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The Role of Law and Policy in Achieving Healthy People's Disability and Health Goals Around Access to Health Care, Activities Promoting Health and Wellness, Independent Living and Participation, and Collecting Data in the United States

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(Rockville MD) Dept. of Health and Human Services, Office of Disease Prevention and Health Promotion (ODPHP). Supported by the Centers for Disease Control and Prevention, ODPHP, and the CDC Foundation through a grant from the Robert Wood Johnson Foundation.



The Role of Law and Policy in Achieving Healthy People's Disability and Health Goals around Access to Health Care, Activities Promoting Health and Wellness, Independent Living and Participation, and Collecting Data in the United States



Welcome from the Assistant Secretary for Health

Dear Colleagues,

For the past 40 years, the Healthy People initiative has worked to improve the health of the nation by identifying core priorities for public health and setting data-driven targets for each decade. Healthy People measures are national benchmarks that inform decision-making across various levels of government, and foster collaborations with other sectors so that all Americans may live long, healthy lives. At the U.S. Department of Health and Human Services (HHS), we believe that law and policy play a critical role in protecting individuals and communities against preventable disease, disability, injury, and premature death. That is why the HHS Office of Disease Prevention and Health Promotion and the Centers for Disease Control and Prevention (CDC) partnered with the CDC Foundation and the Robert Wood Johnson Foundation on the Healthy People 2020 Law and Health Policy Project. As part of this collaboration, we are examining effective, evidence-based legal and policy interventions and tools, and developing resources that communities can use to address health challenges and promote healthier behaviors. We hope this will advance the discussion about the power of legal and policy tools to support the achievement of Healthy People objectives.

Ensuring that the almost 60 million Americans with disabilities live as healthy and independent lives as possible is an important goal for our nation. This second evidence-based report, *The Role of Law and Policy in Achieving Healthy People's Disability and Health Goals around Access to Health Care, Activities Promoting Health and Wellness, Independent Living and Participation, and Collecting Data in the United States*, highlights efforts to better use law and policy to support and protect people with disabilities. These efforts can include improving healthcare services and delivery, reducing barriers and improving accommodations to public health and community resources, and increasing the collection of data about people with disabilities. This report also highlights innovative policy solutions from communities and organizations. While this report focuses on four specific Healthy People 2020 objectives, the lessons and information from the report will continue to be relevant as we move to focus on our Health People 2030 goals.

By increasing our understanding of how laws and policies can advance public health, this report and related resources offer ideas for leaders to take action at the local, state, and national level by creating social and physical environments that promote health for all, health by all, and health in all communities.

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Preface

Legal and policy interventions play an important role in improving public health and creating a society in which all individuals live long, healthy lives. However, many people may not be aware of the precise impact these tools can have on population health. For 40 years, the Healthy People initiative has established comprehensive sets of 10-year national objectives with measurable targets that provide a strategic framework to motivate, guide, and focus action to improve the nation's health and communicate a vision for achieving health equity. The ability to reach Healthy People targets is vital to our nation—it means lives saved, illnesses avoided, and injuries averted; it means stronger and more resilient public health and healthcare systems; and it creates alignment across sectors and geography to create and sustain environments where all can achieve their full potential for health and well-being across the lifespan.

This report is part of the Healthy People 2020 Law and Health Policy Project (henceforth referred to as “the Project”), which seeks to increase awareness about the role law and policy play in improving health. The Project includes this series of reports, as well as other products and webinars, related to a diverse set of Healthy People 2020 (HP2020) national health objectives. Some of these will continue to be areas of focus in a more streamlined Healthy People 2030 (HP2030), although all are still important focus areas for the public health and disability communities. All demonstrate how these approaches have improved, and can continue to improve, health for individuals, families, and communities. Each report highlights the practical application of law and policy across various settings and is intended for diverse audiences including community and tribal leaders, government officials, public health professionals, healthcare providers, lawyers, and social service providers. As the current iteration of the initiative comes to a close and HP2030 comes to the fore, the Project continues to provide information about the role that evidence-based legal and policy interventions play to improve public health and to help reach critical public health goals.

The Project is a collaborative effort. Within the U.S. Department of Health and Human Services (HHS), the Office of Disease Prevention and Health Promotion (ODPHP) in the Office of the Assistant Secretary for Health leads the Law and Health Policy Project with guidance and support from the Centers for Disease Control and Prevention (CDC). The Project was launched by the CDC Foundation with funding from the Robert Wood Johnson Foundation (RWJF).

These reports discuss legal or policy strategies supported by empirical evidence that can help achieve specific Healthy People targets or objectives—which in this report concentrates on disability and health. Where possible, the reports focus on state, tribal, and local settings, and demonstrate how these approaches can improve health. The reports also feature community and practice examples of Laws and Policies in Action or “Bright Spots” that illustrate how communities can use law and policy to meet their health improvement goals and achieve Healthy People targets. Up to 4 co-authors work on each report with assistance from an ad hoc report working group of experts from varying disciplines and practice areas relevant to the report; all parties involved are selected based on their background and subject matter expertise. Other groups, including the Healthy People Federal Interagency Workgroup (FIW)—the lead entity guiding HP2020 and HP2030 processes—the HP2020 topic area workgroups, and other project partners provide input and support for these reports during their development.

While these reports were written focusing on the HP2020 targets, the objectives will remain important national goals in the years to come. Therefore, the lessons, laws, and policies discussed should be relevant to HP2030 goals, as well as addressing future public health challenges. HP2030 will continue to build on the current decade’s work and will focus on creating a society in which all people can achieve their full potential for health and well-being across the lifespan. Law and policy will continue to be important tools to help achieve this vision.

Healthy People and Disability

Healthy People 2020 (HP2020) is a comprehensive set of 10-year national goals and objectives for improving the health of all Americans. Within the report series, this current report focuses on how law and policy can be leveraged to improve the health of individuals with disability* who represent approximately 20% of the U.S. population.¹

The publication *Healthy People 2010*, released in 2000, was the first of the decennial plans to identify individuals with disability “as a potentially underserved group ... [that] would be expected to experience disadvantages in health and well-being compared with the general population.”² The report suggested that common misconceptions about individuals with disability contributed to disparities in their receipt of health care services, especially lower rates of screening tests, and an under-emphasis on health promotion and disease prevention activities.³ In *Healthy People 2020*, released in 2010, the 13-member Secretary’s Advisory Committee on National Health Promotion and Disease Prevention Objectives for 2020 urged the Secretary and the Healthy People initiative to focus on social and environmental determinants of health in identifying threats to, and proposing strategies for, improving the public’s health.⁴

This focus is consistent with the framework defining disability used by the World Health Organization’s International Classification of Functioning, Disability and Health (ICF)⁵, which the Institute of Medicine (renamed the National Academy of Medicine) recommended adopting to guide disability monitoring and research in the United States.⁶ According to ICF, the word “disability” is an “umbrella term for impairments, activity limitations or participation restrictions,” conceiving “a person’s functioning and disability ... as a dynamic interaction between health conditions (diseases, disorders, injuries, traumas, etc.) and contextual factors,” including the social, attitudinal, and physical environments and personal attributes.⁷ ICF further notes that disability is recognized as “part of human existence, occurring at any point in life.”⁸

* This report uses “individual with a disability,” or the plural “individuals with disabilities” unless the original source provides otherwise. However, the intent is to include individuals with a single disability and individuals with more than one disability.

There are many types of disabilities, and they impact a diverse population, including some 57 million Americans in 2010.⁹ Certain subgroups, such as persons with intellectual or developmental disability or serious mental illness, can experience more disadvantage than other individuals with disability. On average, persons with disability are much more likely than individuals without disability to experience social and environmental circumstances that could threaten their health and well-being. In particular, compared with nondisabled individuals, on average those with disability have:

- Lower levels of education¹⁰
- Lower rates of employment among those seeking jobs^{11 12}
- Higher rates of poverty¹³
- Higher rates of food insecurity, defined as the inability to afford the food necessary for a healthy, active life¹⁴
- Significant problems finding safe, affordable, accessible housing¹⁵
- Substantial difficulties finding safe, reliable, affordable, and accessible transportation
- Higher probabilities of being victims of crime or domestic violence^{16 17}

Consequences relating to intersectionality heighten some of these concerns.¹⁸ Certain racial and ethnic populations have much higher rates of disability than do others. Women with disability experience even greater disparities in income, education, and employment. Women also face far greater risks for many health problems, including cardiac disease, obesity, and depression. Emerging evidence suggests that individuals with disability who are gay, lesbian, bisexual, or transgender are especially vulnerable to many of these disadvantages.¹⁹

Healthy People Disability and Health Objectives Addressed in this Report

The *Healthy People 2010* and *Healthy People 2020* initiatives and a growing number of publications from governmental agencies, advocacy organizations, academic researchers, and others document disparities in health and health care for individuals with disability. A systematic review of this increasing body of evidence is beyond the scope of this report. However, major findings of disparities in health and health risks show that, in comparison with individuals without disability, those with disability:

- Have higher rates of common chronic conditions, such as diabetes, hypertension, and chronic pulmonary disease
- Are more likely to be current or past tobacco smokers
- Are more likely to be overweight or obese
- Report lower rates of leisure time physical activity
- Are more likely to report experiencing symptoms of depression, stress, anxiety, and fears²⁰

In comparison with nondisabled individuals, documented disparities in receipt of health care services include lower rates of the following:

- High-value cancer screening tests, such as screening mammography and Pap tests
- Preventive dental care
- Services relating to contraception, sexuality, and reproductive health
- Quality prenatal care, such as routine weight measurement²¹

The overall goal of HP2020 relating to individuals with disability is to “maximize health, prevent chronic disease, improve social and environmental living conditions, and promote full community participation, choice, health equity, and quality of life among individuals with disabilities of all ages.”²²

HP2020 further notes the following:

To be healthy, all individuals with or without disabilities must have opportunities to take part in meaningful daily activities that add to their growth, development, fulfillment, and community contribution. This principle is central to all objectives outlined in this topic area. Meeting the Disability and Health objectives over the decade will require that all public health programs develop and implement ways to include individuals with disabilities in program activities.²³

To address the wide-ranging concerns reflected in the findings cited above, and consistent with the overall goal of the HP2020 initiative, the Disability and Health topic area identified a total of 20 health objectives to monitor through 2020. This report focuses on how law and policy might affect 4 of these objectives.

HP2020 Disability and Health Objectives Addressed in This Report

- **DH-1:** Increase the number of population-based data systems used to monitor HP2020 objectives that include in their core a standardized set of questions that identify people with disabilities.
- **DH-4:** Reduce the proportion of adults with disabilities aged 18 years and older who experience delays in receiving primary and periodic preventive care due to specific barriers
- **DH-8:** Reduce the proportion of adults with disabilities aged 18 and older who experience physical or program barriers that limit or prevent them from using available local health and wellness programs
- **DH-13:** Increase the proportion of adults with disabilities aged 18 years and older who participate in leisure, social, religious, or community activities

Each of the above objectives requires intervention from different governmental, social, environmental, or other entities, which might respond to laws and policies in different ways. Therefore, these 4 objectives offer different scenarios for how law and policy might drive success in attaining their aims. For example, achieving DH-1 will require actions from governmental agencies at various levels; thus, specific legal

or policy interventions could have direct effects. In contrast, input from numerous private organizations and even individuals will be required to achieve DH-13, although legal and policy interventions could support these efforts. Also, achieving objectives DH-4 and DH-8 will require actions by systems that are complex and highly regulated (e.g., health care delivery organizations, public health providers for DH-4) or that must respond to external oversight or market forces (e.g., wellness or exercise programs, fitness centers for DH-8). However, as described below, broad federal statutes will also affect DH-4, DH-8, and DH-13.

While this report focuses on approaches that should be relevant for all people with disabilities, the data and objectives discussed herein present some limitations. Three objectives (DH-4, DH-8, and DH-13) focus on adults; for these objectives, some services and programs such as Medicaid's Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) benefit* —which provides valuable services for those under 21 years—may not be applicable. Also, for specific subpopulations such as Lesbian, Gay, Bisexual, and Transgender (LGBT) persons, the sample sizes are too small to report stratified results.

