

Health Care Access and Quality for People with Disabilities

A Toolkit for
Interagency Collaboration



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Introduction

Health care access and quality are major factors contributing to health disparities for people with disabilities in the United States. While people with disabilities represent over 13 percent of the population, research investigating issues with access to quality health care for this group is still in its early stages. Access and quality issues differ across disability types, and more research is needed to evaluate these differences and potential solutions. Few evidence-based interventions have been developed to increase access to health care for people with disabilities, and federal interagency collaboration is needed to spur additional research and innovation in this field.

About the ICDR

The Interagency Committee on Disability Research (ICDR) was authorized by the amended 1973 Rehabilitation Act to coordinate federal research efforts surrounding disability, independent living, and rehabilitation research, to include assistive technology research and universal design. The ICDR's vision is to be widely recognized for facilitating and coordinating federal interagency efforts and for promoting collaborative relationships that maximize the best use of federal resources for disability, independent living, and rehabilitation research.

Strategic Plan Goals

The three goals designated in the [ICDR's 2018–2021 Government-Wide Strategic Plan](#) are:

Goal #1: Improve interagency coordination and collaboration in four thematic research areas: transition, economics of disability, accessibility, and disparities.

Goal #2: Develop a government-wide inventory of disability, independent living, and rehabilitation research.

Goal #3: Promote ongoing stakeholder input on gaps and priorities for disability, independent living, and rehabilitation research.

To address Goal #1 (improve interagency coordination and collaboration), the ICDR initiated a focus on creating materials to promote and encourage collaboration related to accessibility, especially as it relates to health care access and quality for people with disabilities. Health care access and quality was identified as a priority by the Health, Functioning, and Wellness Working Group in its 2015 [list of problem statements](#) in the health and wellness field. In 2020, the ICDR released a toolkit on [Health Disparities and Disabilities in Research](#), which this toolkit builds upon.

Purpose of the Toolkit

This toolkit offers resources for future federal research on addressing the issues people with disabilities face with health care access and quality that result in health disparities. It provides an overview of federal programs and research, best practices, and areas for future research on health care access and quality for people with disabilities.

Background

Despite misperceptions that people with disabilities inevitably experience poor health, health status is separate from disability. In the mid-2000s, the Centers for Disease Control and Prevention (CDC) released data showing that adults with disabilities are 4 times more likely to report fair or poor health than people without disabilities (CDC, 2008). Since then, research on health disparities has grown significantly. People with disabilities are more likely to be obese, be diagnosed

Adults with disabilities are 4 times more likely to report fair or poor health than people without disabilities.

with diabetes, or smoke than people without disability (Peters, 2021). Research on health disparities for minority racial and ethnic groups has also found that health disparities are amplified for people of color with disabilities. A study found that for people who identify as Black, 11 percent of people without disabilities self-reported fair or poor health, while 50 percent of people

with a disability reported fair or poor health (Drum et al., 2011). Despite the growing literature on health disparities, research on the cause of these health disparities and interventions to address these disparities for people with disabilities has been limited. Issues with access to quality health care for people with disabilities persist in a variety of areas and contribute to these major health disparities.

Health Care Access for People with Disabilities

People with disabilities represent 13.2 percent of the United States' population, yet inaccessibility is still a pervasive issue in the U.S. health care system (Houtenville & Rafal, 2020). People with disabilities are 2.5 times more likely to forego or delay care due to the cost of health care, despite having higher rates of insurance than

those without disabilities (Krahn et al., 2015). While strides have been made since the passage of the Affordable Care Act, a study found that people with disabilities still face limited prescription coverage, limited provider networks, steep out-of-pocket costs, a lack of timely and accurate plan information, and difficulty with transportation to appointments (Hall et al., 2019).

The population of people with disabilities is extremely diverse, with access issues varying by subgroup and disability type. A study found that people with cognitive disabilities have significantly poorer access to health insurance than people with other types of disabilities (Horner-Johnson et al., 2014). The same study found that

People with disabilities are 2.5 times more likely to forego or delay care due to the cost of health care.

people with physical disabilities are more likely than people with other disability types to report forgoing or delaying necessary care. A study on people with long-term physical disabilities found that physical function, quality of life, status of living with a spouse, diagnostic condition, and sex (male) were significantly associated with experiencing health care access barriers (Wong et al., 2019). The participants' most

cited reason for delaying care was inability to afford out-of-pocket expenses. More research is needed to determine how to increase health care access for these subpopulations of people with disabilities.

There are three main “axes of access” to consider when working to improve access to health care for people with disabilities: **(1) physical access; (2) policy and procedural access; and (3) communication access** (Lagu et al., 2014). Physical access refers to the health care environment and setting and ensuring that it is free of physical barriers. Policy and procedural access describes the accessibility of scheduling, staffing, program and policy design, and administrative resources.

