, and professional training efforts on autism spectrum disorder (ASD)

*Denotes additional discussion below.

Trends in Disability Legislation

There are a few significant trends that can be discerned among federal disability laws enacted over the years, including those listed in the chart above. The earliest federal laws on disability tended to be narrowly directed at either populations of people with specific disabilities or people with disabilities in specific circumstances, or both. Examples are the 1798 law establishing hospitals to care for merchant seaman who acquired disabilities²²⁴ and the 1918 Smith-Sears law

that provided vocational rehabilitation services for soldiers who returned from World War I with disabilities.²²⁵ Some early federal and state benefits and tax laws provided income support to people who were blind.^{226,227} These laws reflected a tendency to recognize a diagnosis, or the circumstances of how a disability is acquired, as the trigger for legal action rather than the overarching needs of people who have functional limitations, regardless of the disability or whether it is congenital or acquired.

While this tendency has been increasingly moderated over the decades, it has not completely disappeared. Strong lobbying from a well-organized group of sympathetic individuals, such as parents who have compelling stories of need to share, can be very influential in the passage of a focused federal law. The autism legislation of 2006, 2011, and 2014 passed with bipartisan support as a federal response to the sharp increase in the cases of autism that have been diagnosed in the United States over the past several years.^{228–230} It is also interesting to note, in the context of a paper on health disparities at the intersections, that “most of the children being diagnosed with autism are male, non-Hispanic white, living in large metropolitan areas, with two parents and with at least one parent with more than a high school education.”²³⁰

Another key point about this first trend is that even where laws address the needs of people with specific disabilities, they are coming to do so in a much more holistically way. The evolution of federal legislation for people with developmental disabilities provide an excellent example. The Mental Retardation Facilities and Community Health Centers Construction Act of 1963²³¹ authorized federal grants for the construction of public and private nonprofit community health centers and tried to increase professional expertise to address the health needs of people with

developmental disabilities. The 1970 amendment to the 1963 act expanded the federal definition of *development disability* (DD) and also authorized the construction of state institutions, state planning, and service delivery for people with DD.²³²

By 1975, there was recognition that the authorization of services would not necessarily translate neatly into the delivery of services to individuals who did not know they had a right to them, or the wherewithal to enforce those rights. The Developmentally Disabled Assistance and Bill of Rights Act²³³ creates a clear set of rights for individuals with DD, and requires each state receiving federal financial assistance under the act to establish a protection and advocacy program that would generally advocate for the rights of persons with DD, as well as provide individual legal and administrative assistance to ensure that persons with DD received services under the federal laws.

Subsequent DD laws and amendments have authorized grant funds to provide civil rights protections and a range of needed services and supports to people with DD,²³⁴⁻²³⁷ including the critical establishment of State Councils on Developmental Disabilities (DD Councils). The councils are located in every state and territory and include appointed volunteers, 60% of whom must be people with DD or family members of people with DD. The work of the councils reflects a sea change in the understanding of people with DD as the councils have a mission “to promote the independence and productivity of people with developmental disabilities and promote systems change in areas such as employment, education, and access to health care.”²²³ The 2000 DD law also funds University Centers for Excellence in Developmental Disabilities (UCEDDs) in every state and territory that train students and professionals, engage in research,

and provide technical assistance and direct services and supports to people with DD of all ages and their families. Other laws have expanded the client base that state protection and advocacy systems may serve.^{238–240}

These newer legal requirements are a significant distance from laws that focused on the construction of state facilities for individuals with DD. At the same time, it is worth noting that the relatively comprehensive range of services, supports, research grants, protection of patient rights, and legal advocacy available to people with DD is rather unique. People who have non-DD disabilities fall outside of the ambit of these laws, even if they have virtually the same functional limitations and face similar accessibility barriers, risk of institutionalization, and discrimination.

Another significant trend, in line with the more holistic recognition of the needs of specific disability populations, is toward the enactment of laws that broadly recognize the cross-disability right of all people with disabilities to be free from discrimination. Section 504 of the Rehabilitation Act (Section 504) is generally recognized as the first U.S. disability civil rights law. The short law does not distinguish between types of disabilities, acknowledges—by virtue of its prohibition—that people with disabilities are subject to discrimination, and applies across the full array of federally conducted *and* federally funded activities, included those conducted by private entities.²⁴¹ All of these factors mark Section 504 as a highly significant advance in disability laws. Moreover, the requirement that particular federal agencies and departments were required to enact regulations under Section 504 and establish standards for disability nondiscrimination meant that the Department of Health and Human Services (or rather, its

precursor agency in 1973, the Department of Health, Education and Welfare [HEW]) had to seriously consider how to identify and redress disability nondiscrimination across all its operations. While HEW, in fact, delayed issuance of regulations for several years, the eventual adoption of final regulations reflects greater input from people with disabilities themselves than any prior law or regulation.²⁴²⁻²⁴⁵

A third significant trend touches on a growing attempt to legislate “rebalancing,” which can be understood as the reorientation of Medicaid long-term services and supports finances and laws toward optional home and community-based services, and away from nursing home and other institutional care that is mandated for coverage in state Medicaid plans. These rebalancing attempts are reflected in laws such as the 1981 authorization of state Medicaid waivers,²⁴⁶ the 1987 Nursing Home Reform Act,²⁴⁷ and the 2006 Money Follows the Person Demonstration act,²⁴⁸ all listed above. While these attempts are imperfect, for instance, the Money Follows the Person process is administratively complex and can be challenging for community-based providers to maintain, their enactment shows that policy and lawmakers are coming to understand that home and community-based services and supports are greatly preferred by people with disabilities, can maximize physical as well as social well-being if done right, can achieve fiscal savings over costly institutionalization, and are a logically necessary component of effective compliance with the civil rights of people with disabilities. (See the Olmstead discussion later in this section, and Section 6 for a short discussion of institutional bias.)

One final element to note in any discussion of federal disability laws is the effect of federalism, which reveals itself as a constant ebb and flow over the decades toward and away from federal

administration's assertion of federal control over the administration of all kinds of topical areas, including health and health care-related matters. The key point to remember about federalism is simply understanding that federal laws and regulations, whether they establish care coordination standards or nondiscrimination requirements in health exchange benefit design, and even when the receipt of federal dollars is clearly linked to state compliance with these laws, tend to always defer to "local" state flexibility of design, implementation, and enforcement to some degree. Practically, this means that individual states can have great discretion over which health services and supports are provided to which people with disabilities, how often they are provided, and how access to them is gained and maintained. States usually have discretion over the administrative application and enrollment process to Medicaid services. At this initial step, if a state does not take seriously its obligations to notify people with disabilities of their ADA rights, and train state workers to provide reasonable accommodations and policy modifications owed to people with disabilities under the ADA, the result is unmet health needs as people with disabilities fail to gain admission to programs for which they are qualified.²⁴⁹ This occurs even though, on paper, California has a considerable network of state laws that address benefits, supports, and disability nondiscrimination that in some ways exceed federal protections.^{250,251}

Highlighted Laws and Cases

Section 504 of the Rehabilitation Act of 1973 (Section 504)

Section 504 of the Rehabilitation Act of 1973, or Section 504,²⁴¹ can be considered the oldest federal disability civil rights law in the U.S. It prohibits discrimination on the basis of disability

in public and private programs and activities that receive federal financial assistance. The law also covers programs and activities that are conducted by the federal government itself, including all federal agencies and the U.S. Postal Service. The law is notable for its breadth. It applies across disabilities and across industries or sectors, from ground transportation to education to health. The law is also brief, with a prohibition on discrimination that is barely over 70 words. In part, that is because each major federal agency was required to develop, promulgate, and enforce more detailed regulations that would apply to its own programs, as well as regulations governing any entity that receives federal financial assistance from the agency. Most recently, in May 2016, this regulatory process was seen in action when HHS published civil rights regulations under the Affordable Care Act (ACA), which explicitly incorporates federal civil rights laws, including Section 504, to the private health insurance marketplaces established under the ACA.

Section 504 is an important precursor to the Americans with Disabilities Act, which emulated both the breadth of Section 504's scope as well as its model of dividing regulatory and enforcement authority among different federal agencies. While Section 504 is perhaps the best-known section of the Rehabilitation Act with the widest applicability to people with disabilities, other sections of the Rehabilitation Act are also important. Section 501 requires federal agencies of the executive branch to provide disability affirmative action and nondiscrimination in employment practices.²⁵² Section 503²⁵³ requires the same employment practices from federal government contractors and subcontractors over a certain size. Section 508²⁵⁴ requires electronic and information technology that is developed, maintained, procured, or used by the federal government to be accessible to people with disabilities, including employees and members of the public.

An important thing to note about the exact wording of Section 504, which is not shared by the ADA, is the fact that Section 504 prohibits discrimination “solely by reason of...disability.” The qualifier solely has been interpreted by courts to mean that plaintiffs must establish that defendant entities did not have mixed motives for their discriminatory actions,²⁵⁵⁻²⁵⁸ and potentially this includes discrimination on the basis of race or ethnicity. This would be a truly unfortunate and narrow conclusion, but it also illustrates how, in general, the black-and-white nature of law may not be the ideal vehicle to address intersectional discrimination.

Individuals with Disabilities Education Act (IDEA)

The Individuals with Disabilities Education Act (IDEA), formerly called the Education for all Handicapped Children Act of 1975, requires public schools to make available to all eligible children with disabilities a free appropriate public education in the least restrictive environment appropriate to the child’s education needs. Under the law, state and local education agencies are provided with federal financial assistance intended to guarantee special education and related services to eligible children with disabilities ages 3–21.

The requirement that public school systems must develop appropriate individualized education programs (IEPs) for each eligible child is at the core of the IDEA. The specific special education and related services outlined in each IEP reflect the individualized needs of students with disabilities. IDEA also establishes procedures that must be followed in the development of the IEP, which also must be reviewed at least once a year. Each student's IEP must be developed by

a team of knowledgeable persons that includes the child's teacher(s); the parents (or educational guardian), subject to certain limited exceptions; the child, if determined appropriate; an education agency representative who is qualified to provide or supervise the provision of special education; and other individuals at the parents' or agency's discretion. For the children to whom it applies, IDEA can overlap considerably with health-related needs. Assistive technology that a child with disabilities needs under her IEP, or speech therapy that is best administered within the school setting for educational benefit, may coincide with the child's overall disability-related health care needs. Ideally, this should prompt some coordination between school districts and local education authorities and a child's health care providers, but that degree of coordination is rare.

IDEA gives parents considerable due process rights and significant responsibilities. If parents disagree with the proposed IEP, they can request a due process hearing and a review from the state educational agency if applicable in that state. Parents can also appeal the state agency's decision to State or Federal court.

Note that not every child with a disability will be qualified under IDEA. IDEA applies to children who are determined by a multidisciplinary team to be eligible within one or more of 13 specific disability categories and who need special education and related services. The categories include autism, deafness, deaf-blindness, hearing impairments, mental retardation, multiple disabilities, orthopedic impairments, other health impairments, serious emotional disturbance, specific learning disabilities, speech or language impairments, traumatic brain injury, and visual impairments. In that way, IDEA retains roots in a diagnostic medical model. Section 504 has the

same broad definition of disability as the ADA, and therefore schools can be required to provide disability-related accommodations and policy modifications where a child with a disability under Section 504 requires such accommodations to gain equal access to educational benefit.