Law and Policy Sources Promoting Disability and Health Objectives

A wide range of laws and policies at federal, state, tribal, and local levels affect disability and health. This report focuses primarily on the following 2 categories of laws and policies:

- Broad disability civil rights laws, including the Americans with Disabilities Act of 1990 (ADA)²⁴ and the Rehabilitation Act of 1973 (Rehabilitation Act)²⁵
- Given the role of health care in various aspects of disability, laws relating to health care services and delivery systems, including the Patient Protection and Affordable Care Act of 2010 (Affordable Care Act)²⁶ and Title XIX of the Social Security Act,²⁷ which established the joint federal and state Medicaid program

* The EPSDT program provides comprehensive and preventive health care services for children under age 21 who are enrolled in Medicaid. EPSDT is key to ensuring that children and adolescents receive appropriate preventive, dental, mental health, and developmental, and specialty services. For more information please see: <https://www.medicaid.gov/medicaid/benefits/epsdt/index.html>

These laws and policies are intended to directly—and sometimes indirectly—reduce disparities in access to, and utilization of, health care and health care services for people with disabilities. As such, they have great potential for effecting changes in areas highlighted by the 4 disability and health objectives addressed this report.* In addition to the 2 categories of laws and policies mentioned above and legislation that impacts disabilities, the report also discusses regulations promulgated by the federal administrative agencies authorized to enforce the statutes identified above, federal guidance on specific access issues, relevant Supreme Court opinions, and the role of state and local laws relating to disability.

A brief review of the disability and health care laws and policies explored in this report follows.

Disability Civil Rights Laws

The ADA provides a clear and comprehensive national mandate for eliminating discrimination against individuals with disability, and enforceable standards to address discrimination against those individuals. This law prohibits discrimination based on disability in employment (Title I), public services (Title II), public transportation and places of public accommodations (Title III), and telecommunications (Title IV). The ADA protects individuals with a physical or mental condition that substantially limits a major life activity, both those with a history of such a disabling condition and those who are regarded as having a disability.²⁸ Congress amended the ADA in 2008 to clarify that the statutory definition of disability should be construed in favor of broad coverage of individuals.²⁹

The ADA expands the protections of the Rehabilitation Act, an earlier federal statute that prohibits discrimination on the basis of disability in federal employment and in programs and activities that are funded

* In some cases, the law directly regulates in a manner that impacts the 4 objectives (e.g., requirement to remove barriers to health care for individuals with disability). In others, it has an indirect impact (e.g., removal of barriers to participation in community life generally). In addition to the laws discussed in this report, there are federal laws that impact other social determinants of health for people with disabilities, including laws that specifically prohibit discrimination based on disability in telecommunications, housing, air travel, voting, and education. U.S. Dept. of Justice, Civil Rights Division, Disability Rights Section, A Guide to Disability Rights Laws [Internet]. Washington (DC): DOJ; 2009 Jul [cited 2019 Apr 12]. Available from: <https://www.ada.gov/cguide.htm>. The protections of the Equal Protection Clause of the Fourteenth Amendment to the U.S. Constitution also apply to people with disability. U.S. Const. Amend. XIV. However, the Supreme Court has held that unlike laws classifying persons based on race or sex, for example, laws classifying people based on disability are subject only to rational basis review. *City of Cleburne, Tex. v. Cleburne Living Ctr.*, 473 U.S. 432 (1983). Rational basis review requires that the law be rationally related to a legitimate government purpose. *Id.*

by federal agencies. Section 504 of the Rehabilitation Act applies to any program or activity receiving federal financial assistance,³⁰ and is an example of the ability of the U.S. Congress to influence state-level policy by setting conditions that the states and other entities must accept to receive federal funds. Although there are differences between the Rehabilitation Act and the ADA, the standards adopted by ADA Title II are generally the same as those required by Section 504 of the Rehabilitation Act.³¹ Together, the Rehabilitation Act and ADA apply to many (but not all) of the facilities, services, programs, and activities contemplated by objectives DH-4, DH-8 and DH-13.



How Federal Legislation Addresses the Needs of People with Disabilities: **Health Coverage**

The Americans with Disabilities Act's (ADA) "safe harbor" exception allowed some insurance plans to treat people with disabilities differently—but the Affordable Care Act prohibits health insurance companies from denying coverage based on pre-existing conditions, like disabilities.

Health Care Laws

The Patient Protection and Affordable Care Act (Affordable Care Act) has many component parts addressing different aspects of health care financing and delivery, including policies intended to expand access to insurance coverage, enhance health care quality, improve health care delivery systems, control health care costs, and eliminate health and health care inequities.³² Many of the Affordable Care Act's general provisions have the potential to benefit individuals with disability.³³ The prevention of health insurance coverage denials relating to pre-existing conditions, for example, is especially important for individuals with disability. Prior to the Affordable Care Act, many health insurers were allowed to exclude or restrict coverage for individuals with a pre-existing condition such as cancer, asthma, or other chronic conditions

or disabilities.^{34, 35} Although the ADA applies to health insurers, its “safe harbor” exception permitted some plans to have terms that treat individuals with disability differently on the basis of underwriting, classifying, or administering risks.³⁶ The Affordable Care Act’s data collection, insurance coverage requirements, and anti-discrimination provisions also address disability health data (DH-1) and specific barriers to primary and periodic care for individuals with disability (DH-4).

The Medicaid program is a joint federal and state public health insurance program for “low-income adults, children, pregnant women, elderly adults, and people with disabilities.”³⁷ Federal Medicaid law sets mandatory and optional standards for eligibility, benefits, and program administration.^{38, 39} Subject to federal standards, states have considerable flexibility to design and administer their own Medicaid programs. Medicaid is a key source of insurance coverage for individuals with disability.⁴⁰

Since the program’s enactment in 1965, federal Medicaid law has required states to cover certain categories of individuals, including low-income and other individuals who are eligible for the federal Supplemental Security Income (SSI) program based on disability in most states.* States may opt to expand eligibility for individuals with disability whose income is above the federal Medicaid eligibility requirements and who are receiving services in the community that would be covered in an institutional setting, or who are defined as “medically needy.”⁴¹ Under the Affordable Care Act’s Medicaid expansion provisions, states also have the option to expand eligibility to include certain low-income individuals who are not otherwise eligible, regardless of disability.^{42, 43} Another initiative, the Social Security Disability Insurance program, also pays benefits to individuals and certain family members, including adult children, if they have worked for enough time and paid Social Security taxes.⁴⁴ In this report we do not comprehensively review the impact of each state’s Medicaid program on individuals with disability. However, certain Medicaid benefit and program administration provisions under federal and state law that have important implications for achieving the objectives featured in this report are highlighted. These include specific barriers to primary and periodic care for individuals with disability (DH-4), barriers to health and wellness programs (DH-8), and increased participation in social and community activities (DH-13).

* For more information about the SSI and SSDI programs and eligibility, please see: <https://www.ssa.gov/disability/>.

Implementation of Laws

Federal administrative agencies have the responsibility and authority to enforce federal statutes and to promulgate legally binding regulations to carry out the intent of these laws. The U.S. Department of Justice (DOJ) is charged with enforcing Section 504 of the Rehabilitation Act, Title II and III of the ADA, and the antidiscrimination provision of the Affordable Care Act.* ^{45, 46} To do so, DOJ has issued many regulations, including ADA regulations that set standards for accessible design of buildings and facilities under Title II and III and require that newly constructed and altered state and local government facilities, places of public accommodations, and commercial facilities are readily accessible to, and usable by, individuals with disability (2010 ADA Standards for Accessible Design).⁴⁷

In developing legally enforceable design standards, DOJ frequently relies upon guidelines developed by the U.S. Access Board (formerly the Architectural and Transportation Barriers Compliance Board), an independent federal agency that develops and maintains design criteria for the built environment, transit vehicles, information and communications technologies, and medical diagnostic equipment.⁴⁸ The Board's design guidelines for buildings and facilities under Title II and III of the ADA, known as the ADA Accessibility Guidelines (ADAAG), were used by DOJ to set the legally enforceable 2010 ADA Standards for Accessible Design.

Federal agencies like DOJ may also issue less formal guidance on how best to comply with the statute or regulation. While guidance does not have the force of law, it often provides practical advice, or defines standards or expectations that are part of a rule or requirement. One such example is *Access to Medical Care for Individuals with Mobility Disabilities*, a document that offers specific advice to health care providers on ADA Title II and III requirements in health care settings with respect to individuals with mobility disability.⁴⁹

Role of State, Tribal, and Local Laws

States, tribes, and some counties and cities also have laws prohibiting disability discrimination within their boundaries.^{50 51 52} California's Unruh Civil Rights Act,⁵³ for example, prohibits discrimination by all business

* The HHS Office for Civil Rights (OCR) is responsible for enforcing Title II of the Americans with Disabilities Act of 1990, 42 U.S.C. §§ 12131 - 12134; Section 504 of the Rehabilitation Act of 1973, 29 U.S.C. § 794; and Section 1557 of the Affordable Care Act, 42 U.S.C. § 18116.

establishments in California, including housing and places of public accommodations, because of disability (among other characteristics); its Disabled Persons Act⁵⁴ guarantees equal access to streets, highways, sidewalks, walkways, public buildings, medical facilities, public facilities, and other public places; and Title 24 of the California Building Standards Code⁵⁵ sets access requirements for building design and construction. As California law suggests, state laws often parallel the protections of federal law but can differ in terms of entities covered, specific protections, and enforcement processes. As sovereign entities, American Indian and Alaska Native tribal governments also may establish their own resolutions and programs relating to disability. For the purposes of this report, specific tribal laws and policies have not been analyzed separately.

The interplay between federal and state laws is complex. The U.S. Congress enacts statutes such as the ADA, the Rehabilitation Act, and the Affordable Care Act pursuant to authority enumerated in the U.S. Constitution.* In general, when the federal government uses its authority to regulate a field such as civil rights or health care insurance and delivery, federal law requirements apply in all states and limits or preempts less stringent or lower levels of regulation by states or local governments.⁵⁶ The legal principle of preemption stipulates that a higher level of government may limit, or even override, the authority of a lower level of government to regulate certain issues. However, state law can also address gaps or provide more protections than federal law. For example, Georgia law requires religious or other private institutions to comply with the requirements of its law on access to and use of public facilities,⁵⁷ while the ADA does not.⁵⁸

Similarly, states vary substantially in additional protections for individuals with disability who use dogs and other service animals. Under ADA Title II and III regulations, a service animal is a dog individually trained to do work or perform tasks to benefit an individual with a disability.**^{59, 60} The work must relate directly to the individual's disability and does not include provision of emotional support or comfort. Notwithstanding this exclusion under Title II and Title III of the ADA, other federal laws and some states provide protections for individuals who use dogs and other animals for emotional support and comfort.^{61 62}

* Congress has the authority to enact civil rights laws to enforce the 14th Amendment's guarantee of equal treatment under the law, to impose taxes and spend funds, and to regulate commerce among the states. U.S. Const. art. 1 § 8, cl. 1, amend. XIV and art. I § 8, cl. 3, respectively.

** Although not a service animal, the regulations also provide for a miniature horse with similar training. 28 C.F.R. 35.136(i), 28 C.F.R. 36.302(c)(9).

Although state protections can exceed federal protections, federal law can set a minimum standard or floor below which a state cannot fall. The Affordable Care Act, for example, greatly expanded federal involvement in regulation of health insurance to ensure a basic level of consumer protection across the country. Prior to the Affordable Care Act, many states allowed health plans to exclude or limit coverage for such services as mental and behavior health care, substance abuse disorder services, and maternity care.^{63, 64} The Affordable Care Act specified essential health benefits that individual and group policies must cover, in most cases at a level similar to in-state employer group health plans.⁶⁵ States may continue to adopt and enforce laws and regulations that afford greater protections than the Affordable Care Act requires, but absent a specific exception or waiver, federal law preempts any state law that does not meet the federal minimum standards.*

Specific Legal and Policy Interventions Addressing Disability and Health Objectives

The sections below examine specific legal interventions and policy initiatives relevant to the 4 selected Disability and Health objectives. Primarily drawing from the ADA, the Rehabilitation Act, the Affordable Care Act, and Medicaid, these sections explore laws and policies designed to reduce barriers to primary and preventive care (DH-4) and to local health and wellness programs (DH-8); to increase access to leisure, social, religious or community activities for individuals with disabilities (DH-13); and to generate the data needed to inform and support efforts to reach these and other Disability and Health objectives (DH-1). DH-1 appears last in this report because data collection applies to every Disability and Health objective. Understanding the components and reach of the other objectives would therefore suggest implications for data gathering.