Communication access refers to the ability of a patient with a disability to communicate with providers, understand their care, and arrange for follow-up. To address these barriers to health care for people with all disability types, it is important that the disability research community collaborate to develop innovative solutions for ensuring access and quality.

PHYSICAL ACCESS

One of the major barriers for people with disabilities in accessing health care is physical access. Despite progress with the passage of the Americans with Disabilities Act (ADA), inaccessible medical equipment persists, such as exam

Only 3.6 percent of providers had an accessible weight scale, and only 8.4 percent had a height-adjustable exam table.

tables, weight scales, and imaging technologies (Peacock et al., 2015). This prevents people with physical disabilities from accessing the most basic of health services and preventive care, such as getting weighed. A study by five California health plans found that only 3.6 percent of their providers had an accessible weight scale, and only 8.4 percent had a height-adjustable exam table (Mudrick et al., 2012).

A study of four cities in the U.S. found that 22 percent of medical practices could not accommodate a patient in a wheelchair (Lagu et al., 2013). A study of patients with long-term physical disabilities found that 69 percent of participants reported their most frequent barrier to health care was medical offices not having a safe transfer device to move them to an exam table (Wong et al., 2019). While telehealth can assist with increasing access in some cases, there are many essential services that remain in-person and must be physically accessible, such as lab services and annual physical exams.

Even when medical facilities are accessible, inaccessible public transportation can cause access issues (Peacock et al., 2015). A study found that people with disabilities face longer trips to medical care than people without disabilities, despite similar access to private vehicles and similar total distance traveled (Brucker & Rollins, 2016). A recent study also confirmed that people with disabilities spend more total time in medical care than patients without disabilities, which cannot be accounted for by sociodemographic disparities or poorer self-rated health (Shandra, 2019).

Cost of equipment and limited space are two major barriers physicians face with offering accessible medical equipment. However, a recent study found that even when providers did have accessible equipment, they did not always use it when examining patients with disabilities (Agaronnik et al., 2019). The participating physicians reported inadequate payment for extra time required to care for people with disabilities, which could contribute to this issue.

POLICY & PROCEDURAL ACCESS

Another major barrier to health care access is the design of health care policies and procedures. The complicated health insurance system in the United States often increases difficulty with accessing health care. While health insurance rates are comparable between people with and without disabilities, their type of insurance coverage differs. Around 75 percent of people without disabilities have private insurance, while fewer than 50 percent of people with severe disabilities have private insurance (Krahn et al., 2015). While public insurance covers many people in this category who lack private insurance, people with emotional disabilities face the largest coverage gaps with 28 percent of people uninsured.

Policies and procedures related to telehealth represent additional potential barriers for people with disabilities when accessing care. While telehealth platforms offer a unique solution to physical inaccessibility for people with disabilities, this industry has often considered accessibility too late in the design process. The rapid transition

to telehealth platforms during the COVID-19 pandemic has caused access issues for people with disabilities due to inaccessible or unusable health IT. Even when telehealth platforms are designed accessibly, providers who are using the system may not understand and address accessibility issues (Annaswamy et al., 2020).

Policies surrounding public health and emergency preparedness illustrate another major area of health care that has lacked inclusion for people with disabilities. These services and systems were designed without collecting data on or considering the needs of people with disabilities (Peacock et al., 2015). During Hurricane Katrina, 38 percent of people who did not evacuate to safety had a mobility disability or were a care provider for someone with a disability (Krahn et al., 2015). The COVID-19 pandemic has further highlighted this historical lack of inclusion in emergency and public health planning. More data collection and research is needed in this field.

COMMUNICATION ACCESS

Communication barriers present another category of issues with access to health care for people with disabilities. Deaf patients face issues accessing health care due to communication barriers with providers and a lack of practices offering sign-language interpreters (Peacock et al., 2015). A study where ASL interpreters observed interactions between deaf patients and their providers found that in nearly half of appointments, patients did not understand providers' instructions (Hommes et al., 2018). Other patients who might experience communication access issues in the health care system are those with cognitive disabilities who may not have access to plain language explanations regarding preventive care, health conditions, or their insurance coverage.

During a study of providers' interactions with deaf patients, patients did not understand the providers' instructions in nearly half the appointments.