Procedural and funding requirements differ under IDEA and Section 504.

Fair Housing Act (FHA)

For the most part, the Fair Housing Act (FHA),²⁵⁹ as amended in 1988, is the major law that governs disability housing discrimination (as well as housing discrimination on the basis of race, color, religion, sex, familial status, and national origin). FHA's scope includes private housing, housing that receives federal financial assistance, and state and local government housing. It is unlawful to discriminate in any aspect of selling or renting housing or to deny a dwelling to a buyer or renter because of the buyer or renter's disability, or the fact of disability in an individual associated with the buyer or renter or an individual who intends to live in the residence.

Discrimination is also prohibited in such housing-related activities as, for example, financing, zoning practices, new construction design, and advertising.

The Fair Housing Act requires owners of housing facilities to make reasonable exceptions in their policies and operations to ensure that people with disabilities get equal housing opportunities. For example, a landlord with a “no pets” policy may be required to grant an exception to this rule and allow an individual who is blind to keep a guide dog in the residence. The Fair Housing Act also requires landlords to allow tenants with disabilities to make reasonable access-related modifications to their private living space, as well as to common use

spaces such as laundry facilities or mail rooms. The landlord is required to allow the tenant with disabilities to make the changes. However, the landlord is not required to pay to make the changes. The act further requires that new multifamily housing with four or more units be designed and built to allow access for persons with disabilities. This includes accessible common use areas, doors that are wide enough for wheelchairs, kitchens and bathrooms that allow a person using a wheelchair to maneuver, and other adaptable features within the units.

The U.S. Department of Housing and Urban Development (HUD) is the federal agency authorized to make regulations and enforce the Fair Housing Act. Individuals who have experienced housing discrimination may file a complaint with HUD. The Fair Housing Act also allows for a private right of action. The correlation between health and access to adequate, safe, affordable, and accessible housing is well documented²⁶⁰⁻²⁶² and has also been explored in Section III, above. The need is shared equally by disability, race, and ethnic groups, but those with mobility disabilities or specific accommodation needs such as housing for an assistance animal, face additional barriers to finding and keeping affordable housing.

*Americans with Disabilities (ADA)*²⁶³

The Americans with Disabilities Act (ADA) is a civil rights law that critically extended Section 504's disability nondiscrimination mandate to the private sector. The ADA reaches such entities as private employers (with 15 or more employees), retailers, service establishments, transportation companies, and telecommunication companies, regardless of whether they receive federal financial assistance. The law is organized in "titles" that each deal with specific topics.

Title I concerns employment, and gives regulatory and enforcement authority to the federal Equal Employment Opportunity Commission (EEOC). Title II concerns state and local governments with regulatory and enforcement authority given to the federal Department of Justice (DOJ). Title II also covers public transportation, with regulatory and enforcement authority given to the Federal Transit Administration (FTA), as well as health care services such as state health care programs and municipal hospitals, with regulatory and enforcement authority given to HHS. Title III concerns “places of public accommodation” (i.e., privately owned retail and service establishments), with regulatory and enforcement primarily given to the federal DOJ. Title III explicitly covers the private entities of a “pharmacy, insurance office, professional office of a health care provider, hospital, or other service establishment.”²⁶³ Title IV concerns telecommunications relay services with regulatory and enforcement authority given to the Federal Communications Commission. Title V contains miscellaneous but important provisions relating to disability nondiscrimination, such as protection from retaliation for people with disabilities who seek to enforce their rights under the ADA and protection from discrimination because of an association with a person with a disability.

While the different federal agencies noted above are given implementation and enforcement authority under the ADA, they do not generally have exclusive enforcement authority. That is, individuals with disabilities may choose to file an administrative complaint with the relevant federal agency when they have been discriminated against. An individual with a disability also has the right to file a private lawsuit in federal court without having to go first to the federal agency, with the exception of Title I in the area of employment.

To file a complaint or a lawsuit under the ADA, one must have a disability or have a relationship or association with an individual with a disability. An individual with a disability is defined under the ADA as a person who has a physical or mental impairment that substantially limits one or more major life activities, a person who has a history or record of such an impairment, or a person who is regarded by others as having such an impairment. This third definition incorporates the social model of disability by recognizing that one can be disabled by external barriers and how others treat one. The ADA does not contain an exhaustive listing of all impairments that could be considered a disability, but the ADA Amendments Act of 2008 incorporated a list of physiological conditions that, in the context of litigation, has helped some individuals with disabilities to move past the threshold stage of being recognized as a person with a disability so as to invoke the law. Other important conceptual innovations in the ADA include the groundbreaking concepts of “reasonable accommodations” and “reasonable modifications of policies and procedures” that provided a way to address nonphysical barriers.

Even though they are different laws, courts have interpreted Section 504 and the ADA in essentially similar ways when it comes to the obligation of a covered entity to be physically accessible and provide reasonable accommodations, reasonable modifications of policies and procedures, and effective communication. Health care providers, hospitals, and managed care organization are to operate in physical spaces that enable people with disabilities physical access and freedom to move about and use the entire facility as independently as possible. Covered entities are required to ensure that they meet specified dimensions for such things as doorways widths, sink height, clear pathways of travel, and elevator Braille signage.

Reasonable accommodations and modifications of policies and procedures means that entities must adjust the way the office “typically” does things to ensure that people with disabilities receive equally effective services. So, for instance, an office may typically require patients to independently undress and get on an exam table. An individual who uses a mobility device such as a wheelchair may not be able to undress without assistance or independently transfer to an exam table, especially one that is not height-adjustable. The office or hospital cannot refuse to serve a person with a disability because its “procedures” don’t usually include personal assistance and cannot require the person with a disability to bring their own personal assistant.²⁶⁴

Similarly, health care entities cannot require a person who is deaf or hard of hearing to bring their own interpreter or charge them extra for interpretation services. Instead, health care entities are obligated to provide “effective communication” that can include sign language interpretation to patients with disabilities, written communications in alternate formats such as Braille or large-font print, and additional time to accommodate people with speech or developmental disabilities so they can convey and receive information from providers. These obligations are not unlimited, and a covered entity’s degree of obligation under Section 504 and the ADA will vary somewhat depending on whether an entity falls under Title II or Title III of the ADA or receives federal funding.

Olmstead v. L.C.

The United States Supreme Court’s 1999 decision in *Olmstead v. L.C.*,²⁶⁵ that unjustified segregation of persons with disabilities constitutes discrimination in violation of Title II of the

ADA, gave the disability community and advocates a vital legal victory. The Court held that public entities must provide community-based services to persons with disabilities when (1) such services are appropriate; (2) the affected persons do not oppose community-based treatment; and (3) community-based services can be reasonably accommodated, taking into account the resources available to the public entity and the needs of others who are receiving disability services from the entity.

Moreover, the majority decision stated that its holding “reflects two evident judgments.” First, “institutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable of or unworthy of participating in community life.” Second, “confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment.”²⁶⁶ While these words have been a rallying cry for the disability community, *Olmstead* litigation has tended to be more successful at closing down institutions than ensuring that people with disabilities gain access to the multiple layers of supports, services, and barrier removal that they need to live and contribute fully to their communities.²⁶⁷ Such services and supports draw from a complex mix of federal and state funding and programs that often have distinct eligibility criteria. The *Olmstead* decision, in and of itself, did not address the fundamental need for community-based accessible and affordable housing, or the long-standing institutional bias in Medicaid (see discussion in Section 6 concerning Medicaid, long-term services and supports, and institutional bias.) The Supreme Court decision called out the institutionalization of people with disabilities as discrimination. The case does not provide a clear road map forward when it comes to either

policy or legal development. Many lawyers and lawmakers would argue that is not the role of litigation in any event.

Other Disability Rights and Health Care Cases and Settlements

One of the first disability rights class action lawsuits brought in the health care context was *Metzler v. Kaiser Permanente*, initiated in 2000 and settled in 2001. The case alleged three wheelchair users and others with physical disabilities received inadequate and unequal health care services from Kaiser Permanente (KP), the largest non-profit U.S. health management organization (HMO). Filed in California state court under state access laws that incorporate the ADA as a floor, the complaint highlighted inaccessible examination equipment amid a plethora of other barriers to accessibility. The innovative settlement was influential on a number of fronts.²⁶⁸ First, it required KP to address inaccessibility across the board, in terms of architecture, equipment, and policies and procedures. Second, the obligation to install accessible equipment throughout its facilities, because of KP's sheer size, actually spurred medical equipment manufacturers to develop better equipment such as height-adjustable exam tables. This equipment, in turn, has become more widely available and less expensive. Third, the settlement's 7-year implementation period included significant monitoring and review of KP's progress over a lengthy time period.

While the KP settlement was a victory for lead plaintiffs and all KP members with disabilities, it did not initiate a voluntary and rapid revolution among HMOs, hospitals, and the provider-owned clinics and facilities where over 83% of outpatient visits take place.²⁶⁹ This is not

necessarily a fault of the case. According to the final federal regulation concerning nondiscrimination under the Affordable Care Act, there are 133,343 hospitals, health centers, nursing facilities, laboratories, health-related schools, and state health agencies that receive some form of federal financial assistance, and over 900,000 physicians that receive some form of federal financial assistance other than Medicare Part B (outpatient services).²⁷⁰ These are covered entities under Section 504, and do not include purely private hospitals or physicians who take only Medicare patients, both categories of which are nonetheless subject to Title III of the ADA. No case, no matter how groundbreaking, could sweep through such a large field and spur wide-scale awareness and proactive responsiveness, particularly among professions that traditionally have far greater concern for malpractice liability than disability rights.

The first KP settlement, did, however, prompt a series of subsequent strong hospital and facility settlements around disability health care access for and across a variety of disabilities. For example, one case resulted in a consent decree negotiated on behalf of seven deaf individuals after suit was brought under federal law against a Maryland hospital.²⁷¹ The decision was notable for both the involvement of the Civil Rights Division of the Department of Justice (DOJ), which has jurisdiction over health care facilities and providers under Titles III and II of the ADA, and as the first ADA case resolution to include standards for the use of video interpreting services (VIS). Other health care cases have reached resolution through the use of “structured negotiations,” where complainants and entities subject to federal disability rights law agree to negotiate a settlement of concerns without filing an actual lawsuit. Examples of successful structured negotiation include major teaching hospitals in Boston²⁷² and the University of California Medical Center in San Francisco,²⁷³ where attorneys achieved agreements on

improving physical accessibility, assessing and meeting the need for accessible medical equipment, and thorough review of policies and procedures that affect people with disabilities.