* Short-term health plans are an illustration of an exemption that may impact persons with disability, as these plans which can be renewed for up to 3 years under 2018 federal regulations, may limit or deny coverage for pre-existing conditions, impose lifetime or annual coverage limits, or exclude coverage for some essential health benefits. States may limit or prohibit the sale of short-term plans.

DH-4: Access to Primary and Preventive Care

Disability and Health objective DH-4 calls for reducing the proportion of adults with disability (ages 18 and older) who experience delays in receiving primary and periodic preventive care due to disability-related barriers. This objective is proposed to continue as a core measurable objective in HP2030. The ADA, Rehabilitation Act, and Affordable Care Act* each address a wide range of barriers to primary care and preventive services for individuals with disabilities, with both the ADA and Rehabilitation Act requiring equal access to health care programs, services, and facilities for these individuals.^{66, 67, 68} The ADA and Rehabilitation Act require the following:

- Physical access to health care services and facilities, including accessible spaces and the removal of barriers⁶⁹
- Effective communication, including auxiliary aids and services such as the provision of sign language interpreters or materials in alternative formats**⁷⁰
- Reasonable modification of policies, practices, and procedures when necessary to accommodate individual needs^{71, 72}

ADA regulations and guidance documents address these requirements in various health care settings. In terms of physical access, nearly all health care offices and facilities are covered by the 2010 ADA Standards for Accessible Design.

These ADA and Rehabilitation Act requirements are enforced by DOJ (public enforcement) as well as actions brought by private individuals and groups (private enforcement). Public and private ADA enforcement actions and settlement agreements have addressed a wide range of barriers to health care services for individuals with disabilities. DOJ's U.S. Attorneys' offices across the country and its Civil Rights Division

* Title II of the ADA applies to health care services, programs, or activities offered by state and local governments, including state Medicaid programs. Title III of the ADA applies to private hospitals and medical offices as accommodations open to the public. Section 504 of the Rehabilitation Act applies to services, programs, or activities that receive federal funding, which can include Medicare or Medicaid reimbursement.

** For additional resources on effective communication with individuals with disability in health care settings, please see: U.S. Dept. of Health and Human Services, Office of Civil Rights, Disability Resources for Effective Communication, available at <https://www.hhs.gov/civil-rights/for-individuals/special-topics/hospitals-effective-communication/disability-resources-effective-communication/index.html>.

hone ADA enforcement targets under ADA's Barrier-Free Health Care Initiative begun in 2012.⁷³ This multiphase initiative promotes effective communication for individuals who are deaf or hard of hearing, physical access for individuals with mobility disabilities, and equal access to health care for individuals living with HIV/AIDS. The nationwide scope of the DOJ partnership strives to leverage resources already being deployed in various regions to underscore the illegality and unacceptability of disability discrimination in health care. Despite this enforcement activity, however, many individuals with disabilities continue to experience barriers to health care services, including primary and preventive care services.

As noted above, the Affordable Care Act broadly addresses financial barriers to care by reforming private insurance, creating more opportunities to obtain private insurance, and expanding Medicaid in states that chose that option.^{74 75} Among the Affordable Care Act's required essential benefits for private insurance plans are preventive services (e.g., services recommended by the U.S. Preventive Services Task Force) without any patient cost-sharing when provided in network.⁷⁶

In addition, the Affordable Care Act builds upon and expands existing anti-discrimination protections in health care programs, activities, and settings. Section 1557 of the Affordable Care Act explicitly incorporates the requirements of existing antidiscrimination laws, including Section 504 for disability, and prohibits discrimination based on race, color, national origin, sex, age, or disability by any health program or activity that receives federal financial assistance, that is administered by an executive agency, or is an entity established under the Act.^{77 78}

Accessible Medical Diagnostic Equipment

In addition to these broad provisions, Section 4203 of the Affordable Care Act addresses inaccessible medical diagnostic equipment (MDE), a barrier to primary and preventive care for many individuals with physical disabilities and thus relevant to DH-4. Examples of MDE needed for primary and preventive care include examination tables, weight scales, mammography equipment, and other diagnostic imaging technologies. This equipment is frequently inaccessible to individuals with disabilities, a situation that likely contributes to the testing disparities documented in *Healthy People 2020* mentioned previously.⁷⁹

Precise estimates of how often inaccessible equipment impedes service use are unavailable. Nonetheless, a growing body of primarily qualitative studies and some larger investigations suggest the extent

of these barriers. For example, Stillman and colleagues conducted an online survey of 432 wheelchair users.⁸⁰ Almost all (97.2%) had visited a primary care provider within the prior year, and 73.8% encountered barriers during these primary care visits. During these primary care encounters, 76.1% remained clothed during their evaluations, and 69.7% were examined while sitting in their wheelchairs. More than half (54.1%) reported feeling their care was incomplete.



How Federal Legislation Addresses the Needs of People with Disabilities: **Accessibility Standards for Health Facilities**

The Americans with Disabilities Act (ADA) sets accessibility standards for nearly all physical structures of health care facilities except for their furnishings and equipment. The Affordable Care Act addresses that gap by requiring accessibility standards for medical diagnostic equipment.

Other studies have identified inaccessible equipment as a barrier to care for women with physical disability. For instance, a study of 22 women with significant physical disability who had recently given birth found that none had been routinely weighed during prenatal visits even though weight assessment is considered part of standard prenatal care.⁸¹ As the women explained, their obstetrical care settings did not have accessible weight scales; some were told simply just not to gain too much during pregnancy. In a study of 20 women with significant physical disability who subsequently developed early-stage breast cancer, women report not being transferred onto fixed-height examination tables for complete breast or physical exams, but instead being examined while seated in their wheelchairs.⁸² In another study, some women with significant physical disability reported never having received Pap tests because their primary care physician would not transfer them to a fixed-height examination table.⁸³

Another set of studies have looked more broadly at physical accessibility within health care settings. Mudrick and collaborators reviewed the accessibility of providers in 5 health plans serving California Medicaid recipients.⁸⁴ Their 55-item survey went to 2,389 physicians who provided services to enrollees in 5 health plans and assessed the accessibility of medical office or clinic parking, exterior entrances, building access, interior public spaces, physician office interiors, and availability of accessible examination equipment. Although van-accessible parking was inadequate, general parking, exterior access, building access, and interior public spaces generally complied with accessibility criteria. They also found that restrooms and examination rooms frequently had barriers; only 3.6% of practice sites had an accessible weight scale, for example, and just 8.4% had a height-adjustable examination table.⁸⁵

In another study, Frost and collaborators examined accessibility of 30 primary care and specialty clinics in Kentucky.⁸⁶ They found that 83% of restrooms and 93% of examination rooms failed to meet 1 or more accessibility requirements under ADA regulations. In addition, 70% of clinic managers reported not having a height-adjustable examination table or wheelchair-accessible weight scale. In addition, 70%-87% of patients were examined seated in wheelchairs, 30% were asked to bring their own assistant to aid in transfers, and 6% were referred elsewhere citing clinic inaccessibility. These accommodation methods do not comply with ADA requirements.

Lagu and colleagues performed a secret-shopper type study, where researchers called physician offices in 4 U.S. cities to schedule an appointment for a fictitious patient with hemiparesis who was obese, used a wheelchair, and could not transfer independently from a wheelchair chair onto an examination table.⁸⁷ The researchers contacted endocrinology, gynecology, orthopedic surgery, rheumatology, urology, ophthalmology, otolaryngology, and psychiatry practices. In addition to their appointment query, they asked about practice accessibility, types of reported access problems, and the method planned to transfer the fictitious patient to an examination table.

Of the 256 practices contacted, 22% said they could not accommodate the patient, 4% blamed their inaccessible building, and 18% said they could not transfer the patient onto an examination table from a wheelchair. Only 9% reported having either a lifting device or height-adjustable examination table. Gynecology practices had the highest inaccessibility rate (44%).⁸⁸ Clinic staff answering the survey appeared

not to be aware that their refusal to schedule the patient failed to comply with ADA requirements.

Legal actions and initiatives addressing barriers to health care services for individuals with disabilities also suggest the extent of these barriers. Claiming injuries from inadequate care caused by inaccessible equipment, individuals with disabilities have brought legal actions against health care providers under the ADA. For example, on July 26, 2000—10 years following the signing of the ADA—3 wheelchair users sued Kaiser Permanente in California. One plaintiff, John Lonberg, paralyzed below the chest since 1983, indicated that Kaiser physicians prescribed medication dosages based on guesses about his weight; they never weighed him because of lack of an accessible weight scale.⁸⁹ Mr. Lonberg also reported not having been fully examined for over a year because clinicians never got him out of his wheelchair; he developed a pressure ulcer, which required surgery and months of bed rest to heal.

In the March 2001 private settlement agreement, *Metzler et al. v. Kaiser Foundation Health Plan, Inc. et al.*,⁹⁰ Kaiser agreed to provisions for defining accessible medical equipment, surveying facilities to “determine what accessible medical equipment is needed and can and should be obtained for each Kaiser hospital and medical office building to ensure that people with disability have full and equal access to all health services,” and for establishing “a reasonable action plan and timeline” for “procurement and installation of the ‘high-priority’ accessible medical equipment that is most important for delivering health services to people with disabilities.”

The 2005 DOJ settlement with the Washington Hospital Center (WHC) in the District of Columbia represents another high visibility legal action addressing accessible medical equipment. Four former patients with disability brought this lawsuit, describing numerous instances of substandard care caused by inaccessible equipment.⁹¹ The WHC settlement agreement designated highly detailed steps required to meet the needs of individuals with disabilities.⁹² In particular, it specified the following:

For purposes of this Agreement, in order to be deemed accessible, any piece of medical equipment to which patients must transfer for examination or treatment purposes, including, but not limited to, examination tables and chairs, tables used for radiologic exams, and gurneys, shall lower to a point no greater than 17 - 19 inches from the floor, shall be capable of being locked or otherwise fixed into position so as to permit a safe transfer from a wheelchair or other mobility device without slipping, and shall have a protective padded surface (unless such a surface is inconsistent with the table's intended use). Tables and gurneys that can be lowered closest to the floor (i.e., to 17 inches) are preferred because they will provide better access for more individuals with disabilities, and WHC is encouraged to select such tables.⁹³

The WHC settlement also specified procedures for equipment reviews, along with purchases and dates for complying with the requirements. With this level of detail, the WHC settlement offers a model for ensuring the accessibility of equipment in health care facilities.

Statutory Requirements of the Affordable Care Act

The Meltzer settlement calls for a process to define features that make medical equipment accessible, and the WHC settlement defines at least some of those features. Both reflect the fact that the 2010 ADA Standards for Accessible Design set specific standards for the accessibility of nearly all physical structures of health care delivery offices and facilities except for their furnishings and equipment. The Affordable Care Act addresses that gap. Section 4203 of the Affordable Care Act amends Title V of the Rehabilitation Act of 1973 by adding Section 510, which required the U.S. Access Board, in consultation with the U.S. Food and Drug Administration (FDA), to issue accessibility standards for MDE.* The U.S. Access Board issued a final rule effective February 8, 2017, that delineates minimum technical criteria for the accessibility of examination tables, examination chairs, weight scales, mammography equipment, and other diagnostic imaging equipment.⁹⁴

It is too soon to tell how much these new standards for MDE accessibility will reduce barriers to primary and preventive services as called for in DH-4. The MDE standards, as issued by the U.S. Access Board, are not

* The standards were to be set within 2 years of the ACA's passage. This rulemaking explicitly excluded MDE for pediatric populations.

mandatory unless adopted by another federal agency. Agencies can make these mandatory for entities under their respective jurisdictions through separate rulemaking. To date, DOJ has not adopted them as enforceable ADA and Rehabilitation Act standards. However, some promising examples of the use of MDE standards are featured below.

Laws and Policies in Action: VA Adoption of MDE Standards

On April 20, 2017, the U.S. Department of Veterans Affairs (VA) announced that it would adopt the new MDE accessibility standards as mandatory for its health care facilities. The VA adopted the standards to “help meet responsibilities under Section 504 of the Rehabilitation Act which requires access to federally funded programs and services.”⁹⁵

This pending action is particularly important because the VA’s health care network is the largest integrated health care system in the country, and includes 152 medical centers, nearly 800 community-based outpatient clinics, and over 125 nursing home care units.⁹⁶ Nearly 6 million veterans use VA health care facilities each year.⁹⁷ The VA has a strong history of ensuring accessibility in its facilities, so it is unclear whether adoption of the new MDE accessibility standards for new equipment will make it easier for individuals with disabilities to receive primary or preventive services in VA settings. Nonetheless, adoption of the standards reflects and reinforces a commitment to accessibility and will ensure a consistent approach toward MDE accessibility across all VA facilities.