Another major communication barrier is the stigmatizing attitudes of providers about specific disabilities, such as mental health or intellectual disabilities (Peacock et al., 2015). A 2019 review by the National Council on Disability (NCD) found several examples of doctors misperceiving people with disabilities as experiencing a low quality of life, when most report a high quality of life and happiness (NCD, 2019). These misperceptions may result from physicians failing to separate the patients' underlying disability from their acute symptoms. Ultimately, these attitudes and misperceptions about people with disabilities can result in patients avoiding and/or delaying care and can affect the quality of care provided.

Health Care Quality for People with Disabilities

Many of the barriers to health care access also directly impact the quality of care people with disabilities receive. Stigma and misperceptions about people with disabilities can lead to lapses in quality of care for people with disabilities when compared to those without disabilities. Misperceptions about lower quality of life can lead to prematurely rationing or withdrawing care, another important issue highlighted during the COVID-19 pandemic. During 2020, multiple cases of disability discrimination in health care during the pandemic were filed with the Oregon State Senate by Disability Rights Oregon (Fuentes et al., 2021). In April 2020, a complaint was filed with the Office of Civil Rights in the U.S. Department of Health and Human Services (HHS) regarding ventilator rationing guidelines that categorically excluded individuals with profound intellectual disabilities in Alabama (HHS, 2020).

However, instances of discrimination for people with disabilities in health care occurred prior to the pandemic as well. A study of patients with Stage I lung cancer found that patients with disabilities were less likely to receive surgery than people without disabilities (Iezzoni et al., 2008). A study of preventive care services for people with disabilities found that while the relationship between disability severity and receipt of services is complex, women with more severe disabilities received

fewer Papanicolaou tests and clinical breast examinations than women with less severe disabilities (Diab & Johnston, 2004). The study also found that in the year examined, people with the most severe level of disabilities received vaccinations least frequently. When looking at barriers to physical examination, a study found that nearly half of health administrators acknowledged that part of an exam was skipped by physicians when an access barrier was encountered (Pharr, 2013). However, this is unacceptable by the standards outlined in the ADA, as people with disabilities should receive medical services that are equal to those received by people without disabilities. More research into health care quality for people with disabilities is needed to determine what improvements can be made to health disparities by addressing these major differences in care.

HEALTH CARE QUALITY FOR WOMEN WITH DISABILITIES

Women with disabilities face issues with the quality of health care they receive when compared to nondisabled women. One study found that women with cognitive disabilities received fewer cervical cancer and breast cancer screenings compared to nondisabled women (Parish et al., 2006). Another study found that women with mobility limitations are less likely to be current on cervical cancer and breast cancer screenings than women without disabilities (Krahn et al., 2015). Additionally, women with disabilities reported being less satisfied with their medical care than nondisabled women (Parish et al., 2006). Another study found that women with disabilities receiving SSDI and Medicare had lower rates of breast-conserving surgery, received radiotherapy less frequently, and had lower survival rates than women without disabilities (McCarthy et al., 2006). Additional focus is needed on increasing health care access for women with disabilities to address these differences in receipt of quality health care.

Relevant Legislation on Health Care Access & Quality for People with Disabilities

ARCHITECTURAL BARRIERS ACTS OF 1968

The **Architectural Barriers Act of 1968** created standards for the built environment to ensure that people with disabilities have equal access (U.S. Access Board, n.d.). This law states that all facilities using federal funds built after August 12, 1968, or leased by the federal government must be accessible to people with disabilities. Facilities built prior to this law are typically not covered; however, if a federal lease begins after this date the law typically applies. The U.S. Department of Defense, the U.S. Department of Housing and Urban Development, the General Services Administration, and the U.S. Postal Service all enforce the Architectural Barriers Act. The details provided in the Act require certain standards and specifications to be met for elements such as ramps, parking spaces, bathrooms, fire alarms, signs, etc.

THE REHABILITATION ACT OF 1973

The **Rehabilitation Act of 1973** bans discrimination based upon disability in federal programs, as well as programs receiving federal assistance, federal employment, and federal contractors (U.S. Department of Justice [DOJ], 2020). This law was the first major piece of legislation to protect the civil rights of individuals with disabilities. The Rehabilitation Act outlines grants to states for vocational rehabilitation, supported employment, independent living, and personal assistance. It has several different sections, all aimed at rights, advocacy, and protections for individuals with disabilities. The Rehabilitation Act also established the U.S. Access Board, an independent federal agency that develops accessibility guidelines and standards for the physical environment, transportation, communication, medical diagnostic equipment, and information technology to ensure that people with disabilities have equal access (U.S. Access Board, n.d.). Section 504 of the Act prohibits discrimination based on disability by programs receiving federal assistance. This includes any

health care practitioners who receive federal reimbursement funds from Medicare or Medicaid (American Medical Association [AMA], 2018).