In July 2012, on the 22nd anniversary of the ADA, the Department of Justice launched the Barrier-Free Health Care Initiative to recognize collaborative efforts between private U.S. attorneys and the Department of Justice to improve health care accessibility across the country. Over 45 U.S. attorney's offices participate in the initiative. Settlement agreements have been reached on behalf of people with vision, hearing, mobility, and mental health disabilities who encounter barriers at a range of hospitals, clinics, and specialist providers, and also include people confronted with HIV discrimination.²⁷⁴ One of the most recent settlement agreements circles back to KP, who negotiated with the California Counsel of the Blind and their counsel, to achieve accessibility of health services to California KP members with vision disabilities.²⁷⁴

Patient Protection and Affordable Care Act (ACA)

The Patient Protection and Affordable Care Act²⁷⁵ (ACA) includes numerous provisions that greatly benefit people with disabilities when it comes to both public and private health coverage. The most important changes that the ACA has brought about are prohibiting preexisting condition exclusions; eliminating annual and lifetime caps; prohibiting discrimination based on health status and disability; guaranteeing issuance and renewability to employers and individuals, and expanding Medicaid eligibility to cover individuals with incomes up to 133% of the federal poverty line. In addition, the ACA includes data provisions specific to people with disabilities. Section 4302 mandates the inclusion of questions concerning disability status in all federal

national data collection efforts, including national population health surveys to the extent practical. Section 4302 also gives HHS the opportunity to ask for additional information to further our understanding of health care disparities. Information concerning where people with disabilities typically receive care could be collected here. Unfortunately, funding for this section was not appropriated beyond an initial multiyear period that has now lapsed and it is unclear whether and how HHS could choose to appropriate funds to pursue this information.

Section 1557 of the act mandates nondiscrimination in health activities and programs created and funded under the ACA, including the federal and state marketplaces. The final Section 1557 rules were issued very recently by the HHS Office for Civil Rights. One critical area of ongoing concern for people with disabilities is the degree to which Section 1557 can be used to combat discrimination in private insurance benefit design. While Section 1557 clearly applies to the marketplace plans and all of their insurance products, disability discrimination is historically and deeply embedded in private insurance coverage of many important benefits ranging from mental health to durable medical equipment. While the Final Rule has explicitly recognized some examples of discrimination in benefit design, such as placing all of drug treatments and regimens for a specific condition like HIV/AIDS on the top drug formulary tier with the highest copays, the rule declined to include other clear examples of de facto discrimination in benefit design.

While the Final Rule language does not include an explicit reference to the intersectional discrimination that can be experienced by people with disabilities who are also subject to the

disparities experienced owing to race and ethnicity, the preamble acknowledges that such discrimination “should” be covered under the provisions of Section 1557.²⁷⁶

SECTION 5B: LIMITATIONS OF LAW

As can be seen in Part A above, strong laws and private class actions and settlement agreements, or DOJ investigations and lawsuits prompted by a complaint or a “pattern and practice of discrimination,”²⁷⁷ can and certainly do have an impact on individual defendant entities. Federal disability rights laws have led directly to managed care organizations, hospital complexes, clinics, and provider offices undergoing disability rights training, purchasing accessible exam equipment, providing alternate formats and sign language interpreters, and various modifications in policies and procedures that an individual with disabilities may need to receive effective health care. The fact remains, though, that these successes, even as they accumulate, have not led to wholesale transformation of a health care system that still fails to give a coordinated and urgent response to disability accommodation needs and health and health care disparities.

The inability of federal disability rights laws to bring about transformative change in our health care system is due to three main reasons. First, the judicial and administrative systems that enforce the laws are primarily complaint driven. This places great weight on the shoulders of individuals who may be in the midst of a health crisis, are frequently low income, and quite possibly unaware that they have accommodation rights under federal law, particularly if they are

among the many individuals who have a disability that is newly acquired as they age. Second, the sheer multiplicity of possible defendant entities (see above subsection on other disability rights and health care cases and settlements) means that a victory in a lawsuit may affect similar kinds of providers in a local area, but it will not necessarily raise national awareness of the needs of people with disabilities across a wide range of providers and facilities. Third, individual rights and lawsuits arguably are inherently poorly suited to bring about systemic transformation and foster innovative best practices to ensure quality health care for people with disabilities.

The lawyer(s) and client(s) in an individual case, or even in a class action, are not necessarily equipped by training or temperament to make detailed concrete proposals on something like technical standards for what constitutes accessible exam equipment, or scoping standards that would establish the number of kinds of accessible equipment that must be maintained in different sizes and kinds of facilities in order for the defendant to provide accessible services to people with disabilities. Such a proposal requires extensive research, stakeholder input, and technical expertise. The Affordable Care Act (ACA) recognized this fact when it directed the U.S. Access Board, an independent federal agency that develops and maintains design criteria for the built environment, to establish new access standards for medical diagnostic equipment.²⁷⁸ On the other hand, the Access Board was directed to develop those standards within 2 years of the ACA's enactment, but has still not managed to conclude the standard process. Once the Access Board develops the standards, DOJ has stated that it will adopt those standards as enforceable regulations. The delay in the process provides covered entities with an excuse to put off purchasing accessible equipment and leaves attorneys with little choice but to try and create a

workable bottom-line standard when the opportunity arises to create one in a settlement proposal, even though the results may vary from case to case and circumstance to circumstance.

In other areas important to systemic reform, the application of disability discrimination law can be complex and fraught with practical difficulty. For example, the importance of including people with disabilities in clinical drug trials is increasingly important as the health care system turns to evidence-based decision making and value-based benefit design. If people without disabilities are not included in clinical trials, there may be literally no evidence to support prescribing a new expensive treatment to someone with chronic conditions or disabilities, for example. But it is difficult to establish how any given person has an individual “right” to participate in a particular clinical trial, and courts can be reluctant to intervene in such clear areas of medical expertise as pharmaceutical research where the gold standard is double blind trials that involve control groups with close to identical health characteristics. Similarly, discrimination and accessibility law is not the best tool for forcing provider education to include disability competency training. Scholars have made eloquent arguments for how such training would benefit all patients, and not just patients with disabilities,²⁷⁹ but a court will not necessarily trace the needed direct line of causation from the injury sustained when a person with a disability fails to receive needed accommodations to the providers failure to receive disability competency training in medical school. In these and myriad other ways, rights laws and lawsuits are ill suited to drive sustained and consistent ongoing modification and achieve long-term results in systemic practices.

Disability rights laws, lawsuits and administrative investigations are an invaluable tool as part of arsenal of policy and other initiatives. Perhaps the ideal is achieved if “each case is viewed less as a goal in itself, and litigation is understood as a policy tool that can advance broader ongoing policy negotiations for more comprehensive solutions by equalizing the bargaining position of people with disability.”²⁸⁰ This recognizes the unique place of law, litigation, and settlement proposals within a larger advocacy context, and avoids placing an impossible burden of almost revolutionary systemic change on the backs of legal actions.

Recommendations

- 1. Improve independent “pattern and practice” investigation, administrative monitoring, and enforcement under Section 504 and the ADA by federal and state agencies to relieve the enforcement burden on individual complainants and plaintiffs.**
- 2. Develop laws that directly incorporate key data, education, research, and education/training/certification goals on disability discrimination and health and health care disparities.**
- 3. Implement training and technical assistance to people with disabilities on their disability rights in a health care context, incorporating ethnically and racially sensitive outreach and education of older individuals with newly acquired disabilities who do not necessarily culturally identify with the disability community, and**

need not do so, but nonetheless have a right to reasonable accommodations, policy modifications, and equally effective health care.

Section 6

Various Supports and Services for People with Disabilities: Health Care Access, Care Coordination, and Accessible Care Delivery

SECTION 6A: HEALTH CARE ACCESS

Federal law and policy establish extensive health care services that benefit people with disabilities directly or that affect them because they are present in significant numbers within a larger targeted demographic group such as low-income individuals who are served by Federally Qualified Health Centers (FQHCs). These programs have already been described in detail elsewhere; therefore, in the following section we provide only a brief reference to several of these key federal initiatives simply to establish the context for the examples that follow. These examples illustrate both promising and proven supports and services that aim to reduce health and health care disparities and improve health outcomes for certain groups of people with disabilities, many of whom are also members of racial and ethnic demographic groups. It has long been understood that with poverty comes an increase in disability and that disability can itself lead to poverty. This cyclic interaction thrusts many people with disabilities into life situations that increase the probability of poor health. Some of the examples presented in the following section therefore recognize and attempt to address the complex health problems that arise with certain social determinants of health, especially poverty, but also unstable housing, and inadequate long-term services and supports (LTSS). Others aim to improve care and

outcomes for people with specific disabilities such as mental health conditions, alcohol and substance use disorders, or developmental disabilities, while still others challenge physical and programmatic barriers to care through innovative policy solutions. These examples are not intended to be exhaustive. Rather, they illustrate how diverse organizations are working creatively and collaboratively in an attempt to remove or reduce barriers to care that contribute to poor health status and undesirable health outcomes for far too many people with disabilities living in twenty-first century America.

Medicare and Medicaid

Medicare and Medicaid are the government's primary health insurance programs for people with disabilities including older adults with and without disabilities. Of 55 million Medicare beneficiaries, 17% are under age 65 and qualify for Medicare because of a permanent disability. The number of older Americans is expected to double in the next 40 years, and the number of Medicare beneficiaries over age 65 who have functional or cognitive limitations will increase as the population ages.²⁸¹ Medicaid is the primary publicly financed health insurance program covering both acute and LTSS for low-income people with disabilities of all ages, who make up about 15% of the population the program serves.²⁸²

Long-Term Services and Supports (LTSS)

Historically, many people with significant disabilities who needed help with activities of daily living were consigned to lives in warehouse-like institutions with few options for living in the

community. Broader societal support for community-based LTSS gained momentum in the 1960s and 1970s as disability advocates challenged the premise of institutionalization and sought community living alternatives. The battle for home and community-based services (HCBS) is particularly challenging for low-income individuals due to Medicaid's structural bias toward institutional care.²⁸² Under federal law, states must include nursing home services as a Medicaid benefit, but HCBS is an *optional* benefit. Consequently, HCBS spending as a percentage of total Medicaid LTSS expenditures varies widely among states, from 21% to 78% in 2013.²⁸²

When needed services and supports are available in home and community-based settings people with disabilities have the choice to live independently, go to school, work, raise families, and fully participate in community life. Exemplary LTSS therefore promotes health and well-being, community living and integration, and encourages and supports social participation.²⁸³

Moreover, LTSS is less expensive when provided in noninstitutional, community-based settings.

LTSS includes the broad range of paid and unpaid medical and personal care assistance that people might need as a result of aging, chronic illness, or disability. LTSS help with activities such as bathing, dressing, preparing meals, eating, managing medication, and housekeeping.²⁸³

An estimated 11 million people living in the United States get help with daily tasks from paid workers, friends, or family members.²⁸² However, unpaid caregivers—families and friends—provide the majority of LTSS.²⁸⁴

Publicly supported LTSS enable community living for a group that is becoming more racially and ethnically diverse and whose numbers are growing rapidly as the population ages.²⁸² In

2012, more than 3.2 million people accessed paid LTSS through Medicaid. The year 2013 marked the first time that services provided at home accounted for the majority of national Medicaid LTSS dollars (51%). LTSS expenditures for HCBS vary across population groups. HCBS accounted for 75% of spending in programs aimed at people with developmental disabilities, compared to 41% for programs serving older people or people with physical disabilities, and people with serious mental illness or serious emotional disturbance.²⁸⁵ Regardless of how LTSS is funded or who provides it, these services often make it possible for many older adults and younger people with disabilities to remain in their own homes and in the community rather than being placed in institutions.