Laws and Policies in Action: MassHealth Accessibility Efforts

The U.S. Access Board final rule regarding MDE accessibility can bolster local efforts to improve accessibility. The Boston Center for Independent Living, the Disability Law Center, and Greater Boston Legal Services have been negotiating with Massachusetts Medicaid (MassHealth) to ensure MassHealth meets its obligations under the ADA and Medicaid-managed care regulations to make care accessible to patients with disabilities. A core component of the accessibility plan advanced by advocates requires MassHealth provider contracts to include provisions that require accessible medical equipment to be available in offices and facilities. In these continuing negotiations thus far, agreement has been reached on the following:⁹⁸

- Implement mechanisms to identify individuals with disabilities and assess their needs for accommodations, including accessible equipment

- Adopt a hospital incentive program that requires hospitals to provide an inventory of accessible medical equipment and develop plans for acquiring needed equipment
- Develop an online provider directory with detailed information about accessibility, including availability of accessible equipment
- Develop a provider education program on accessible services, including use of accessible equipment
- Fund a grant program to enable small providers to acquire accessible equipment
- Revise the survey used to assess MassHealth recipients' care experiences to incorporate questions addressing accessibility
- Incorporate new provider network adequacy standards that explicitly consider availability of accessible medical equipment in future MassHealth contracts with managed-care organizations and accountable-care organizations

Although it is too early to know whether these provisions will affect primary and preventive care among MassHealth recipients, the new MDE accessibility standards and attention to this issue have raised awareness among Massachusetts providers and health plans.

Laws and Policies in Action: The Pendleton Project in Oregon

Even prior to the final rule regarding MDE accessibility, certain local communities have focused advocacy on improving accessibility of health care services and facilities more broadly. Since 1997, the Oregon Office on Disability and Health (OODH), which is housed at the Oregon Health & Science University, has undertaken several Community Engagement Initiatives using a 3-step process to engage diverse community members in improving access for Oregon residents with disability. In 2013, the OODH launched the Pendleton Project, an initiative that brings together local government officials, health care providers, and advocates representing different types of disability to identify barriers to health care for individuals with disabilities and work together to delineate strategies to address them.⁹⁹

Working through the 3-step process, the Pendleton Project collaborators conducted the following activities:

- Held a town hall meeting to obtain input from various constituents

- Presented a list of concerns to the town’s health care infrastructure, which included representatives of hospitals, health care professionals, community care organizations, transportation providers, and disability services providers; and formulated an action plan
- Divided volunteers from the town hall meeting into teams to work with providers and local officials in 3 priority areas: transportation; facility access and services; and health care provider knowledge, attitudes, and communication

The Northwest (NW) ADA Center provided technical assistance throughout the process. Funded by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR), this entity is 1 of 10 regional ADA centers around the country that provide guidance, information, and training to support goals of the ADA making “it possible for everyone with a disability to live a life of freedom and equality.”¹⁰⁰ NW ADA Center contributions include clarifying legal obligations under the ADA; training surveyors and researching accessibility questions relating to building accessibility standards; identifying best practices strategies; producing fact sheets relating to health care access issues; and developing an online course entitled “Respectful Interactions: Disability Language and Etiquette.”¹⁰¹

The Pendleton Project’s collaborative efforts have resulted in significant progress toward improving health care access for local residents with disability. Achievements include the following:

- Health care facilities replaced inaccessible equipment with accessible models.
- Accessible parking spaces and patient drop-off areas were expanded, along with instituting new valet and shuttle services to assist patient transit.
- The city reinstated a public bus route that had been cancelled but was the only public transportation to the hospital; in addition, Pendleton’s Commission on Transit appointed a member with disability.
- Disability awareness and sensitivity training were instituted for new hospital employee orientation programs.¹⁰²

Interactions between patients with disability and their providers have reportedly been improved by these interventions.¹⁰³



How Federal Legislation Addresses the Needs of People with Disabilities: **Accessing Community Spaces**

- The Rehabilitation Act requires states, religious institutions, and other organizations that take federal funding to meet the same accessibility standards as other public spaces.
- The U.S. Access Board has developed accessibility standards for fitness facilities and exercise equipment.
- The Americans with Disabilities Act (ADA) requires streets, sidewalks, and public transportation to meet certain accessibility standards.

DH-8: Access to Programs and Activities that Promote Health and Wellness

Disability and Health objective DH-8 aims to reduce the proportion of adults with disability (ages 18 and older) who experience physical or program barriers that limit or prevent them from using available local health and wellness programs, including health clubs, wellness programs, and fitness facilities.* The ADA and the Rehabilitation Act both address barriers to using local health and wellness facilities and programs for individuals with disabilities. The ADA (Title II) and the Rehabilitation Act apply to state or local government-sponsored health and wellness programs, services, or activities, along with government-sponsored leisure, social, and community activities. The ADA (Title III) also applies to non-governmental or private health clubs, wellness

* This objective's goal of reducing barriers of those with disabilities to be able to participate in healthy and community activities is at the core of the ADA and other laws and efforts. While this objective was not proposed to be included in Healthy People 2030, which has a smaller set of core objectives, the goal and data will still be monitored and followed as possible.

programs, fitness facilities, beaches, or parks open to the public; and to many—but not all—leisure, social, and community activities contemplated by DH-13. Related regulations prohibit discrimination in access to health and wellness programs and activities. They also set requirements for physical access, effective communication, and reasonable modification of policies, practices, and procedures when necessary to accommodate individual needs and to ensure access.

With respect to physical barriers, the 2010 ADA Standards for Accessible Design set specific and enforceable standards for accessible design that apply to recreation facilities, including gyms, play areas, swimming pools, sports facilities, fishing piers, boating facilities, golf courses, and amusement rides.¹⁰⁴ The U.S. Access Board has promulgated guidelines for accessibility of certain aspects of physical fitness facilities, such as the space required around installation of different types of fitness equipment.¹⁰⁵ However, few public or private actions have addressed barriers to health and wellness activities, or barriers to covered leisure, social, or community activities for individuals with disabilities.

Federal Regulation of Workplace Wellness Plans

Wellness programs for purposes of DH-8 can include employer-sponsored wellness programs. Many employers offer these programs to promote employee health and productivity and reduce health-related costs.¹⁰⁶ Examples include programs for smoking cessation, weight management, stress management, physical fitness, nutrition, heart disease prevention, healthy lifestyle support, diabetes prevention, and other purposes designed to promote employee health and well-being. Most programs offer incentives in the form of discounts for participation on the employee's insurance premiums or other insurance costs (participatory program) or for meeting certain health goals (health-contingent program).¹⁰⁷ However, some incentives have been challenged as being in conflict with the antidiscrimination requirements of the ADA.*

The Departments of Labor, Health and Human Services, and Treasury issued the 2013 HIPAA Nondiscrimination and Wellness Program Design (2013 HIPAA Rule)¹⁰⁸ to reflect requirements under both HIPAA and the Affordable Care Act. These requirements prohibit discrimination

* For more on the regulation of workplace wellness plans see Elizabeth Pendo and Brandon Hall, Permitted Incentives for Workplace Wellness Plans under the ADA and GINA: The Regulatory Gap, 31(4) *The Health Lawyer* 1 (Apr. 2019)

by employer-sponsored group health plans based on an individual's health status, but contain an exception that allows workplace wellness programs to offer premium or cost-sharing discounts based on an individual's health status in certain circumstances.^{109, 110}

The requirements of the ADA apply to workplace wellness plans. Title I of the ADA prohibits employers from denying employees access to wellness programs on the basis of disability and requires employers to provide reasonable accommodations that allow employees with disability to participate in wellness programs.¹¹¹ The ADA places significant limits on an employer's ability to request medical information from employees, but makes an exception for medical examinations and inquiries that are "voluntary."¹¹² However, the term "voluntary" is not defined in the statute. Prior to the Affordable Care Act, the Equal Employment Opportunity Commission (EEOC)—the federal agency with authority to enforce Title I of the ADA—issued an ADA enforcement guidance stating that a workplace wellness program is voluntary as long as an employer neither requires participation nor penalizes employees who do not participate.¹¹³

The Affordable Care Act also addresses workplace wellness plans, and permits incentives of up to 30% of the total cost of coverage (including both employer and employee contributions) in exchange for an employee's participation in a participatory program or health-contingent program.¹¹⁴ In 2016, the EEOC issued a new final rule clarifying its interpretation of "voluntary" to include wellness plans that offer incentives of up to 30% of the total cost of employee-only coverage, among other requirements. Under this rule, employers could obtain medical information from employees with a disability who are unable or unwilling to forego the financial incentive.¹¹⁵ The EEOC's new final rule was challenged in court, and the court vacated the challenged portions of the rule effective January 1, 2019.¹¹⁶ Consistent with the court ruling, the EEOC removed the incentive limit from its final rule and has indicated that it will issue a revised rule.¹¹⁷

Workplace wellness plans warrant continued attention.* Anecdotal reports and enforcement activity by the EEOC^{118 119} reflect concerns about their impact on individuals with disabilities. However, data about the efficacy and impact of workplace wellness plans, including on individuals with disabilities, are needed.

Disability and Wellness

Disability does not equal poor health. For example, athletes with various types of disability can compete and achieve at elite levels, as evidenced by their performances at competitions such as the Paralympic Games and Special Olympics. Nevertheless, a persistent but erroneous societal assumption of poor health endures. Certainly, chronic disease frequently causes disability. Furthermore, over time, living with disability can increase risks of developing secondary conditions such as urinary tract infections, pressure ulcers, injuries from falls, and depression.¹²⁰ Accumulating evidence also suggests that individuals aging with certain disability types acquired in early or midlife show signs of more rapid physiological aging than nondisabled individuals, although reasons for this are unknown.^{121,122} The physiological aging process—with or without disability—heightens the likelihood of developing chronic health conditions, such as cardiovascular diseases, chronic respiratory disorders, and many cancers, which themselves can be disabling. Therefore, many individuals with disabilities strive to improve or maximize their health and wellness just as do individuals without disability. It is important to recognize that disability is not synonymous with poor health; persons can age with disability and remain healthy.

In 2005, to commemorate the fifteenth anniversary of the signing of the ADA, the U.S. Surgeon General Richard Carmona in his *Call to Action* focused on improving the health and wellness of individuals with disabilities.^{** 123, 124} Carmona described aspects of the clinical workforce and health care delivery system that can impede care for individuals with disabilities. Cautioning that individuals with disabilities may not have equitable access to health care, the *Call to Action* asked that health care providers gain knowledge and methods to screen, diagnose, and treat individuals with disabilities with dignity as whole persons; and that health care and related services be made fully accessible to maximize the independence of patients with disability. It further stated the following:

* For additional information on the regulation of workplace wellness plans, please see: Pendo E, Hall B. Permitted Incentives for Workplace Wellness Plans under the ADA and GINA: The Regulatory Gap. *The Health Lawyer*. American Bar Association. Vol. 31, No. 4, April 2019.

** The 4 goals for this Call to Action were: (1) People nationwide understand that persons with disabilities can lead long, healthy, productive lives; (2) Health care providers have the knowledge and tools to screen, diagnose, and treat the whole person with a disability with dignity; (3) Persons with disabilities can promote their own good health by developing and maintaining healthy lifestyles; and (4) Accessible health care and support services promote independence for persons with disabilities.

The principle underlying this *Call to Action* is that, with good health, persons with disabilities have the freedom to work, learn and engage actively in their families and their communities. Health and wellness are not the same as the presence or absence of a disability; they are broader concepts that directly affect the quality of a person's life experience. ... Persons with disabilities can lead long, healthy, productive lives. ... Challenging the misconceptions about persons with disabilities—and elevating the importance of their health and wellness in the public consciousness—are steps that can begin to help improve the health status of persons with disabilities.¹²⁵

The *Call to Action* warned that disability must be treated in the larger context of a person's life and all their health and wellness needs.