LTSS Needs Among Older Members of Racial and Ethnic Groups and Women

Members of racial and ethnic demographic groups in the United States continue to face a disproportionate burden of chronic illness and disparities related to health care access.²⁸⁶ Older adults with multiple chronic conditions are at greater risk for premature death, poor functional status, and unnecessary hospitalizations.²⁸⁷ Among older adults, women are more likely to need LTSS than men, and people of color are more likely to have an LTSS need than non-Hispanic whites. More than half of African-American/black (54%) or Hispanic or Latino (58%) older adults have an LTSS need, compared to 45% of Non-Hispanic whites. Some of these differences likely are related to income.²⁸⁸ Even as the emphasis on HCBS in recent years has generated more public funding for community-based care and services, many people still receive LTSS in skilled nursing facilities. Moreover, between 1999 and 2008, the number of older adults who are members of nonwhite racial and ethnic groups residing in U.S. nursing homes increased steadily,

in marked contrast to consistently declining numbers of white residents. Changing community demographics, including the growth in the number of older people of color, have contributed to the significant change in nursing home resident characteristics. Other factors that could explain this change might be changes in the structure of families, thus reducing availability of family caregivers, and potentially less awareness among nonwhite nursing home residents of the right to community integration under the Americans with Disabilities Act. (See Olmstead discussion in Section 5A, Services, Supports, and Inclusion Laws Related to Health Care.)

Some research suggests that African-American/black adults are less likely than whites to be in nursing homes with the highest staffing level of direct-care providers and the highest ratio of registered nurses to all nursing staff. They were more likely to be in understaffed facilities and in facilities housing predominantly Medicaid residents. Whites, on the other hand, have increasingly shifted to alternatives such as home care and private pay assisted living.²⁸⁹

LTSS Intersections with Health Care

Many people with disabilities require LTSS that intersect or overlap with clinical care and that support health maintenance. For example, LTSS can assist people who require help with insulin injections, ostomy care, or healthy meal preparation. It can assist people with serious mental health conditions function safely and autonomously in community-based settings, and certain services can facilitate employment for some beneficiaries. Yet many of these types of supports are unfunded or have no regular funding source, and are not coordinated, integrated, or subject to quality standards along with clinical care. Recognizing these gaps and intersections, the

Affordable Care Act (ACA) created the option for a number of innovative programs to test coordination and integration of clinical care and an array of LTSS.

Affordable Care Act Innovations

The 2010 Affordable Care Act (ACA) created new initiatives that held the potential to directly affect people with disabilities including enhanced disability data collection, training for health care practitioners to improve disability literacy, and setting of accessibility standards for medical exam and diagnostic equipment. The ACA also prohibited exclusion from health care coverage for people with preexisting conditions, thus improving their access to the private insurance market. While some ACA disability initiatives were not fully implemented owing to lack of funding, others received significant support. The ACA authorized the Centers for Medicare and Medicaid Services (CMS) to fund new innovations and demonstrations that focus attention on providers who serve populations with the highest health needs, including Medicaid beneficiaries. Some of these demonstrations are testing methods to integrate traditional acute care services with LTSS, including incorporating community-based services into the payment model.

Demonstration grants are also testing models that attempt to align services and payment schemes under Medicare and Medicaid for beneficiaries who are dually eligible for both programs, many of whom also have disabilities. Program goals include improving and expanding the scope of care coordination, improving health outcomes, eliminating cost shifting, and reducing costs. The ACA also promotes other models of care that might improve care coordination, including:

- Patient-centered medical homes for high-risk patients;

- Advanced payment accountable care organizations (ACOs);
- Geriatric assessment and comprehensive care plans;
- Care coordination through health information technology (HIT) and telehealth for high-risk patients;
- Community-based health teams to improve self-management; and
- Home health providers who offer multidisciplinary care teams.²⁹⁰

SECTION 6B: CARE COORDINATION AND CARE DELIVERY

Care coordination has been widely promoted as a method of improving health care for diverse populations including people with disabilities. Care coordination involves health care professionals working with patients to ensure that the right person is providing the appropriate care at the right time so the patients' health needs are being met. In the primary care practice, care coordination involves proactively organizing patient care activities and sharing information among all of the participants concerned with a patient's care to achieve safer and more effective care. Lack of coordination can cause harm to patients and can lead to unnecessary diagnostic tests, medication errors, unnecessary emergency department visits, and preventable hospital readmissions.²⁹¹

The ACA envisions enhanced care coordination as an essential tool for improving care and health outcomes and saving costs. In light of the extensive structural problems and gaps that contribute to health and health care inequalities and disparities for people with disabilities, however, it is unlikely that even enhanced use of care coordination will fully bridge those gaps

unless other innovative policy, training, and case management tools are brought to bear. For example, it is generally beyond the capacity of most care coordinators to resolve systemic barriers to care such as lack of accessibility of provider facilities and offices or inaccessible exam and diagnostic equipment. While they might be able to resolve some programmatic access problems for a few individual patients such as arranging for sign language interpreters, lifting assistance, or extra exam time that might be needed to ensure effective communication, these individual interventions do not achieve operational change within the practice or clinic that would benefit others. In another example, lack of behavioral health integration in primary care can create insurmountable barriers to care for people with certain mental health conditions regardless of whether or not care coordination is available. Moreover, as previously described, poor provider disability education and literacy can only be resolved through structural reforms within professional medical education programs. However, even as systemic barriers to care can limit the effect of care coordination, some important new models are evolving.

Innovative Behavioral Health Care Models

Progress in understanding behavioral health disorders have created new opportunities to diagnose and effectively treat these conditions and help people maintain homes, preserve family life, and avoid encounters with the criminal justice system. In response, treatment models are evolving that integrate behavioral health, including both mental health and chemical dependency treatment and primary medical care.²⁹² Collaborative case management, where care or case managers systematically link patients with mental health and primary care providers, has been found to be an effective behavioral health integration model. Improved patient outcomes

are associated with well-trained and supported care managers who systematically follow up with patients and communicate regularly with providers.²⁹³

*Washington State Mental Health Integration Program*²⁹⁴

The Washington State Mental Health Integration Program (MHIP) operates in partnership with the nonprofit health plan, Community Health Plan of Washington (CHPW), Seattle-King County Department of Public Health, and the AIMS Center at the University of Washington. Early program data showed that, compared to counties without MHIP, people who were served had 17% fewer inpatient medical admissions, a larger decrease in number of arrests (24%), a smaller increase in those living in homeless shelters or outdoors (50% vs 100%), and a smaller increase in days spent in state hospitals (33% vs 500%). Hospital costs also decreased for this group. The program has now been in continuous operation for over 8 years and has served over 45,000 patients in more than 150 community health centers.

*Care Coordination for People with Serious Mental Health and Substance Use Disorders in Louisiana*²⁹⁵

Louisiana has taken advantage of new financing mechanisms to implement managed care statewide along with processes intended to improve care coordination. The state included specific care coordination references in its managed care contract and encouraged managed care organizations to strengthen care coordination. Universally, providers, managed care officials, and states agreed that reimbursement for case management and care coordination is critical. In fact, some providers consider the services so essential that they will provide some type of

coordination even when people lose eligibility for these services. There is widespread agreement that local community-based organizations are best suited to locate hard-to-reach clients and identify suitable provider networks.

[Responsibility for care at the local level] has been very positive for the community...through our board we can bring in services and supports that meet the needs on a community basis, rather than having people who aren't on the ground and don't know what our reality is take a cookie cutter approach for the whole state.

—Behavioral Health Provider in Louisiana

*Link2Care, Camden Coalition of Healthcare Providers (CCHP) Camden, New Jersey*²⁹⁶

Camden, New Jersey, health care practitioners, health centers, and hospitals joined forces in 2007 to form the Camden Coalition of Healthcare Providers (CCHP). The first purpose was to create a program to help high users of health care services connect with primary care and later to transition more smoothly between locations of care. With very high levels of poverty, many people did not have access to primary care and they also had a complex mix of social, medical, mental health, and substance use disorders. CCHP created a citywide care management system that included a team made up of a family physician, nurse practitioner, medical assistant, and social worker. The team would see patients wherever they could be found—at home, in a shelter, or on the street. By 2010, the team was actively managing 108 patients, 60 of whom required

weekly or bi-weekly in-home visits. By 2011, CCHP added methods to smooth care transitions from in-patient hospital stays, and RNs, health coaches, and social workers were added to the teams. By 2014, the program was reporting that primary care providers were seeing patients within 8 days of hospital discharge, down from 22.21 days. CCHP reported a 46% reduction in average hospital admissions in the 6 months following enrollment for 80 patients who participated at least 6 months in Link2Care.

Integrated Medical and Behavioral Health and LTSS for People Dually Eligible for Medicare and Medicaid: A Disability Care-Competent Organization (DCCO)

Sometimes referred to as disability care-competent organizations (DCCOs), a few exemplary programs are working to better serve people with disabilities. They strive to balance clinical care and support services for people with complex health care needs and are noted for redefining medical necessity by offering supplemental benefits and services that facilitate independent living. Risk screening, assessment, service plan development, service coordination, transition planning, monitoring, and reassessment are considered important features of successful program components for people with disabilities.²⁹⁷

*Commonwealth Care Alliance, Boston, Massachusetts*²⁹⁸

The Commonwealth Care Alliance (CCA) is a nonprofit, consumer-governed health plan and health care delivery system that has operated for over 20 years and is considered an exemplary example of a DCCO. Currently, CCA provides integrated health care and social services and

supports to nearly 5,500 Medicare and dually eligible beneficiaries, the majority of whom have needs that qualify them for nursing home placement. The organization focuses on integrating home and community-based services and supports with individualized care planning for its members. Services go beyond what typical health plans offer and include in-home care, 24-hour provider access, patient education, and enhanced behavioral health services. CCA focuses on enhanced primary care, care coordination and management, and individualized care planning. Each member is assigned a personalized team of health care practitioners who work collaboratively to meet his or her individual needs.

Interdisciplinary teams provide medical care and support services 24/7, wherever members need them—at home or in a doctor’s office, hospital, or other location in the community. Each individualized care plan is based on an assessment and is specifically tailored, with care decisions made collaboratively by the team, the member, and the member's family or guardian.

The team can make and approve decisions about medical tests, medications, durable medical equipment, dental care, eyeglasses, and transportation based on each member's needs. For those with physical disabilities, CCA uses an individualized, integrated durable medical equipment clinical assessment, management, and allocation process that greatly simplifies access to the services. Behavioral health clinicians are integrated into the interdisciplinary teams providing individualized care plan development and management across physical and behavioral health needs. For members requiring long-term services and supports, CCA brings in staff from a community-based agency partner to work with the member and interdisciplinary team.

*Housing Options for High-Need Dually Eligible Individuals:
Health Plan of San Mateo, California—Pilot²⁹⁹*

The Health Plan of San Mateo (HPSM), a nonprofit public health plan that covers more than 140,000 residents of San Mateo County in California, implemented the Community Care Settings Pilot program in 2014. Made possible by flexible funding established by the ACA, the program is designed to avoid institutionalization of members who have both Medicare and Medicaid health coverage and to transition individuals from institutions back to community living. The 5-year pilot aims to connect more than 800 members with housing and care coordination services. Care managers oversee a phased approach that ensures successful transitions to the community.

Jim is a 58-year-old, single male who was admitted to a skilled nursing facility in September 2014 for rehabilitation following knee replacement surgery. He had a long history of homelessness prior to admission and had no home to go to after discharge. Jim had a history of alcohol abuse and had been to a residential alcohol and drug rehabilitation program. He also had multiple suicide attempts and voluntary psychiatric hospitalizations. After evaluation by HPSM's interdisciplinary team and the Pilot Core Group, he was approved for a scattered site housing unit and moved into it in March 2015....He has not had any relapses or suicide attempts and has started riding his bike to regain his strength. His family visits with him regularly, and Jim reports that he loves his new home.

As of January 2016, HPSM's pilot transitioned 70 individuals to community settings. Successful elements of the pilot will be integrated into HPSM's care management program for individuals at risk of placement in skilled nursing facilities. Initial data are promising and show high member satisfaction with services, reduced health care service use, and stable community placements. These efforts are helping more individuals to live in the community, thereby promoting a higher quality of life, improved health, and lower costs of care. HPSM will continue to track these data, evaluate pilot successes, and potentially extend select services and supports to broader at-risk populations.

Collaborations Between Health Plans, Disability Service Organizations, and Health Care Providers

While managed care organizations have a long history of coordinating care and managing financial risks associated with health care, many do not have experience providing LTSS to people who have significant physical or mental limitations or disabilities. As LTSS are increasingly included as a component of managed health care, managed care organizations have the unique opportunity to gain the expertise they require by partnering with community-based organizations that have extensive experience providing such services for people with disabilities. Such organizations include independent living centers, which are community-based, cross-disability, nonprofit organizations that are designed and operated by people with disabilities. Similarly, the Aging and Disability Networks (ADRC) have a long history of assisting older adults and people with disabilities by assessing and coordinating their social care needs, as well as effectively delivering quality LTSS, care transitions programs, and chronic disease self-care management trainings. The growth of managed LTSS presents an opportunity for managed care

organizations, independent living centers, and the Aging and Disability Networks to build on their complementary expertise to provide quality LTSS.

*Care Transitions Intervention: A Unique Collaboration Between Community Groups and Health Providers in Rural Grass Valley, California*³⁰⁰

The Aging and Disability Resource Collaborative (ADRC) launched the Care Transition Intervention Program in 2012 with the FREED Center for Independent Living, the Western Sierra Medical Clinic (WSMC), Community Recovery Resources (CoRR), and Sierra Nevada Memorial Hospital, the only local hospital in rural Western Nevada County, California. An evidence-based program, the goal of the Care Transition Intervention Program is to reduce hospital readmissions and emergency department visits within 30 days of discharge for high-risk individuals living in rural communities. Program participants are Medicare and/or Medicaid beneficiaries who typically have complex health issues including mental health and substance use disorders. Deeply rooted in a philosophy of consumer direction and control, trained care transition coaches based at FREED, but housed at Sierra Nevada Memorial Hospital, work with individuals referred by hospital staff to reduce barriers to care. They offer medication management techniques, use of personalized health records where individuals can record physician instructions or questions, and schedule timely follow-up appointments with primary care providers. They also connect participants with community services and supports. Preliminary data suggests that 30-day readmissions are lower for program participants and patient satisfaction with care is improved. For example, among 136 people referred in 2014, 6.5% experienced readmission, which compares with a 10% readmission rate for that year for all other populations regardless of diagnosis.

Innovations in Care Coordination and Delivery for People with Intellectual and Developmental Disabilities

*Regional CART Services for Developmental Primary Care, University of California, San Francisco*³⁰¹

Community-based health care systems do not currently have the expertise and capacity to serve the most medically fragile and behaviorally complex adults with developmental disabilities. In 2006 a group of stakeholders in the Bay Area of Northern California from academic, clinical, community, social service, and public insurance sectors came together with the goal to develop a proposal for a pilot model system of care. The vision was to ensure that all transition age youth and adults with developmental disabilities (DD) have access to the health care services they need to maximize their wellness and function. Health care for people with DD is defined as interdisciplinary, team-based care, with patients and caregivers at the center of the team. Through an iterative process including stakeholder interviews and literature review, the group identified the key components of a comprehensive, sustainable system of care. The components are encapsulated in the mnemonic, *CART*, which stands for: Clinical services for both primary care and assessment and consultation, Advocacy for patients who need support to access care, Research programs in health surveillance and health services, Technical assistance for clinicians at the point-of-care, and Training to ensure an adequate workforce. The *CART* model was initially proposed in the context of both national and statewide health care reform.

CART services are funded in part by a coalition of Northern California regional center agencies who are responsible for administering California's entitlement to services and supports for people with developmental disabilities. Regional center clients and those who care for and serve them are eligible to receive clinical consultation and training. Components of the model include the Office of Developmental Primary Care in the University of California, San Francisco; Department of Family and Community Medicine; the Wellness Health Advocacy Program at the Arc of San Francisco; a pilot Health Advocacy Program at the Family Health Center at the main Family Medicine residency training site in the area; and a multidisciplinary clinic. The team also provides technical assistance regarding policy for health care delivery to the California Department of Developmental Services and participating regional center agencies.

A core, mobile, consultation team of clinical experts staffs regional CART services, and includes primary care, nursing, and psychiatry personnel. Services include:

- Limited comprehensive clinical consultations and assessments, in person or via telemedicine;
- Phone and e-mail clinical support for health care providers, caregivers, families, self-advocates, service providers, and case workers;
- Web-based resources on best practices;
- Training for health care providers and others who provide care and support to people with developmental disabilities; and
- Technical assistance to health plans and medical groups for quality improvement and policy development.

**Medical-Legal Partnerships:
Mitigating Complex Social Disadvantages that Affect Health³⁰²**

Medical-legal partnerships (MLP), an innovative strategy to improve the health of low-income and underserved individuals, many of whom are people with disabilities, has grown and evolved over the past decade and integrates civil/legal aid services into clinical care settings. The purpose of MLPs is to resolve some of the complex social and situational problems that frequently undermine health such as loss of food stamps, cash, and disability benefits; substandard housing, and evictions; custody and domestic violence disputes; and special education needs. Sometimes referred to as “health-harming civil-legal needs,” clinicians and other health care professionals receive training to recognize these needs. MLPs help establish processes that create an efficient mechanism for referring a patient to a legal professional who can help resolve the problem. Hundreds of organizations and institutions have developed MLPs, including 139 Federally Qualified Health Centers in the United States.

Health care delivery organizations, policy makers, and patient advocates across the United States are increasingly aware that many factors outside the health clinic’s door affect the health of patients and communities. What is less commonly understood is how law functions as an important social determinant of health, and how lawyers can effectively collaborate with clinicians, case workers, patient navigators, and other members of the health care team to both prevent and remedy the many health-harming factors that have their roots in legal problems.

*Project HEAL, The Kennedy Krieger Institute, Baltimore, Maryland*³⁰³

The Kennedy Krieger Institute in Baltimore, Maryland, provides patient care for people with intellectual and developmental disabilities and conducts research, community programs, education, and professional training. The institute's medical-legal partnership, Project HEAL (Health, Education, Advocacy, and Law), which incorporates advocacy and legal services into pediatric clinical services, served 427 children with developmental disabilities and mental health concerns and their families between 2005 and 2013. Typically these families are low-income, earning less than 50% of Maryland's median income. Working as members of the care team, attorneys assist families to resolve various problems that affect health and well-being, including those concerning the child's right to special education and related services under federal special education law, such as mental health services, and also eligibility for federal disability benefits. Outcomes could involve a change in educational placement and related services, a more appropriate educational placement, or the implementation of the institute's clinical recommendations.

*Lancaster General Hospital Pilot, Lancaster, Pennsylvania*³⁰⁴

In an effort to fulfill the true promise of patient-centered care, Lancaster General Hospital in Lancaster, Pennsylvania, conducted a pilot project during a 12-month period spanning 2011 and 2012 that integrated lawyers into an interdisciplinary care team. The purpose was to

understand the effect on health care cost and use, and also on health effects of integrating civil/legal aid services into the care of patients with multiple chronic conditions and disabilities. An attorney was present during case management discussions to help identify specific civil or legal problems and to assist the group understand how to resolve them. During the pilot, 55 patients were enrolled who were very high users of emergency department and inpatient care. Among this group, 95% (52 people) had two or more civil/legal problems that affected their health. Housing problems, such as securing housing subsidies and preventing evictions, were the most common followed closely by access to public benefits. Some people also experienced problems related to domestic violence, access to health care insurance, and mental and behavioral health problems.

Some of the identified problems required direct legal services while social workers and other medical staff resolved other problems after receiving substantive legal training. About 16% of the legal problems that participants experienced related to disability required direct legal help from an attorney. The case management team with attorney support handled the remaining 84% of the issues. The pilot found civil/legal interventions helped stabilize housing for some participants thus reducing hospitalizations and emergency department visits necessitated by the effects of homelessness. Similarly, increasing someone's income by appealing food stamp or disability benefit denials helped ease the trade-off between affording only prescription medications or food, but not both. (See Section 3, Disabilities, Social Determinants and Health Disparities.)

Pilot data suggest a decrease in both 7-day and 30-day readmission rates among the participants when their civil/legal problems are managed. Similarly, both emergency department and inpatient use dropped by almost 50%. Moreover, patient health improved while overall health care costs fell by 45%.

*Health Resources and Services Administration (HRSA) Guidance: Civil/Legal Aid Services Can Be Included in Services Provided by Federally Qualified Health Centers (FQHCs)*³⁰⁵

Federal data indicates that approximately 7 in 10 health center patients live in poverty and about 9 in 10 live on incomes that are less than 200% of the federal poverty level.³⁰⁶ Two-thirds of health center patients are members of racial or ethnic demographic populations. Studies suggest that between 50% and 85% of health center patients experience unmet legal needs, many of which have a negative effect on their health and well-being. Among the groups health centers serve, those most likely to be in need of legal assistance for civil/legal problems that affect health outcomes are people with disabilities and those who have chronic health conditions.³⁰⁷

While support for MLPs is growing, there historically have been significant funding challenges for the program, which has depended largely on private philanthropy, civil/legal aid organizations, and law schools for support. However, in 2014 the Health Resources and Services Administration (HRSA) issued guidance clarifying that civil/legal aid services can be included in the range of services that health centers are permitted to provide to serve their patients' primary care needs. This clarification has sparked the further growth of medical-legal partnerships, and as of June 2016, 77 such partnerships are operating at HRSA-supported health centers.

SECTION 6C:
PHYSICAL AND PROGRAMMATIC ACCESS TO HEALTH CARE

People with disabilities encounter complex barriers that contribute to difficulties or delays in getting needed health care and increase the likelihood of poor health outcomes. Identified barriers include lack of provider awareness and training, lack of accessible medical offices and facilities, and a dearth of accommodations such as accessible medical and diagnostic equipment, lifting assistance, or sign language interpreters.¹²⁸

Over the past few years, many states, including California, have required that Medicaid beneficiaries with disabilities move into managed health care. Promoted as a strategy to coordinate care and save costs, Medicaid managed care organizations (MCOs) limit beneficiary choice of provider to only those physicians who participate in plan networks. Many Medicaid beneficiaries with disabilities require accessible facilities and diagnostic and exam equipment in order to receive equitable health care, yet MCOs typically do not know if the providers in their networks are located in accessible facilities or have accessible equipment such as height-adjustable exam tables and accessible weight scales.