Wellness is a multifactorial concept, according to the federal Substance Abuse and Mental Health Services Administration (SAMHSA), encompassing 8 different dimensions: emotional, environmental, financial, intellectual, occupational, physical, social, and spiritual.¹²⁶ Here we do not review fully the literature relating to access to health and wellness programs for individuals with disabilities. However, federal surveys and research studies repeatedly show that individuals with disabilities are more likely than others to report being in fair or poor health and more likely to report health-related risk factors, such as tobacco smoking, high rates of being overweight or obese, and low rates of leisure time physical activity.^{127, 128} Little systematic information is available to evaluate wellness for individuals with disabilities across the range of SAMHSA dimensions.

Accessibility of Fitness Facilities and Recreational Settings

To focus the discussion, this report concentrates on the accessibility of fitness centers and other recreational venues, such as parks and sports facilities, where individuals can either exercise on their own or participate in available programs or training opportunities. The relatively limited literature has identified persistent barriers to fitness programs and facilities for individuals with disabilities.^{129, 130, 131} According to Rimmer and colleagues:

Fitness facilities and other locations such as community parks, playgrounds, and ball fields used for competitive games and sports often lack accessibility (i.e., uneven terrain, grass or gravel surfaces), thereby limiting opportunities for participation by individuals with physical/mobility disabilities. Beyond the built environment, programmatic and attitudinal barriers to physical activity exacerbate low participation rates. For instance, many staff of fitness facilities lack the knowledge or desire to develop adaptations that could facilitate participation.¹³²

Several studies have explored accessibility of fitness facilities in specific regions, including Hattiesburg, MS,¹³³ western Wisconsin,¹³⁴ and western Oregon.¹³⁵ Albeit limited, these studies suggest that, while some aspects of fitness facilities do meet accessibility standards, problems remain, primarily related to locker rooms, restrooms, and exercise equipment. To quantify the extent of access barriers to fitness facilities more broadly, Rimmer and collaborators trained evaluators to apply the Accessibility Instrument Measuring Fitness and Recreation Environments (AIMFREE) instrument to a convenience sample of 227 fitness facilities across 10 states.*¹³⁶ AIMFREE addresses 15 content areas through 422 questions, which go beyond ADA regulatory structural accessibility requirements. It also assesses aspects of fitness settings that affect usability for individuals with disabilities. The researchers concluded the following:

... More refined features of access such as information and signage, clear access routes, written policies associated with accessibility, and universally designed exercise equipment do not fall under the purview of the ADA therefore leaving managers and owners with little incentive to make their facilities more accessible to people with disabilities.¹³⁷

According to Rimmer's team, the 3 worst scoring AIMFREE dimensions across the 227 facilities were spas, telephones, and restrooms, while water fountains, programs, and parking got the best scores. Access was significantly better for the 109 facilities built post-ADA compared with the 109 facilities built earlier, specifically for access routes and entrance areas, equipment, information and signage, locker rooms and showers, restrooms, and swimming pools. Nonetheless, even though the post-ADA facilities appeared more accessible than the older ones, important barriers remained.

* All p values in the statistical tests (Wilcoxon rank sum tests) were < 0.0001, a strong indication that these differences are real. lifestyles; and (4) Accessible health care and support services promote independence for persons with disabilities.

Laws and Policies in Action: Voluntary Standards Set for Accessible Fitness Equipment

Although the 2010 ADA Standards for Accessible Design set specific and enforceable standards for accessible design that apply to many types of recreation facilities,^{138, 139} no regulatory standards exist for the exercise equipment and machines within recreational facilities. In its summary of standards relating primarily to the installation of exercise equipment and machines, the U.S. Access Board noted that although exercise equipment and machines do not need to comply with specific requirements regarding controls and operating mechanisms, “designers and operators are encouraged to select exercise equipment that provides fitness opportunities for persons with lower body extremity disabilities.”¹⁴⁰

To fill this gap, ASTM International (formerly the American Society for Testing and Materials)** developed voluntary universal design standards for fitness equipment. ASTM International involves worldwide experts in developing such voluntary consensus standards for a wide range of products and practices across diverse fields.¹⁴¹ ASTM had already developed standards for the design of commercial physical fitness equipment. In an effort to increase the accessibility of this equipment for individuals with disabilities, in 2013 it released ASTM F3021-17, Standard Specification for Universal Design of Fitness Equipment for Inclusive Use by Persons with Functional Limitations and Impairments (Active Standard ASTM F3021, developed by Subcommittee F08.30)¹⁴². It simultaneously released [ASTM F3022](#), Test Method for Evaluating the Universal Design of Fitness Equipment for Inclusive Use by Persons with Functional Limitations and Impairments.¹⁴³ A summary of these standards includes the following points.^{***144}

- “Where users are exercising from a wheelchair, it is the intent of this specification to specify products for use by individuals using manual or powered wheelchairs (including scooters) (A1.4.5).”
- “This standard does not purport to address the needs of every possible user and recognizes that access will not be possible for all individuals or all types of assistive technologies.”

* This a quote; those with upper body disabilities might also be interested in fitness opportunities at gyms.

** ASTM formerly stood for American Society for Testing and Materials, but now the acronym stands on its own.

*** The specifications apply to commercial products meant for indoor use by persons ages 13 and older. The standard does not cover fitness equipment for use in rehabilitation therapy or clinical settings.

- “This standard does not purport to address all of the safety concerns, if any, associated with its use. It is the responsibility of the user of this standard to establish appropriate safety and health practices and determine the applicability of regulatory limitations prior to use.”

In a press release accompanying the introduction of the new accessibility standards, an ASTM F08.30 committee member noted the following:

Accessible mainstream fitness equipment decreases costs and facilitates compliance with the ADA ...Increase in activity level decreases secondary conditions and health costs often associated with disability. Affording people with disabilities the opportunity to exercise in public facilities, rather than specialized medical therapy settings, increases the social opportunity to interact with family and friends.¹⁴⁵

As yet, no federal mandates require commercial fitness facilities to follow these ASTM standards. In the second session of the 113th Congress (2013-2014), former Senator Thomas Harkin introduced a bill entitled the “Exercise and Fitness for All Act” (S. 2888), which aimed to “promote the provision of exercise and fitness equipment that is accessible to individuals with disabilities.”¹⁴⁶ The bill—which advocated for equipment access but not for the ASTM standards specifically—did not pass, and no subsequent legislation has yet addressed fitness equipment standards. Nonetheless, to the extent manufacturers voluntarily adopt these ASTM standards and market pressures increase demand for accessible fitness facilities, access to fitness equipment should improve.

Laws and Policies in Action: National Center on Health, Physical Activity, and Disability

Since 1999, the National Center on Health, Physical Activity and Disability (NCHPAD) has worked to build the infrastructure to support the accessibility and inclusion of adults and children with disabilities in existing and future public health promotion programs in physical activity, nutrition, and healthy weight management.¹⁴⁷ NCHPAD works with local, state, and national organizations to support their implementation of well-accepted guidelines, adaptations, and recommendations promoting the above programs. NCHPAD’s action framework includes 4 phases, as follows:¹⁴⁸

1. Conduct extensive searches to identify evidence-based programs, policies, and practices for promoting active living and adapt them for children and adults with disability
2. Disseminate tools and resources developed in the first phase to key targeted stakeholders in training materials customized to their specific needs and organizational or community contexts
3. Serve as facilitators to help local personnel implement the disability-specific adaptations to their existing services, programs, practices, and policies
4. Document successes, archive the information, and work to disseminate these approaches in other communities and organizations striving to adopt similar changes

The NCHPAD framework treats the second and third phases as conducting knowledge translation.

NCHPAD's target audiences include the following:

- Community-based disability and aging services providers
- Key leaders in relevant sectors, including health care facilities, schools, fitness and recreation providers, public health, and active-living programs
- Community leaders who promote policy and programmatic changes at local, state, and national levels

On its website, NCHPAD notes that the ADA represents a minimum standard and is a good starting point for any public health initiative or health promotion program.¹⁴⁹ Drawing upon the 2010 ADA Standards for Accessible Design and a range of other approaches for improving access, NCHPAD developed a free implementation manual, *Guidelines for Disability Inclusion in Physical Activity, Nutrition, & Obesity Programs and Planning*, which provides guidance relating to a range of disability types.¹⁵⁰

In addition to its educational resources, NCHPAD and America Walks—a network of organizations and advocacy groups that strive to make American communities more walkable—provide funds to local communities through their Designing for Inclusive Health Micro Grant program. These grants support initiatives to expand inclusion of individuals with disabilities within community programs. Two examples of initiatives that were supported by these micro grants are described below.¹⁵¹




Access Portsmouth, Portsmouth, NH. This program aimed to help individuals with mobility disabilities plan their visits to Portsmouth. Located on the Piscataqua River and settled in 1623, this city features buildings from the 17th and 18th centuries, riverside gardens, and a waterfront museum with structures dating from 3 centuries ago. The program developed a web-based guide that provides accessibility information about city restaurants and tourist sites in the historic downtown area. Access Portsmouth planned to input this information into Google maps to make the data more globally available. Using universal design principles, the roll routes and barrier-free loops were intended to assist not only wheelchair users but also those pushing strollers and others in the general public.

Accessibility and Walking Audits, Hanover County, Ashland, VA. Working with The Arc of Hanover, which advocates for individuals with intellectual and developmental disabilities, the Chickahominy Health District taught volunteers to conduct accessibility and walking audits in Hanover County. Located in the Richmond area, Hanover County features many historic landmarks, over 1,500 acres of parkland with trails, and accessible playgrounds. The county's Community Health Assessment/Community Health Improvement Planning report aimed to include the audit findings. The project planned to solicit insights from diverse community members about walking challenges to inform the county's programs and policies. The ultimate goal was to make environmental improvements to provide equal access to all residents to support healthy living.

Figure 1

Policies that Provide Accommodations to Common Barriers Faced by People with Disabilities

People with disabilities may face barriers in many settings, including community spaces, health care settings, and long-term care facilities. Governments and organizations at all levels have the opportunity to improve access to these spaces through laws and policies that require accommodations for people with disabilities.

Barrier	Successful Accommodations
 <p>Lack of access to medical diagnostic equipment like exam tables or weight scales, which can prevent people with physical disabilities from getting primary and preventive care services</p>	<p>A settlement with the Washington Hospital Center in Washington, DC addressed barriers to accessible medical equipment by specifying timelines and criteria for purchasing—including parameters for equipment height and locking capability.</p>
 <p>Limited access to recreation spaces, fitness programs, and facilities due to barriers in built and social environments</p>	<p>To reduce barriers to community resources for people with disabilities, the Access Navigators program in Portsmouth, New Hampshire developed a web-based guide that features accessibility information about community spaces, like restaurants and tourist sites.</p>
 <p>Lack of access to leisure, social, religious, or community activities due to living in an institutional setting rather than at home or in the community</p>	<p>The Center for Medicare and Medicaid Services' Money Follows the Person (MFP) program gives states and tribal partners matching funds to help people who need long-term care transition from institutions back into community settings.</p> <p>Minnesota has 2 programs that help residents move from nursing homes into the community: a MFP demonstration project, and the Return to Community Program, which serves people who have been in a nursing home for less than 90 days. Both of these programs allow people with disabilities to participate more fully in their communities—while still getting necessary health services.</p>

For more information: <https://www.healthypeople.gov/2020/law-and-health-policy>

DH-13: Independent Living and Full Participation in Community Life

Disability and Health objective DH-13 has a broad intent to increase the proportion of adults with disability ages 18 years and older who participate in leisure, social, religious, or community activities.* Full participation in community life as envisioned in DH-13 requires that individuals with disabilities live in the community as they wish. When they need supportive services, both the setting of service delivery and the services themselves must promote their participation in community life. In addition, community-based activities must themselves be accessible or offer reasonable accommodations for participation to individuals with disabilities.

Legal and Policy Frameworks

Several laws and policies are relevant to achieving the broad intent of DH-13. For instance, the ADA prohibits discrimination based on disability in public services (Title II) and places of public accommodations (Title III), which applies to many of the leisure, social, and community activities covered by DH-13.** The Rehabilitation Act and the ADA both intend to remove barriers to participation in community life, including ensuring that individuals with disabilities can live in communities when desired with reasonable accommodations, as appropriate. For example, in addition to the legal requirements of these laws, amendments to the Rehabilitation Act provided federal funding for a national network of community-based Centers for Independent Living to support individuals with disabilities living in the community.*** 152, 153

* DH-13 is a developmental objective for HP2030. It is an important goal to allow those with disabilities to participate in every day live activities and to receive the support and accommodations they deserve. Developmental objectives are those that do not have the required nationally representative data sources. As this has not been resolved over the past decade, the objective was not able to be made measurable and will not meet the requirements to be included in HP2030. The goals and legal requirements should still make this an important focus though.