**New Federal Regulations Acknowledge Accessibility Problems:
The CMS Equity Plan for Improving Quality in Medicare³⁰⁸**

Even as most states have done little to assess Medicaid health care provider accessibility, new proposed federal regulations and initiatives suggest a growing understanding of why this

information is critical to patient care and health outcomes. For example, in September 2015, the federal Centers for Medicare and Medicaid Services (CMS), Office on Minority Health, released, “The CMS Equity Plan for Improving Quality in Medicare,” which, for the first time, ranks as a high priority increasing physical accessibility of health care facilities. At CMS’s request, the independent research organization NORC at the University of Chicago is evaluating ways accessibility can be measured and achieved nationwide. CMS also issued final managed care regulations in April 2016 requiring that each managed care organization ensure that health care practitioners provide physical access, accommodations, and accessible equipment for individuals with physical or mental disabilities. The regulations also indicate that in developing network adequacy standards, the state must consider the ability of providers to ensure physical access, reasonable accommodations, culturally competent communications, and accessible equipment for individuals with physical or mental disabilities. If these regulations are implemented, states will need to find adequate ways to assess the extent to which health care provider networks meet the requirements. (See below, California’s Primary Care Provider Accessibility Survey.)

Dual Eligible Demonstrations—Contract Provisions Promote Accessibility

*Massachusetts OneCare Three-Way Contract*³⁰⁹

A number of states are testing the benefits of integrating care for people who are dually eligible for both Medicare and Medicaid. Some three-way contracts between CMS, participating states, and MCOs have included specific provisions requiring that MCOs assure physical and programmatic access and the provision of accommodations for people with disabilities. For

example, the Massachusetts OneCare Three-Way Contract calls for developing and implementing a strategy to do the following:

Manage the Provider Network with a focus on access to services for Enrollees, quality, consistent practice patterns, the principles of rehabilitation and recovery for Behavioral Health Services, the Independent Living Philosophy, Cultural Competence, integration, and cost effectiveness. The management strategy shall address all providers. Such strategy shall include at a minimum, conducting onsite visits to Network Providers for quality management and quality improvement purposes, and for assessing meaningful compliance with ADA [Americans with Disabilities Act] requirements...[and] the Contractor must...reasonably accommodate persons and ensure that the programs and services are as accessible (including physical and geographic access) to an individual with disabilities as they are to an individual without disabilities.

*Michigan MI Health Link Contract*³¹⁰

Similarly, the Michigan MI Health Link contract states that, “The ICO [Integrated Care Organization] must reasonably accommodate persons and shall ensure that the programs and services are as accessible (including physical and geographic access) to an individual with disabilities as they are to an individual without disabilities.” It goes on to call for, “written policies and procedures to assure compliance [with the Americans with Disabilities Act],

including ensuring that physical, communication, and programmatic barriers do not inhibit individuals with disabilities from obtaining all Covered Services.”

California’s Primary Care Provider Accessibility Survey³¹¹

Since 2011, California has required all MCOs to administer an 86-item accessibility survey, including questions about availability of accessible weight scales and height-adjustable exam tables, at the offices of each primary care provider in the plans’ networks. Trained MCO personnel administer the survey, and health plans post certain basic access results on their websites. They also are required to report results annually to the California Department of Health Care Services. While surveying primary care offices for accessibility does not necessarily rigger action to address access barriers, posted access information helps people with disabilities evaluate a prospective provider site and the information also could help MCOs evaluate network adequacy in terms of certain accessibility features and equipment.

Researchers analyzed data from a similar 55-question predecessor survey administered at 2,389 primary care facilities in California, which disclosed that an accessible weight scale was present only in 3.6% of sites and a height-adjustable examination table in 8.4% of the sites. Even as MCOs are serving the majority of Medicaid beneficiaries with disabilities residing in the state, few primary care facilities have the necessary accessible equipment to accommodate those with certain mobility disabilities. Understanding the extent to which health care providers are accessible is an important first step in shaping future policy aimed at increasing access and

complying with federal disability rights laws and other health care policies previously described.¹⁸⁶

Collecting Functional Limitation Information in Electronic Health Records³¹²

In light of the changing regulatory landscape and a growing understanding of the underlying causes of health and health care disparities among people with disabilities, it is increasingly important to consistently identify and record physical, mental, and intellectual functional limitations in electronic health records (EHR). Patient functional limitation data is required not only so health care providers can plan for accommodations, it is also required in order to understand and plan for the prevalence of such conditions among the patient population. Another purpose is to be able to cross-reference it for research and policy purposes with population health and other demographic information such as race/ethnicity, gender, age, and LGBT status. Including functional limitation queries in the EHR would significantly benefit research into the health care disparities experienced by people who have intersectional bases for discrimination and unequal treatment such as disability and another demographic characteristic because such cross-analysis cannot currently be carried out without reliable information about the prevalence of functional limitation. Furthermore, the medical diagnostic codes that are presently included in medical records do not offer a solution because a single diagnostic code can be associated with a wide variance in functional capacity and does not correspond to or represent the level or degree of a given individual's functional limitations. Therefore, information on functional need is critical to trigger provider administrative processes that result in needed accommodations.

LifeLong Medical Care, Alameda County, California, Tests Value of Collecting Functional Limitation Information in EHRs³¹³

Several years ago, LifeLong Medical Care, a Federally Qualified Health Center located near San Francisco, in Alameda County, California, embedded four functional impairment questions in the health center's registration form in order to alert primary care staff that some patients required accommodations. Patients are asked to indicate if they require extended exam time, mobility assistance, sign language interpreters, or low vision or blind assistance. These questions are included in the clinic's electronic health records and can be flagged in individual patient records. This is likely to be the first time such information has been collected and recorded in electronic health records by a large primary health care practice. For the 2015 calendar year LifeLong reported that among 33,596 unduplicated patients who received care, 2,281 indicated a need for mobility assistance, 39 needed print materials in accessible formats, and 26 needed long appointment times. Twenty-two patients needed more than one accommodation or needed an impairment-related accommodation as well as language interpretation, including sign language. (LifeLong also collects information for people who require only a sign language interpreter, but that figure is not yet available for 2015.) Research is planned to understand how LifeLong uses the functional impairment data and to determine how it affects patient care, availability of accommodations, and health outcomes, especially routine preventive care.

Conclusion

We must find ways to focus increased attention on the known multiple and often compound barriers to health and health care that the heterogeneous population of people with disabilities

frequently encounters. Moreover, many people with disabilities also have specific, additional health care needs that must be recognized and addressed or poor health outcomes will continue unchanged.

As health care practitioners, policy makers, and other stakeholders become increasingly aware of and understand the mutable nature of disability, the implication for the population as a whole becomes ever more important. With age, everyone will eventually experience an increasing propensity to develop functional limitations and disability. At the same time, health care advances enable people of all ages with functional impairments and disabilities to live longer, productive lives and to remain at home in their communities rather than live in institutions. Logically, therefore, almost everyone at some point in their lives inevitably will need access to innovative, coordinated, and sustainable health care programs and services that account for the complex intersections of race, ethnicity, disability, age and other demographic factors.

Thus, thoroughly evaluating promising and best practices and scaling those that succeed in improving long-term health outcomes are critical first steps toward transforming a health care system that is biased toward urgent care rather than chronic care coordination and maintenance of health, and institutionalization rather than long-term services and supports that emphasize home and community-based services.³¹⁴

Recommendations

Long-Term Services and Supports

- 1. Instead of requiring states to provide institutional care for people with disabilities in order to qualify for federal Medicaid payments, Congress should instead require states to provide community-based long-term services and supports for individuals who are financially eligible and who require an institutional level of care.**

In 1999, the U.S. Supreme Court issued a ruling in *Olmstead v. L.C.* stating that people with disabilities have the right to live in the community instead of an institution. In response, states have slowly reduced the proportion of LTSS provided in institutional settings even as the number of Asians, blacks, and Hispanics residing in nursing homes has increased. Broad legal reform is required to reverse the bias built into the Medicaid statute that requires states to provide LTSS for people with disabilities in institutions instead of home and community-based settings in order to qualify for federal Medicaid funding.

- 2. HHS should urge states to strengthen and streamline access to home and community-based services (HCBS) and reduce restrictive eligibility and other barriers to participation.**

LTSS programs tend to be fragmented. Eligibility for services also varies from state to state, and people with different disabilities are treated differently depending on funding categories. Thus reforms are required that streamline access to LTSS.

Care Coordination and Care Delivery

- 1. HHS should identify, thoroughly evaluate, and bring to scale the care coordination and integration service delivery models that show the greatest promise for improving health outcomes for people with disabilities.**
- 2. Accountable care organizations, accountable care communities, and medical homes/health homes should integrate nonmedical, community-based services and resources into their comprehensive service model of care.**
- 3. Behavioral and physical health care services should be integrated across health care delivery settings, including interoperable health information technology (HIT), while recognizing the additional rights of privacy over some components of their health records to which individuals are entitled.**

Certain models of care coordination have been shown to benefit certain groups of people with disabilities such as mental health and substance use disorders, or those who have complex medical needs and also require significant long-term services and supports. Some of these care models began operating at the community level in response to overwhelming unmet need among people with diverse disabilities. While a few have gained the attention of federal policy makers, others have not yet been recognized even as they are innovating at the local level. These emerging care models deserve increased attention from researchers and policy makers, and some likely will warrant being brought to scale with government support.

- 4. The U.S. Department of Health and Human Services (HHS) should continue to explore, test, and adopt innovative financial payment models that support care coordination and the integration of health and social and community services for people with diverse disabilities.**

Stakeholders associated with some of the coordinated service models consistently identify financial payment for care coordination and care management innovations as the single most essential requirement if the sometimes-complex needs of patients with disabilities are to be met reliably over time.

Physical and Programmatic Access to Health Care (See also Legal Monitoring and Enforcement Recommendations)

- 1. The Office of the National Coordinator for Health Information Technology (ONC/HIT) must require the capacity to include functional limitation information within electronic health records.**

Placing cognitively tested and validated questions such as the American Community Survey set of six disability questions into patient electronic health records can trigger alerts signaling the need for disability accommodations in health care settings. These or other, similar cognitively tested and validated questions can also help answer the need for data about the presence of activity limitations among people seeking health care. Moreover, the presence of impairment-related information in the health record also enables cross-analysis with race, ethnicity, age,

LGBT status, and geographic location in order to provide a fuller picture about individuals at the intersections of these multiple demographic characteristics. The data can also be tied to numerous meaningful use objectives such as better health outcomes.

- 2. The Health Resources and Services Administration (HRSA) should require that the Federally Qualified Health Centers (FQHC) incorporate functional limitation questions into their intake and health information technology record keeping processes and that FQHCs regularly report outcome data.**

FQHCs provide clinical services for low-income populations who experience higher-than-average levels of disability and therefore are excellent settings for incorporating impairment-related questions. These queries can be used to trigger awareness of potential accommodations that patients with various activity limitations might require. Data showing how many people need accommodations and what they specifically require will inform future initiatives aimed at improving health outcomes for the FQHC patient population.

- 3. The U. S. Department of Health and Human Services and the Center on Medicare and Medicaid Services should incentivize health care provider capacity to increase access and to accommodate people with disabilities.**

Innovative methods to increase access and provider capacity to accommodate people with disabilities in clinical settings could include using various means to incentivize health plans to solve access problems. For example, the cost of accommodations such as accessible weight

scales and exam tables, extended exam time, or a sign language interpreter, could be included as elements of medical loss ratio calculations.

- 4. The Center on Medicare and Medicaid Services should strengthen managed care organization's provider network adequacy standards by requiring a showing of accessibility and capacity to accommodate people with disabilities and by calling for networks to be expanded if found to be deficient.**

Some three-way contracts between CMS, participating states, and MCOs that implement a demonstration program to align services for beneficiaries who are covered by both Medicare and Medicaid have included specific provisions requiring that MCOs assure physical and programmatic access and the provision of accommodations for people with disabilities.

Meaningful implementation of these contract provisions at a minimum requires MCOs to survey their provider network for accessibility. While, few states have taken such action, California has been using a survey instrument since 2012 that could serve as a starting point.

Section 7

Conclusions and Summary of Recommendations

This paper is an exercise in connecting dots. Those “dots” or policy conclusions include the following:

- The prevalence of disability type and extent varies significantly between different ethnic and racial groups, with variance observed between men and women, different age brackets, and even among children prior to age 18. [Section 2]
- Adults and children with disabilities consistently show “unhealthier” results when viewed in the context of many social determinants of health such as education, income, employment, social and community context, housing, neighborhood and built environment, and health care access. [Section 3]
- Conscious and unconscious biases and stereotypes among health care providers and public health practitioners about specific racial and ethnic groups, and people with disabilities, contribute to observable differences in the quality of health care and adverse health outcomes among individual within those groups. [Section 4A]

- Current research efforts have evolved to place primary responsibility for health literacy within health care systems and professionals. A major thrust of this research is to place health literacy interventions in the sociocultural contexts of individuals and groups—linking its relevance to everyday life experiences. Unfortunately, disability has been conceptually and virtually excluded from many of these health literacy research efforts, which also fail to take into account the cultural and linguistic heterogeneity among people with disabilities. The result is the systemic exclusion of this population from the potential of this research. [Section.4B]
- Research specifically investigating how the health care barriers faced by people with disabilities may be compounded by race or ethnicity is virtually nonexistent. For example, we know that members of non-white racial and ethnic groups are much less likely than whites to participate in randomized controlled trials or other research that produces the scientific evidence base documenting effective treatments. Persons with disabilities are also systemically excluded, although there is less research on this issue. We do not know whether or how race/ethnicity and disability effects could be compounding the lack of scientific evidence to guide treatment decisions for these populations. [Section 4C]
- Federal disability rights laws that were intended to remove barriers to participation for people with disabilities in all walks of American life have not yet sufficiently transformed health care coverage, service delivery, or accessibility to enable people with disabilities to receive equally effective health care. [Section 5]

- Social, income, and service supports needed by people with disabilities are highly fragmented according to payment source and delivery method. People with disabilities who face inevitable transitions as they reach certain points in age, employment, income level, and family status need the efficient development and dissemination of promising practices in health care access, care coordination, and accessible care delivery. [Section 6]

Each “dot” above represents a finding presented in this paper. When we connect the dots, we find that a pattern emerges suggesting especially serious disparities for people with disabilities in underserved racial and ethnic groups. However, considerably more work is needed to fully understand that apparent pattern. Currently, very little health disparity investigation or research is taking place that addresses the intersection of disability, race, and ethnicity. This can be attributed to a number of factors that include, but are not limited to (1) a lack of specifically targeted research funding and other directed financial incentives, (2) limitations of established research priorities, and (3) a reflection of the long-standing inadequate collection of information within health care settings about disability and activity limitations as a demographic characteristic rather than an undesirable health outcome.

Our first set of recommendations, therefore, addresses data and research.

Data and Research

1. Mandate the expanded collection of disability data that, at a minimum, captures functional impairment status.

The ACS set of six disability questions or a validated equivalent set, such as the Washington Short Set of questions on disability, must be established as a minimum demographic element across all federally conducted *and federally funded* data sources, including state and local programs such as Medicaid and state health disparity investigations. Inclusion of a disability question set must be required, but as with race and ethnicity questions, the questions should remain voluntary for survey takers. All levels of government programs should seek to incorporate additional data elements wherever possible that examine the complexity and duration of disability experienced by those surveyed.

2. Collect disability information on a consistent and ongoing basis.

The overall population of people with disabilities will increase as the U.S. population ages and as medical advances enable children and people with disabilities to live longer. Health and other trends in a growing and increasingly heterogeneous population of people with disabilities cannot be detected and tracked accurately without a commitment to collect consistent data on the characteristics of the disability population across multiple years. This will allow for the pooling of multiple years of data to ensure adequate representation of smaller disability subgroups.

3. Maintain and expand sources of detailed disability and intersectional information.

What we now know about health disparities experienced by people with disabilities is owed in large part to the more detailed examination of disability that has historically been undertaken in the National Health Interview Survey (NHIS), the Medical Expenditure Panel Survey (MEPS), and the Survey of Income and Program Participation (SIPP). Revisions to these surveys must *expand*, not reduce, the disability data collected or we will be unable to examine in a comprehensive manner the disparities that occur within identified racial and ethnic population groups.

4. Recognize disability within public and private systems as a population that experiences disparities in health and social determinants.

If disability-specific information is not included within the processes to monitor social determinants of health and health outcomes across populations, it will be impossible to make comparisons between people with and without disabilities, or understand how disability intersects with other characteristics such as race, ethnicity, gender, age, sexual orientation, and gender identity. Federal and state-sponsored health disparities surveillance must lead the way in collecting consistent disability measures over multiple successive years, including disability status, type, and complexity. This approach to data collection and monitoring sets an example on the importance of disability identifiers for such privately funded disparities proposals as the National Health Equity Index.

5. Explicitly include disability in health equity research and programs.

Disability status should be included routinely in all research and programs that address health equity.

6. Include disability information in electronic health record (EHR) standards and certification criteria issued by the Office of the National Coordinator for Health Information Technology.

The 2015 standards included many items related to health and health care disparities, but they did not require collection of information about disability status. There is nothing about disability in the long list for the Common Clinical Data Set, though many other demographic issues including sex, age, race, ethnicity, preferred language, and so on. The absence of any requirement to collect information about disability in EHRs makes it difficult, if not impossible, to examine disparities for people with disabilities as a group, and as a population that intersects with other demographic characteristics.

7. Conduct and encourage publicly and privately funded health and public health research that is specifically directed at understanding health status and health care experiences of people with disabilities who are also members of other underserved populations.

While “person-centered care” has become a common approach to health care treatment, it is less commonly associated with research design. The complex and little-understood interplay

of social, physical, procedural, and attitudinal barriers encountered by people with multiple marginalized identities requires community-based participatory research approaches. Members of the study population need to be involved in designing and conducting research to ensure that research prioritizes the most relevant concerns of these population groups. Both quantitative and qualitative studies are needed to further define the experiences of people with disabilities across diverse racial, ethnic, linguistic, and cultural groups, and the implication of the sociocultural contexts of their everyday life experiences across all fields of public health research.

8. Funders need to require documentation that health literacy research includes principles of cultural, linguistic, and disability competence.

Public health policy is needed that encourages the principles and practices of cultural and linguistic competence and health equity intervention research in the conduct of research on health literacy. Such policy needs to be supported by professional development for many within the research community to mitigate biases and stereotypes that are barriers to and perpetuate the segregation of people with disabilities in health literacy studies.

Specific actionable items for key actors related to data and research:

- The U.S. Department of Health and Human Services (HHS) should commission a report that investigates the intersectionality of disability with other demographic factors such as race and ethnicity.

- HHS should establish funding opportunity announcements (FOAs) focused on ways to examine the extent of disability and intersectional health disparities. Given the relative novelty of the subject, FOAs should provide examples of potential projects such as research:
 - That seeks to understand how racial, ethnic, and cultural factors influence voluntary self-acknowledgement of different functional limitations;
 - On the development of practical tools that will help providers and office staff to acquire disability, functional limitation, and needed accommodation information in culturally sensitive ways;
 - Aimed at understanding the impact on health outcomes when electronic patient records contain information about functional limitations and accommodation needs;
 - Into whether and how patient data that may be entered in clinical document architecture templates developed or being developed under federally required electronic health record (EHR) standards may provide a proxy for disability status and functional limitation for individual patients, and potentially link to EHR questions on, and tracking of, accommodation needs;
 - Focused on health care providers who currently choose to work with underserved populations, to understand factors that interfere with the provision of high-quality care to people with disabilities within their chosen subpopulation, and to learn the supports and tools needed for equal access.

- HHS must clarify to all states that there is no federal regulation that *prohibits* states from asking voluntary demographic questions, including 42 CFR 435.907(e) which establishes what states can *require* in the single streamlined marketplace/Medicaid application. States are not prohibited from including disability status questions such as the ACS set of six disability questions, much as questions about race, ethnicity, and language preference are currently asked. At the same time, CMS should require states to notify applicants that disability-specific demographic information cannot be used for eligibility or benefit decisions in public or marketplace insurance, and to affirm this practice in fact.
- Other federal and state agencies should formally recognize people with disabilities as a health disparity population, as has the CMS.
- Lawmakers should amend clinical trial reporting requirements so clinical trial research designs and proposals in National Institutes of Health (NIH)-funded clinical trials include the functional limitations of clinical trial participants. This would be similar to what was done under the NIH Revitalization Act of 1993 when it ensured the inclusion of women and of diverse racial groups by requiring reporting of racial and gender makeup of clinical trial participants.
- The Centers for Disease Control and Prevention (CDC) and NIH should adopt use of Health-Adjusted Life Years instead of Disability-Adjusted Life Years measures as a quality outcome standard in their own publications, and strongly encourage private journals that publish peer-reviewed research to do so as well.

Data and research recommendations highlight the many gaps in our knowledge about people at the intersections of disability, race and ethnicity. Nonetheless, this paper documents that

persistent barriers to health care are reflected in poorer health outcomes experienced by people with disabilities across racial and ethnic lines. Therefore, while we need data, we also need immediate action on known barriers.

Our next set of recommendations therefore addresses the need for action on various fronts to address existing barriers.

Provider Education and Training on Disability

1. Disability competence must address several topical components.

Subject matter content should include at a minimum such topics as disability sensitivity and stereotypes, physical and programmatic accessibility required by law, and clinical expertise.

2. Disability competence must be required at multiple levels and across disciplines.

Training on disability competence should be provided at the preservice, professional licensure, and continuing-education levels, and as a component of ongoing accreditation. Disability training must be directed at primary care and all health care professionals, including mental health, dental, and rehabilitation/habilitation practitioners. It should also include public health and human services practitioners and researchers, as well as policy makers within federal and state departments of health, human services, and public health.