** The Internet and websites play a critical role in a wide range of areas and activities, including those addressed by this report. Many websites, however, are not fully accessible to individuals with disabilities. Web access for individuals with disability is an important issue to watch, as courts have taken different positions on the application of Title III of the ADA to websites. To date DOJ has not adopted enforceable ADA standards for accessible website design. For more please see: National Council on Disability, National Disability Policy: A Progress Report Publication (October 7, 2016), available at <https://ncd.gov/progressreport/2016/progress-report-october-2016>.

*** Centers for Independent Living "are consumer-controlled, community-based, cross-disability, nonresidential, private nonprofit" agencies designed and operated "within a local community by individuals with disabilities and provides an array of independent living services." For more please see: <https://acl.gov/programs/aging-and-disability-networks/centers-independent-living>

In the landmark 1999 case *Olmstead v. L.C.*, 527 U.S. 581,¹⁵⁴ the Supreme Court made clear that unnecessary segregation of individuals with disabilities constitutes discrimination in violation of Title II of the ADA. The Court held that public entities must provide community-based services to individuals with disabilities when such services are appropriate, desired by the recipient, and can be reasonably accommodated by the public entity. The Court relied on the “integration mandate” in the Title II regulations that requires public entities to “administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities.” The regulations define the “most integrated setting” as one that “enables individuals with disabilities to interact with non-disabled persons to the fullest extent possible...”¹⁵⁵ This means that individuals with disabilities, including individuals with cognitive and intellectual disabilities and individuals with mental illness, cannot be required to live in institutions or group settings to obtain the services they need.

DOJ and the HHS Office for Civil Rights have taken actions to enforce the *Olmstead* decision and the integration mandate of Title II, and have worked with state and local governments to meet these requirements.¹⁵⁶

¹⁵⁷ Legal aid agencies, public interest law firms, and the nationwide network of protection and advocacy systems have also brought actions under *Olmstead*.¹⁵⁸

Considerations Relating to Religious Organizations

DH-13 includes religious activities in its list of community activities. However, the ADA, unlike Section 504 of the Rehabilitation Act, explicitly exempts religious organizations from its places of public accommodations accessibility mandates,¹⁵⁹ and therefore does not directly contribute to the aim of increasing participation in religious activities. If religious organizations sponsor non-faith programs, such as preschools or playgrounds, those components are subject to ADA requirements. However, aspects related to religious activities are not.

This exemption of religious organizations from ADA mandates led to several initiatives over the last several decades to voluntarily raise awareness about and improve disability access to religious institutions. Established in 1989, the Religion and Disability Program of the National Organization on Disability (NOD) launched the Accessible Congregations Campaign, which aimed to solicit the voluntary participation of 2,000 congregations by the year 2000. One of 3 principles central to participation was the following commitment: “Our congregation is

endeavoring to remove barriers of architecture, communications and attitudes that exclude people with disabilities from full and active participation.”¹⁶⁰

More recently, leaders of different religions and faith denominations have made the case for disability access by using religious arguments for inclusion and eliminating barriers that exclude anyone. As an advocate noted, while religious institutions may be legally exempt from ADA requirements, the same does not hold true for moral or religious obligations.¹⁶¹

Implications of Medicaid for Participation in Community Life

In addition to legal mandates, aspects of the federal-state Medicaid health insurance program have important implications for its recipients with disabilities participating in community activities. According to the Medicaid and CHIP Payment and Access Commission (MACPAC), more than 10 million individuals nationwide qualify for Medicaid because of disability.¹⁶² Although many of these individuals are also beneficiaries of federal Medicare health insurance, MACPAC estimates that 6.2 million only have Medicaid coverage.

To participate fully in community life as envisioned in DH-13, individuals with different disability types require diverse accommodations broadly categorized as long-term services and supports (LTSS). LTSS encompasses a variety of items and services, including equipment (e.g., augmentative communication devices, assistive devices for vision and hearing, and mobility aides), home-based modifications (e.g., grab bars, ramps, and specialized beds). Also included are personal assistance services (PAS) to support activities of daily living (ADLs; e.g., feeding, bathing, dressing, toileting, and movement within the home) and instrumental ADLs (e.g., meal preparation, shopping, light housework, banking, and similar activities).

By definition, LTSS are long-term and thus often costly. Most Americans do not have the resources to pay out-of-pocket for PAS. In 2016, based on 30 hours per week of personal care assistant (PCA) services, the average annual cost was estimated at \$31,200, or 76% of the median annual income for households of individuals ages 65 and older. Median total financial assets were only \$40,500 for households of individuals ages 65 and older—enough for just over 1 year of PAS.¹⁶³ A 2017 survey found that 67% of Americans ages 40 and older have done little or no

planning to address their long-term care needs; only 29% correctly estimated the monthly costs of part-time home PAS.¹⁶⁴ Given their lower average incomes and household resources, individuals with long-term disabilities would face particular financial hardships.

A major challenge is that health insurers generally do not cover LTSS, which typically fall outside the boundaries of so-called “medical necessity”—the standard that Medicare regulations use to justify coverage of specific items or services.¹⁶⁵ By statute, Medicare explicitly covers only services that are “reasonable and necessary for the diagnosis or treatment of illness or injury or to improve the functioning of a malformed body member.”¹⁶⁶ Statutory exclusions—such as routine foot or dental care, hearing aids, and “personal comfort” items, such as grab bars,¹⁶⁷ have important implications for disability-related items and services. Medical necessity definitions tie directly to the determination of covered services: services required to diagnose or treat a medical condition that are not primarily for the “convenience” of the patient or physician. Medicare typically views items that “accommodate” disability—such as mobility aides for use outside individuals’ homes—as convenience items, for which coverage is typically denied.¹⁶⁸ Private insurers have typically followed Medicare’s lead, covering only services that meet medical necessity provisions.

Policy makers designing Medicaid recognized early on that individuals eligible for Medicaid through disability would have substantial LTSS needs but few resources to cover them themselves. Medicaid diverged from Medicare in including LTSS among a list of optional services that states could choose to cover, including some rehabilitative services that can be helpful to improving functional abilities (e.g., physical therapy; occupational therapy; and speech, hearing, and language disorder services) and items (e.g., prosthetics, dentures, and eyeglasses).¹⁶⁹ Additionally, under the 1915(i) and 1915(j) state plan options, Medicaid services include, respectively, home and community-based services (HCBS) and consumer-directed personal assistance services.¹⁷⁰ As mandatory benefits, Medicaid also covers long-term nursing home and institutional care for specified individuals with documented severe functional impairments or chronic skilled nursing needs.¹⁷¹ Trends toward deinstitutionalization and the *Olmstead* decision have led recently to efforts—especially in states that chose to spend Medicaid funds on HCBS and LTSS—to “rebalance” Medicaid expenditure, away from facilities and into communities.¹⁷² However, individual state Medicaid programs decide how expansively to cover LTSS, especially PCAs; thus, the generosity of LTSS coverage varies widely from state to state.

Medicaid Innovations and Community Participation

In recent years, innovation and experimentation with Medicaid—especially around HCBS and PAS—have led to many encouraging efforts that could further the aims of DH-13. Examples include the following:

- Medicaid programs in 7 states (Alaska, Arizona, Arkansas, Idaho, Minnesota, Virginia, and Washington) launched efforts to improve PCA training, including expanding hours, instituting a state-specified or endorsed exam, competencies, and/or training curricula.¹⁷³
- Washington State passed ballot measures that supported higher training, certification standards and background checks for home care workers, which provided the impetus for establishing the nonprofit Training Partnership in 2007 governed by a labor-management partnership.¹⁷⁴
- Spurred by Affordable Care Act provisions, various waivers and demonstration programs have been established to expand home-based PAS, including the Nursing Home Diversion/Community Living Program, Money Follows the Person, Aging and Disability Resource Centers, Medicaid's Community First Choice Option, and the State Balancing Incentive Program.¹⁷⁵
- A federal rule on community living has been adopted that requires Medicaid 1915(i) HCBS programs to assess the needs of family caregivers when that care is part of the service plan for a Medicaid recipient with disability. The rule's goal is to provide respite for the caregivers using home-based PAS.¹⁷⁶
- Some states have developed "matching service registry" (MSR) programs that allow those needing home-based PAS to connect directly with qualified PCAs, rather than go through an agency; 33 such nonprofit registries were recently identified across 23 states.¹⁷⁷
- From 2002-2006, a national demonstration program called Better Jobs, Better Care introduced 9 elements to improve job quality for direct care workers, including PCAs.¹⁷⁸
- Recognizing the complexity and ensuing confusion of the many programs providing LTSS (including PAS), the No Wrong Door initiative in 6 states (Connecticut, Michigan, New Hampshire, Virginia, Washington, and Wisconsin) and the District of Columbia facilitates access to appropriate and needed services, regardless of how potential clients enter the portal.¹⁷⁹

- The Personal and Home Care Aide State Training demonstration program from 2010-2012 enabled 6 grantees—in California, Iowa, Maine, Massachusetts, Michigan, and North Carolina—to receive Affordable Care Act funding to train competent direct care workers to care for an aging population.¹⁸⁰

This report does not systematically catalog evidence that these various programs have been successful in advancing DH-13, although all contain components that should support its aims. Below, we highlight several programs that have substantially helped individuals with disabilities to participate in community life.

Laws and Policies in Action: Money Follows the Person

State law, state Medicaid plans, and state budgets can present barriers to receiving long-term HCBS in the home or community instead of in an institution. Often, the resources of the state and what Medicaid will reimburse dictate decisions, rather than the needs or preferences of the individual.¹⁸¹ To comply with *Olmstead*, a state may have to change how it pays for services through its Medicaid program. The national Money Follows the Person (MFP) rebalancing demonstration provides federal matching funds to participating states and tribal partners to develop systems and services that help individuals receive long-term care in the settings of their choice.¹⁸² MFP also addresses policy barriers to Medicaid reimbursement for HCBS. For example, the Centers for Medicare & Medicaid Services (CMS) issued a rule on Medicaid spending for HCBS that standardized requirements for these services.¹⁸³ The Affordable Care Act strengthened and expanded the MFP program, allowing more states to apply.¹⁸⁴ Transitions of MFP participants from institutions to communities began in 2007.

According to a 2017 report evaluating MFP as of 2016,¹⁸⁵ 43 states and the District of Columbia were conducting MFP demonstrations and actively transitioning participants. MFP demonstrations must have several components, including the following:

- Efforts to identify qualifying Medicaid recipients living in institutions who want to move into communities
- Programs to help these individuals transition into communities
- Rebalancing initiatives that permit Medicaid long-term care dollars to go to HCBS

By statute, individuals are eligible for the MFP demonstration only if they have resided for at least 90 consecutive days in an institutional setting (defined as a hospital, skilled nursing facility, or intermediate care facility for individuals with intellectual disabilities).¹⁸⁶ If state Medicaid programs cover individuals institutionalized for serious mental illness, these individuals would also qualify for MFP. Specific MFP demonstration designs are unique to each state, tailored to their particular contexts. When MFP participants transition to the community, they immediately begin receiving LTSS support appropriate to their needs, for up to 365 days. Afterward, 1915(c) waivers or other funds are used, as determined by states, to support LTSS.

CMS first awarded MFP demonstration grants in January 2007, making 17 awards. CMS made 14 additional awards in May 2007 and 13 in January 2011.¹⁸⁷ Planning grants went to Alabama, Montana, and South Dakota in 2012. By the end of 2012, 46 states plus the District of Columbia had MFP grants. New Mexico and Florida formally dropped out of the program in 2012 and 2013, respectively, and Oregon withdrew in 2014. Since 2012, approximately 10,000 individuals have been transitioned each year across the MFP programs, representing about 1% of eligible individuals. By the end of December 2015, a total of 63,337 individuals had transitioned.¹⁸⁸ According to the 2017 evaluation,

Estimates indicate that the transitions through the end of 2013 (the sixth year of MFP transitions) generated health care cost savings in the range of \$204 to \$978 million depending on the number of transitions that can be attributed to the MFP demonstration. In addition, consistently throughout the demonstration, MFP participants have reported significant improvement in the quality of their lives while state grantees have benefited from the flexibility afforded by the grant funding to develop transition programs, expand community-based LTSS offerings, design new services, and remove programmatic barriers to transition.¹⁸⁹

The quality of life improvements through MFP moved toward the aims envisioned in DH-13. MFP participants were reported to be substantially more satisfied with their community living arrangements compared to their institutional residences; and community integration and support of their ADL needs had improved significantly. The evaluation also found

that “MFP participants reported significant improvements in all seven quality-of-life domains 1 year after moving to the community.”*¹⁹⁰

All target groups reported these improvements, which were largely sustained 2 years later. In particular, while residing in institutions, 54% reported barriers to community integration. After 1 year in the community, only 34% reported barriers to community integration; this percentage fell to 30% 2 years after the community transition.¹⁹¹ With fewer barriers, MFP participants experienced greater autonomy and independence. The study found that greater community integration was associated with lower rates of depressive symptoms.