Specific actionable items for key actors related to training:

- Federal agencies that fund or provide student financial assistance to educational institutions that train direct care and public health professionals should require those entities, as a condition for receiving funding, to include disability competence as a component of or in addition to cultural competence training.
- Accreditation entities for health and public health professional schools should include information about the availability and quality of a school's disability and cultural competence training in their school reviews and ranking.
- Professional licensure bodies should require candidates for professional practice to demonstrate disability competence.
- Managed care organizations that administer Medicaid or are involved in Medicare and Medicaid dually-eligible demonstration projects implemented under the Affordable Care Act must ensure their provider network receives ongoing disability literacy and competence training given the higher incidence of disability and functional limitation within the Medicaid and dually-eligible population. Primary care providers, in particular, must demonstrate disability competence given the role of the primary care provider in managed care organizations as the central referral point to further needed services. The same reasoning holds true for nurses and social workers who managed care entities employ or contract with to assess long-term services and support needs, including home- and community-based services.
- Dental and mental/behavioral health services that are carved out of integrated managed care services and not administered through a plan must receive disability literacy and

competence training on their own professional education and certification tracks.

Medicare, state, county, and local government entities that contract with dental and mental health provider networks should ensure that prospective providers have received distinct training before contracts are awarded.

- Public health and clinical researchers need professional development and training that will help them to mitigate disability biases and stereotypes that perpetuate the segregation of people with disabilities in all areas of health studies, and encourage cultural and linguistic competence and health equity in public policy.
- Public health and clinical researchers need to receive training and tools that will enable them to identify and measure the multiple cultural identities held by people with disabilities and investigate the barriers experienced by those with multiple marginalized identities.
- Disability competence training and best practices should be tailored to specialty procedures, such as mammography, dental health, oral surgery, nutrition counseling, health risk assessment, depression screenings, and so forth to support the capacity of specific professions to adapt methods and procedures to meet individual needs.
- HHS should encourage and support the development of centers of excellence on specific areas of advanced disability competence.

Legal Monitoring and Enforcement

- 1. Federal and state enforcement agencies and departments and covered entities must improve independent “pattern and practice” investigation, administrative monitoring, and enforcement under Section 504 and the Americans with Disabilities Act to relieve the enforcement burden on individual complainants and plaintiffs.**

Section 504, the Americans with Disabilities Act, the Affordable Care Act, and other legislation explicitly prohibits discrimination on the grounds of disability. Discrimination includes the failure to provide reasonable accommodations, policy modifications, and effective communication required by people with disabilities to receive effective health care services. Full implementation of long-standing nondiscrimination standards requires consistent federal and state monitoring that is not primarily dependent on actions initiated through individual complaints, technical assistance to all covered entities, and consequences for noncompliance that are widely known and enforced.

- 2. Develop legal requirements that directly incorporate key data, education, research, and education/training/certification goals on disability discrimination and health and health care disparities.**

Many health professional licensure and certification bodies are not operated by, nor receive funding from, any level of government. Nonetheless, there is a strong public health interest in ensuring that health professionals and facilities of all kinds are adequately prepared to meet the needs of the American public. State and federal governments should, to the extent

possible, work with state licensure bodies and state and national accreditation and certification bodies to incorporate disability-specific training and competence standards.

3. Implement training and technical assistance to people with disabilities on their disability rights in a health care context, incorporating ethnically and racially sensitive outreach and education of older individuals with newly acquired disabilities.

Many individuals do not necessarily culturally identify with the disability community, and they need not do so, but they nonetheless have a right to effective health care delivery through the receipt of reasonable accommodations, policy modifications, and equally effective health care. Such individuals and population groups need to receive information about their rights in a culturally sensitive manner that emphasizes universal need.

Specific actionable items for key actors related to legal monitoring and enforcement:

- CMS must establish clear standards, monitoring tools, and civil rights complaint/appeal guidance for the managed care entities that enter into Medicare and Medicaid contracts with CMS and with states. While Medicaid managed care regulations, Medicaid 1115 waivers, Medicare Advantage and Part D Plans contracts, and various Medicare-Medicaid duals demonstration 3-way contracts almost invariably include some disability

accommodation language, practical methods to monitor, implement, and enforce the language are currently absent

- Federal and state regulation of Medicare and Medicaid plan “provider network adequacy” must explicitly require plans to establish that they contract with providers that are physically accessible, capable of providing needed reasonable accommodations and policy modifications, and compliant with effective communication requirements. If a plan cannot demonstrate its capacity to accommodate the needs of geographically diffuse members with diverse disabilities in the community, they must expand their networks or provide out-of-network contracts with accessible providers.
- Professional hospital accreditation bodies should be required to incorporate federal accessibility requirements in their accreditation process so these standards become a regular part of all facility and services reviews as well as any related periodic monitoring.
- Managed care organizations must incorporate federal accessibility requirements into their own operation and as a mechanism to assess the adequacy of their provider networks. The presence of inaccessible elements needs to be incorporated and accounted for in consumer and quality ratings systems such as Medicare star ratings.
- The U.S. Access Board should conclude its mandate under the ACA to establish accessibility standards for medical diagnostic equipment, and the Department of Justice should adopt those standards into federal regulations with the addition of scoping requirements.
- HHS/CMS must take steps to standardize and disseminate an architectural and programmatic access survey instrument that will measure accessibility consistently across various medical facility contexts. Federal and state laws are beginning to require

accessibility information in managed care provider directories, but without standardized site review tools, reporting requirements and public correction processes in place, directory information will be unreliable.

- Interagency work within HHS, such as between CMS and the Health Resources and Services Administration (HRSA), and between federal and state agencies must include the development of practical ways to implement 18 or more sections in the Affordable Care Act that call for increased cultural competence and health literacy, and *also ensure that disability cultural competence and literacy is fully and practically included when provisions are discussed and implemented*. These provisions can play a critical role in revealing and mitigating the compound barriers faced by individuals who have multiple intersecting demographic characteristics including disability, race, and ethnicity. This potential will not be fulfilled, however, unless agencies with primary responsibility, such as the HHS Office of Minority Health, which is authorized under Section 10334 of the ACA to develop measures to improve cultural and linguistic competence and reduce disparities, recognizes disability-related health disparities as falling within their realm of responsibility.
- CMS should expand the legal definition of the medical loss ratios that are required of health plans and private insurers to include spending on improving health care accessibility and quality and reducing health disparities for people with disabilities, much as spending on other underserved population groups is already recognized.

- 1. Instead of requiring states to provide institutional care for people with disabilities in order to qualify for federal Medicaid payments, Congress should require states to provide community-based long-term services and supports for individuals who are financially eligible and who require an institutional level of care.**

In 1999, the U.S. Supreme Court issued a ruling in *Olmstead v. L.C.* stating that people with disabilities have the right to live in the community instead of an institution. In response, states have slowly reduced the proportion of LTSS provided in institutional settings even as the number of Asians, African Americans/blacks, and Hispanics or Latinos residing in nursing homes has increased. Broad legal reform is required to reverse the bias built into the Medicaid statute that requires states to provide LTSS for people with disabilities in institutions instead of home and community-based settings in order to qualify for federal Medicaid funding.

- 2. HHS should urge states to strengthen and streamline access to home and community-based services and reduce restrictive eligibility and other barriers to participation.**

LTSS programs tend to be fragmented. Eligibility for services also varies from state to state, and people with different disabilities are treated differently depending on funding categories. Thus reforms are required that streamline access to LTSS.

Specific actionable items for key actors related to LTSS:

- HHS should identify methods to provide consumers with greater control and choice over their LTSS, especially in order to ensure they have the option to return to the community from an institutional setting, if they so choose.
- HHS should implement mechanisms to accurately measure LTSS outcomes and quality from the consumer perspective rather than relying primarily on administrative data.
- Quality LTSS relies on a reliable and available workforce; therefore, federal and state policies should support job stability and employment satisfaction especially for family caregivers.
- LTSS consumers' rights must be protected; they should have ready access to complaint procedures and due process mechanisms. Individuals who do not have a conflict of interest must carry out assessments of need, and consumers should have adequate support for resolving conflicts, especially unnecessary limits on their opportunity to direct their own services and make their own life decisions.

Care Coordination and Care Delivery

- 1. HHS should identify, thoroughly evaluate, and bring to scale the care coordination and integration service delivery models that show the greatest promise for improving health outcomes for people with disabilities.**

- 2. Accountable care organizations, accountable care communities, and medical homes/health homes should integrate nonmedical community-based services and resources into their comprehensive service model of care.**

- 3. Behavioral and physical health care services should be integrated across health care delivery settings, including interoperable health information technology, while recognizing the additional rights of privacy over some components of their health records to which individuals are entitled.**

Certain models of care coordination have been shown to benefit certain groups of people with disabilities such as mental health and substance use disorders or those who have complex medical needs and also require significant long-term services and supports. Some of these care models began operating at the community level in response to overwhelming unmet need among people with diverse disabilities. While a few have gained the attention of federal policy makers, others have not yet been recognized even as they are innovating at the local level. These emerging care models deserve increased attention from researchers and policy makers, and some likely will warrant being brought to scale with government support.

- 4. HHS should continue to explore, test, and adopt innovative financial payment models that support care coordination and integration of health, and social and community services for people with diverse disabilities.**

Stakeholders associated with some of the coordinated service models consistently identify financial payment for care coordination and care management innovations as the single most essential requirement if the sometimes-complex needs of patients with disabilities are to be met reliably over time.

Physical and Programmatic Access to Health Care (See also Legal Monitoring and Enforcement Recommendations)

- 1. The Office of the National Coordinator for Health Information Technology must require the capacity to include functional limitation information within electronic health records.**

Placing cognitively tested and validated questions such as the American Community Survey set of six disability questions into patient electronic health records can trigger alerts signaling the need for disability accommodations in health care settings. These or other, similar cognitively tested and validated questions can also help answer the need for data about the presence of activity limitations among people seeking health care. Moreover, the presence of impairment-related information in the health record also enables cross-analysis with race, ethnicity, age, LGBT status, and geographic location in order to provide a fuller picture about individuals at the intersections of these multiple demographic characteristics. The data can also be tied to numerous meaningful use objectives such as better health outcomes.

- 2. Health Resources and Services Administration (HRSA) should require that the Federally Qualified Health Centers (FQHC) incorporate functional limitation questions into their intake and health information technology record keeping processes and that FQHCs regularly report outcome data.**

FQHCs provide clinical services for low-income populations who experience higher-than-average levels of disability and therefore are excellent settings for incorporating impairment related questions. These queries can be used to trigger awareness of potential accommodations that patients with various activity limitations might require. Data showing how many people need accommodations and what they specifically require will inform future initiatives aimed at improving health outcomes for the FQHC patient population.

- 3. HHS and CMS should incentivize health care provider capacity to increase access and to accommodate people with disabilities.**

Innovative methods to increase access and provider capacity to accommodate people with disabilities in clinical settings could include using various means to incentivize health plans to solve access problems. For example, the cost of accommodations such as accessible weight scales and exam tables, extended exam time, or a sign language interpreter could be included as elements of medical loss ratio calculations.

- 4. CMS should strengthen managed care organization's provider network adequacy standards by requiring a showing of accessibility and capacity to accommodate**

people with disabilities and by calling for networks to be expanded if found to be deficient.

Some three-way contracts between CMS, participating states, and MCOs that implement a demonstration program to align services for beneficiaries who are covered by both Medicare and Medicaid have included specific provisions requiring that MCOs assure physical and programmatic access and the provision of accommodations for people with disabilities. Meaningful implementation of these contract provisions at a minimum requires MCOs to survey their provider network for accessibility. While, few states have taken such action, California has been using a survey instrument since 2012 that could serve as a starting point.

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