Pursuant to the ACA, funding for the MFP Program was appropriated through 2016.¹⁹² Unused awarded grant funds carry over to the next year, and funds awarded in 2016 can be used through 2020. However, as of the date of this report no additional funding has been appropriated.

Laws and Policies in Action: LTSS in Minnesota

AARP, the Commonwealth Fund, and the Scan Foundation produce the *State Long-Term Services and Supports Scorecard*, which ranks all states on 25 indicators reflecting their performance in HCBS and LTSS affecting older adults, individuals with physical disabilities, and family caregivers.¹⁹³ Minnesota has relatively low disability rates: among state residents ages 18-64, only 1.4% have difficulty performing at least 1 ADL compared to 1.8% nationwide; and among residents ages 65 and over, 6.0% have problems with at least 1 ADL compared with 8.8% nationwide.¹⁹⁴ As such, over multiple years, Minnesota has ranked first overall on the scorecard.

This success represents the downstream benefits of more than 20 years of planning, and of understanding local population trends and their implications for LTSS. In 1998, Minnesota published estimates of population aging by 2030 by county.¹⁹⁵ These data stimulated policy discussions about planning for dramatic increases in demand for LTSS. For example, in 2007, Minnesota published its *Blueprint for 2010: Preparing for the Age Wave*, and the Minnesota Aging 2030 initiative is preparing for the aging of “baby boom” residents.¹⁹⁶

* The 7 quality of life domains that were assessed include: (1) overall life satisfaction, (2) mood status, (3) satisfaction with life, (4) unmet need for personal assistance services, (5) respect and dignity, (6) satisfaction with living arrangements, and (7) barriers to community integration.

Minnesota is also a leader in HCBS rather than institutional care. Notably, in 2012, Minnesota ranked first in the country in the percentage of LTSS users first receiving LTSS in the community: 83.3% for Minnesota compared with a national median across states of 49.9%.¹⁹⁷ For more than 2 decades, strong leaders from the Minnesota Department of Human Services (DHS) and its Aging and Adult Services and Disability Services Divisions moved state policy toward HCBS. In its Framework for the Future: 2012, DHS outlined its 4-part vision to include focusing on individuals, not programs; providing ladders up and safety nets for individuals served; working in partnership with others; and accountability for results.¹⁹⁸

A primary imperative of the 'people' focus is to increase the number of Minnesotans served in their homes and communities rather than in institutions. Other features include the integration of primary care, behavioral health, and long-term care and a campaign to encourage people to plan for future LTSS needs. The Framework calls for implementation of MnCHOICES, an automated web-based 'assessment tool to better align services to individual needs.'¹⁹⁹

Minnesota has 2 programs that assist residents in moving from nursing homes to the community. Started in 2010, the Return to Community program serves Minnesotans who have a nursing home stay of less than 90 days, who both want to be returned to the community and are likely to be discharged there, and who are at risk of long nursing home stays.²⁰⁰ A year later, in 2011, the MFP demonstration in Minnesota began. Minnesota's DHS has supported the program by regularly providing lists to various state agencies of individuals interested in transferring from institutions to the community, focusing on counties with the largest number of individuals desiring transitioning.

In one of the largest counties in Minnesota, information regarding people expressing an interest in transitioning is sent directly to a lead manager with the county who, together with an aid [sic], assists in assigning transition coordinators, expediting assessments, and facilitating communication between the MFP program and lead agency staff. In another of the largest counties in the state, case managers are assigned to work with specific nursing home. [sic]... To promote consumer choice, Minnesota uses an on-line housing survey to gather people's preferences. The state also uses a Housing Benefits 101 website to help people understand what options are available.²⁰¹

DHS also conducts a separate waiver program for children and adults with physical disabilities and individuals with mental illness. This Community Alternatives for Disabled Individuals (CADI) Waiver funds HCBS for children and adults who would otherwise require nursing home level care.²⁰² Individuals may receive CADI Waiver services in their own home, their biological or adoptive family's home, a relative's home, a family or corporate foster care home, a board and lodging home, or an assisted living facility. Spending for the CADI Waiver was \$468.1 million in FY 2011; it served 15,695 participants on average each month at a monthly average cost of \$2,515.²⁰³

Minnesota was also ranked in the top 25% on the relative rate of employment of adults with physical disabilities compared with employment rates for all adults.²⁰⁴ Bolstering employment among individuals with physical disabilities has been a state objective for many years. In 1999, Minnesota initiated a Medicaid buy-in program called Medical Assistance for Employed Persons with Disabilities. In 2000, Minnesota received a Medicaid Infrastructure Grant, which officials used to establish the Pathways to Employment program. Other efforts to increase employment of individuals with disabilities included the following:

- Supporting the Minnesota Employment Training and Technical Assistance Support Center
- Holding annual disability and employment conferences
- Maintaining a Disability Linkage Line, a free information and referral resource across Minnesota that provides information about work
- Conducting periodic consumer satisfaction surveys
- Including various employment-related services through HCBS waivers and other programs
- Initiating a monitoring system to track employment and earning of individuals who received services from counties and county contractors²⁰⁵
- Expanding the state Medicaid program, allowing more individuals with disabilities to work without losing eligibility.

Employment is an important dimension of community participation and engagement, and research suggested that Medicaid expansion may improve employment outcomes.²⁰⁶ A critical vision of Minnesota's efforts

to increase employment among individuals with disabilities involves the quality and dignity of the work. They emphasize that individuals with disabilities must have opportunities for “real jobs” (not just “make work”) in the community and live in their own homes. Minnesota furthers this goal through data systems that track employment income by county and contractor. If counties and contractors fall behind employment targets they must develop corrective action plans. The state also emphasizes the importance of having individuals with disabilities live in their own homes as an essential component to building sustainable programs.²⁰⁷

DH-1: Collection of Standardized Disability Health Data

Collecting better disability data at the federal and state level is needed to inform policy and program development regarding critical issues of health disparities and health equity experienced by individuals living with disability. This includes programs, policies, and interventions related to barriers to our previously discussed Healthy People objectives for primary and periodic preventive care (DH-4); barriers to participation in local health and wellness programs (DH-8); and participation in leisure, social, religious, or community activities (DH-13). Disability and Health objective DH-1 calls for increasing the number of population-based data systems used to monitor HP2020 objectives that include in their core a standardized set of questions identifying individuals with disabilities.²⁰⁸ The goals of DH-1 also call for analyzing and publishing data in a standard demographic format to help monitor progress toward reducing health disparities and achieving health equity.²⁰⁹ Through ensuring that national surveys and data sources include standard information about people with disability, better information will be readily available when needed for programmatic and policy-making purposes.*

* The goal of having more data systems capture information about people with disability is one that has been a focus of HP2020. The need will continue over the next decade and will be included as part of a new category of Healthy People objectives for 2030—“research objectives.” These objectives point out areas where additional opportunities exist to make progress, or identify issues that need additional research and focus. The need to capture standard information about people with disabilities will be an important focus over the next decade.

Affordable Care Act and Existing Disability Data Standards

The Affordable Care Act provides new legal tools to collect, analyze, and share standardized disability health data necessary to monitor progress on programs, policies, and interventions related to the Disability and Health topic area objectives. Section 4302 of the Affordable Care Act requires that HHS—reporting on federally-conducted or supported health care or public health programs—collect data on race, ethnicity, sex, primary language, and disability status.²¹⁰ Section 4302 also requires the collection of data on barriers to health care experienced by individuals with disabilities. It directs HHS to identify locations where individuals with disabilities access different types of care. In addition, HHS must also determine the number of providers with accessible facilities and accessible medical and diagnostic equipment, as well as the number of employees trained in disability awareness and in caring for patients with disability.

In response to the mandates outlined in Section 4302 of the Affordable Care Act, workgroups were formed within HHS and tasked to make recommendations for data collection standards for race, ethnicity, sex, primary language, and disability status.²¹¹ The disability standards work group drew upon many years of work conducted by the U.S. Census Bureau, Office of Management and Budget (OMB), National Center for Health Statistics (NCHS), and various interagency work groups²¹² to identify a set of questions addressing a range of policy interests.²¹³ The work group's final recommended disability measure for HHS data collections was the American Community Survey (ACS) disability question set.

As part of the periodic redesign of the content administered in the U.S. Census Bureau's American Community Survey (ACS), a set of 6 disability questions was developed for use in the Census long form format. The OMB Interagency Committee for the ACS convened an ACS Subcommittee on Disability Measurement and asked NCHS to take the lead in assessing the adequacy of the Census disability questions administered as part of the ACS. All federal agencies were invited to participate. The 6 questions developed, commonly referred to as the "ACS disability" questions, were first administered in the 2008 ACS survey. This new set reflected conceptual changes in the way disability is defined, and measurement improvements in the collection of disability data. Considerable time was spent in developing and testing the questions, which capture limitations in 6 domains of functioning: seeing, hearing, mobility, cognition, self-care,

and independence. The Census Bureau and NCHS collaborated on the cognitive testing of the questions using several administration modalities (e.g., paper-and-pencil, telephone, and in-person interviews). After extensive testing, the Census Bureau revised the original question set to improve clarity and reliability, and to optimize response variance.

The 6 ACS disability questions were intended to serve as a minimum standard at the time. A number of restrictions were placed on the question set during its development, primarily the amount of space that could be used on the paper version of the ACS survey instrument. As a result, key domains of functioning (e.g., psychosocial functioning), which would require more than 1 question to measure, were omitted from the set. In addition, the limited space on the survey form restricted the use of anything but a dichotomous response set. The resulting set of questions follows:

1. Are you deaf or do you have serious difficulty hearing?
 Yes No
2. Are you blind or do you have serious difficulty seeing, even when wearing glasses?
 Yes No
3. Because of a physical, mental, or emotional condition, do you have serious difficulty concentrating, remembering, or making decisions? (5 years old or older)
 Yes No
4. Do you have serious difficulty walking or climbing stairs? (5 years old or older)
 Yes No
5. Do you have difficulty dressing or bathing? (5 years old or older)
 Yes No
6. Because of a physical, mental, or emotional condition, do you have difficulty doing errands alone such as visiting a doctor's office or shopping? (15 years old or older)
 Yes No

Figure 2: Surveys that Have Included the 6 ACS Disability Questions

Managed by CDC or NCHS

- Behavioral Risk Factor Surveillance System (BRFSS)
- National Health and Nutrition Examination Survey (NHANES)
- National Health Interview Survey (NHIS)
- National HIV Behavioral Surveillance Survey (NHBS)
- National Survey of Family Growth

Managed by Other HHS Agencies

- Health Information National Trends Survey (HINTS), supported by the National Institutes of Health and the affiliated National Cancer Institute
- Medical Expenditure Panel Survey - Health Status Section (MEPS-HE), supported by the Agency for Healthcare Research and Quality²¹⁶
- National Health and Aging Trends Study (NHATS), supported by the National Institutes of Health, National Institute on Aging
- National Survey of Children's Health (NSCH), supported by the Health Resources and Services Administration, Maternal and Child Health Bureau
- National Survey on Drug Use and Health (NSDUH), supported by the Substance Abuse and Mental Health Services Administration

Managed by Other U.S. Governmental Departments

- American Community Survey (ACS), U.S. Census Bureau
- American Housing Survey (AHS), U.S. Department of Housing and Urban Development
- Current Population Survey (CPS), U.S. Department of Labor/Bureau of Labor Statistics
- National Crime Victimization Survey, U.S. Department of Justice/Bureau of Justice Statistics

Note: This chart includes all surveys that have included the 6 ACS questions. The set of questions might not currently still be included.

These 6 questions are intended to reflect both functioning in key domains (questions 1-4) and activity limitations (questions 5-6), as conceptualized by the World Health Organization's *International Classification of Functioning, Health and Disability*.²¹⁴ Extensive field testing and cognitive testing have found that using all 6 questions provides the most meaningful disability measurement.²¹⁵

As required by section 4302 of the Affordable Care Act, federal data gathering initiatives have added these 6 standard questions from the ACS to their surveys. The box below lists these data collection efforts, grouping them by the agency charged with conducting the survey. Under the box we highlight 2 of these surveys as examples of Laws and Policies in Action for DH-1.

Laws and Policies in Action: Behavioral Risk Factor Surveillance System (BRFSS™)

BRFSS is conducted annually in each of the 50 states, the District of Columbia, and 3 U.S. territories. Overseen by CDC, BRFSS started with 15 states in 1984 and now completes more than 400,000 interviews per year.²¹⁷ Using random-digit dialing of telephones (now both landlines and cell phones), the survey aims to represent civilian, non-institutionalized individuals ages 18 and older.

BRFSS has a history of asking about disability, with the goal of using these data to support public health initiatives addressing the needs of individuals with disabilities.²¹⁸ Starting in 1998, BRFSS began asking the following questions to identify disability: "Are you limited in any way in any activities because of an impairment or health problem?" and "If you use special equipment or help from others to get around, what type do you use?"²¹⁹

Beginning in 2003, the core BRFSS asked 2 slightly different questions, as follows: "Are you limited in any way in any activities because of physical, mental, or emotional problems?" and "Do you now have any health problem that requires you to use special equipment, such as a cane, a wheelchair, a special bed, or a special telephone?"

In 2013, omitting the query about hearing and deafness, BRFSS added 5 of the 6 standard HHS disability questions to their annual survey. These new functional status-based questions found that mobility disability was reported most frequently (8.5% to 20.7% across states), followed by cognitive disability (6.9% to 16.8%).²²⁰ In the 2015 publication reporting disability prevalence from the 2013 BRFSS data, CDC analysts noted the following:

These are the first data on functional disability types available in a state-based health survey. This information can help public health programs identify the prevalence of and demographic characteristics associated with different disability types among U.S. adults and better target appropriate interventions to reduce health disparities.²²¹


The decision to exclude the hearing question from BRFSS caused considerable consternation among advocates for individuals who are deaf or hard of hearing.²²² In response, CDC explained that its exclusion was caused by concerns that the mode of BRFSS administration—by telephone after random digit dialing individuals ages 18 and older—could lead to inaccuracies in estimates of the population prevalence of hearing difficulties. However, their position changed. The 2016 BRFSS did include the question (“Are you deaf or do you have serious difficulty hearing?”) as specified in the data standard.²²³

Laws and Policies in Action: National Survey of Family Growth (NSFG)

Conducted by CDC’s NCHS, the NSFG collects nationally-representative data on marriage and divorce, family life, contraception use, fertility, pregnancy, and general and reproductive health.²²⁴ When it began in 1973 with home-based interviews, NSFG aimed to represent civilian non-institutionalized women ages 15-44 years. Over the years, NSFG expanded to include men (aged 15-44) in 2002 and extended the age of women participants to 49 years (2015). NSFG continues to use individual interviews to gather data, with certain sensitive questions answered privately by participants using self-administered questionnaires. The survey contains 2 broad questions that address disability: whether the respondent was “limited in any way in any activities because of physical, mental, or emotional problems” and whether the respondent had “health problems that require ... use [of] special equipment, such as a cane, a wheelchair, a special bed, or a special telephone.” These global questions provided little specific information about disability.

In 2011-2013, NSFG added the 6 HHS disability questions. The NSFG data are now being used in research about sexual and reproductive health of individuals by disability status—an area long understudied.²²⁵ For example, Mosher and colleagues used 2011-2015 NSFG data on 11,300 women ages 15-44 to examine receipt of family planning

services.²²⁶ Multivariate models showed that, after adjusting for sociodemographic characteristics, women with physical disability alone or women with both physical and cognitive disabilities were significantly less likely to receive birth control services than women without disabilities. Wu and collaborators also used the same NSFG disability data to compare rates of female sterilization between women with and without disability, studying 4,966 NSFG participants.²²⁷ Among women with disability, 28.2% reported sterilization as compared with 15.0% without disability. After controlling for sociodemographic characteristics, women with physical and/or sensory disability remained more likely to have undergone sterilization than other women.



How Federal Legislation Addresses the Needs of People with Disabilities: Data Collection

The Affordable Care Act requires all federally conducted or supported health care and public health programs to collect data on disability status. It also requires these programs to collect data on the barriers that people with disabilities face in health care. Collecting this data helps identify barriers and inform solutions.

Opportunities to Promote Healthy People Disability and Health Objectives

The requirements and incentives of existing federal laws—the ADA, the Rehabilitation Act, the Affordable Care Act, and Medicaid laws—are strong tools to address Healthy People’s Disability and Health objectives. Opportunities to leverage these tools to make further progress towards improving health, well-being, and community participation of individuals with disabilities are listed below.

Continue to strengthen existing laws. Opportunities exist to implement the ADA, the Rehabilitation Act, the Affordable Care Act, and Medicaid in ways that could advance each of the objectives identified in this report. DOJ could adopt or create more detailed ADA and Rehabilitation Act standards. By adopting the MDE accessibility standards as enforceable under the ADA and Rehabilitation Act, for example, DOJ would clarify requirements for health care offices and institutions, thus advancing efforts to reduce a significant barrier to primary and preventive care. Development of scoping standards addressing the minimum number or percentage of accessible MDE that must be available would also provide clarity. Similarly, DOJ adoption of the ASTM standards for fitness equipment would clarify requirements for manufacturers of fitness equipment and for commercial fitness facilities. Another opportunity for advancing progress would be for the U.S. Congress to appropriate funding for data collection on disability-specific barriers to care, along with continuing to support community-based approaches like the MFP program.

Enforce existing laws. Laws are powerful tools to promote the health and wellness of individuals with disabilities, but they require enforcement to be effective. The ADA, the Rehabilitation Act, and the antidiscrimination provision of the Affordable Care Act are designed to be enforced by the federal government and through actions brought by private individuals and groups. DOJ is responsible for enforcing these laws (with the exception of Title I of the ADA), and has broad authority to investigate, mediate, litigate, and settle individual and class-based claims. Governmental agencies, advocacy organizations, academic researchers, and others have documented that the ADA and Rehabilitation Act are underenforced.^{228, 229, 230, 231, 232} This report draws attention to the impact of public enforcement activities in some areas, such as challenging certain barriers to primary and periodic preventive care under the ADA for individuals with disabilities and enforcing the “integration mandate” of *Olmstead*. Other public enforcement needs include challenging barriers to health and wellness activities in general, and barriers to covered leisure, social, or community activities for individuals with disabilities.

Encourage and ensure state and local initiatives. Federal law and policy create opportunities for states to innovate and experiment in ways that advance disability and health objectives, along with promoting the health and wellness of individuals within the state. For example, states may expand Medicaid coverage under the Affordable Care Act, include coverage of LTSS and PAS under Medicaid, and increase HCBS to meet the needs of its residents through the MFP program.

Federal law and policy also create a framework for local initiatives addressing access to care, to health and wellness programs, and to life in the community. Maintaining and strengthening opportunities for state and local innovations are important tools to help promote the goals and reach the targets of the Disability and Health objectives.

Continue to educate health care providers, institutions, and systems about the requirements of existing laws. Health care providers, institutions, and systems need education about barriers to care, along with the existing civil rights protections that protect and promote accessible health care for individuals with disabilities. Topics might include requirements of the law regarding MDE and the MDE accessibility guidelines, the benefits of accessible MDE for patient care, and tax incentives for the purchase of accessible MDE.²³³

Collect Standardized Disability Data. Better disability data are needed to inform policy and program development and evaluation related to critical issues of health disparities and health equity for individuals with disabilities. To advance the 4 HP2020 objectives highlighted in this report, data gathering must include programs, policies, and interventions related to barriers to primary and periodic care; barriers to participation in local health and wellness program; and participation in leisure, social, or community activities. Federal data-gathering initiatives have added the 6 HHS disability items to a number of surveys following efforts started with Section 4302 of the Affordable Care Act, thus generating valuable new data about disability. Continued implementation over time and across surveys will magnify the benefits, facilitating comparisons of results across survey populations and time periods. New national research or data about the health status of individuals with disabilities could also be a valuable step to update information about this important population.

The Interagency Committee on Disability Research (ICDR) is charged with promoting coordination and cooperation among federal departments and agencies conducting research programs related to disability, independent living, and rehabilitation. The ICDR released a strategic plan for fiscal years 2018-2021 to guide and coordinate federal research into these areas.²³⁴ The strategic plan identified three key goals:

- Improve interagency coordination and collaboration in 4 thematic research areas—transition, economics of disability, accessibility, and disparities
- Develop a government-wide inventory (GWI) of disability, independent living, and rehabilitation research
- Promote ongoing stakeholder input on gaps and priorities for disability, independent living, and rehabilitation research²³⁵

Implementing this strategic plan could serve to improve dissemination of existing research and scholarship on effective policy and program interventions, as well as systematically convene partners and stakeholders to identify and address gaps.

Another necessary component is implementation of the requirement to collect disability-specific data regarding barriers to health care experienced by individuals with disabilities. Some barriers to care constitute discrimination under the ADA. However, DOJ does not have comprehensive records of ADA-related complaints because no requirement for them to be filed with DOJ exists.* Nevertheless, reporting perceived access barriers to DOJ (and through state systems, where appropriate) might help compile information that could support efforts to improve access. An important complementary effort would be to work with federal, state, local, and institutional programs to identify locations where individuals with disabilities access different types of care, and to measure the number of providers and facilities equipped to provide care consistent with the provisions of Section 4302.

* The Equal Employment Opportunity Commission has records of Title I complaints because of a requirement to file a complaint with the EEOC prior to initiating a suit under that Title. 42 U.S.C. 12117.

Opportunities to Build the Evidence Base through Additional Research

This report highlights the need for better disability data and inclusion of individuals with disabilities in health research. Research is needed on the causes and effects of barriers to health care, local health and wellness programs, and life in the community; this will enable better evaluation of the effectiveness of current initiatives and development of strategies for adherence to existing laws and policies. Research findings can also inform policy and program development, help monitor progress toward achieving Healthy People objectives, and provide valuable support toward reaching the upcoming HP2030 goals related to disability and health. Supporting rigorous evaluations of individual and policy outcomes resulting from existing strategies and initiatives would help identify “lessons learned” that could generalize to other settings, although local factors will drive advancement toward the objectives, especially those relating to community participation.

Much federally funded research on health disparities does not recognize and include individuals with disabilities as a disparity population.²³⁶ An example is the Minority Health and Health Disparities Research and Education Act of 2000 (MHHREA), which aimed to improve the health of racial or ethnic minority groups and health disparity populations,²³⁷ the latter defined as groups experiencing “significant disparity in the quality, outcomes, cost, or use of health care services or access to or satisfaction with such services as compared to the general population.”²³⁸ As noted by *Healthy People 2010* and *2020*, individuals with disabilities fit within the MHHREA definition of a health disparity population. However, initiatives addressing population disparities often exclude disability.^{239, 240, 241} Recognition as a health disparity population is important because the MHHREA directs the National Institute of Health’s National Center on Minority Health and Health Disparities (now the National Institute on Minority Health and Health Disparities) to conduct and support research with respect to minority health conditions and other populations with health disparities. Perhaps other federal agencies and offices could consider designating people with disabilities as a priority population for research.²⁴²

Conclusion

This report highlights how existing federal laws and policies could be leveraged by states, communities, and other sectors to reduce barriers to primary and preventive care (DH-4); reduce barriers to local health and wellness programs (DH-8); increase access to leisure, social, or community activities (and indirectly, to religious activities) for individuals with disabilities (DH-13); and generate better disability data needed to inform and support efforts to reach these and other disability and health objectives (DH-1). This report also features specific, real-world examples of legal community strategies or interventions, or Laws and Policies in Action, to illustrate how law and policy is used to make progress on each of these objectives. However, much work needs to be done to meet the goals of the HP2020 objectives included in this report and to begin making progress on goals for the next decade—to ensure that data is collected and analyzed, that opportunities are provided and barriers removed, and ultimately, to improve the health and wellness of individuals with disabilities.

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