THE AMERICANS WITH DISABILITIES ACT OF 1990

The **Americans with Disabilities Act (ADA) of 1990** is the federal civil rights law that protects people with disabilities from discrimination in a wide range of activities, including medical services (AMA, 2018). The ADA defines disability as “a physical or mental impairment that substantially limits one or more major life activities, a person who has a history or record of such impairment, or a person who is perceived by others as having such an impairment” (DOJ, 2020). Title I prohibits employment discrimination, which extends to employer-sponsored health insurance (Rosenbaum, 2007). Title II of the ADA extends the reach of the Rehabilitation Act of 1973 by prohibiting the denial of benefits in public services and programs and creating a standard of “equality of opportunity” rather than just nondiscrimination. In regards to health care, Title III is the most far-reaching ADA title. It prevents discrimination in private health care services by considering them public accommodations, whether or not they receive federal funding. Title III also lists the ADA Standards for Accessible Design requirements for construction and alteration of medical facilities and outlines minimum requirements (AMA, 2018).

THE PATIENT PROTECTION & AFFORDABLE CARE ACT OF 2010

The **Patient Protection and Affordable Care Act (ACA)**, passed in 2010, expands access to health care for many Americans and mandates standards for essential benefits. Section 1557 specifically prohibits health care clinicians who receive federal funding from refusing to treat an individual based on disability (AMA, 2018). One of the most important provisions of the law was preventing insurers from rejecting applications based upon preexisting health conditions (Peacock et al., 2015). The ACA requires that people with disabilities receive equal access to participate in the health care system and attempts to reduce disproportionate costs for health care for people with disabilities. This law addressed health care costs

through mandating caps on annual out-of-pocket expenditures, lifting total lifetime limits, and expanding Medicaid. Another important provision of the ACA for people with disabilities is the authorization to collect information on disability status as part of federal health care surveys and programs in Section 4302 (Krahn et al., 2015). The ACA also calls for the creation of standards of accessible medical equipment in Section 4203, which the U.S. Access Board and the Food and Drug Administration work together to develop (Peacock et al., 2015). In Section 5307 of the ACA, federal funding is authorized for training health care professionals in disability cultural competence and on understanding the needs of people with disabilities.

Federal Research & Resources on Health Care Access & Quality for People with Disabilities

Interagency Collaboration

FEDERAL COLLABORATION ON HEALTH DISPARITIES RESEARCH

In 2006, the Federal Collaboration on Health Disparities Research (FCHDR) was established and co-led by the ICDR (then housed in the U.S. Department of Education) together with the HHS's Health Disparities Council and the National Institutes of Health's National Center on Minority Health and Health Disparities. The goal of the FCHDR was to provide critical leadership for active collaboration across federal agencies to plan health disparities research, including funding, monitoring, and dissemination of findings. Health care access is one of the risk factors for health disparities identified by the FCHDR and discussed in [this essay](#). A detailed description of the FCHDR's accomplishments and collaborative efforts is available in [this report](#).

U.S. DEPARTMENT OF JUSTICE & U.S. DEPARTMENT OF HEALTH & HUMAN SERVICES

The Disability Rights Section in the DOJ and the Office for Civil Rights in HHS collaborated to produce a joint technical assistance publication on [Access to Medical Care for Individuals with Mobility Impairments](#). This publication outlines requirements for fulfilling the ADA and answers commonly asked questions about accessibility requirements for people with mobility impairments. It also provides detailed information about accessible examination rooms and accessible medical equipment.

U.S. DEPARTMENT OF LABOR & U.S. DEPARTMENT OF HEALTH & HUMAN SERVICES

The Office of Disability Employment Policy within the U.S. Department of Labor hosted a [policy roundtable](#) in 2014 on career trends and best practices for health professionals with disabilities. The Office of Disability Employment Policy collaborated with the National Organization of Nurses with Disabilities, and the event was co-sponsored by the U.S. Department of Labor's Employment and Training Administration and the Health Resources and Services Administration within HHS. The roundtable brought together over 40 key employers, federal and state policy-makers, researchers, and educational administrators from around the country. This event recognized the increasing need for health care workers and identified people with disabilities as an untapped talent pool with the ability to improve this shortage and offer unique insights into patient care. The main goal of this event was to establish collaboration and promote the employment of people with disabilities in the health care industry.

National Council on Disability

The NCD is an independent federal agency that, in collaboration with people with disabilities, advises the President, Congress, and other federal agencies on issues that affect the disability community. The Council engages in a variety of roles to advance equal opportunities for people with disabilities, to include convening stakeholders for input and recommendations, gathering and analyzing data, engaging in current debates and agendas, developing solutions to both long-term and emerging challenges, and offering tools to further effective implementation (NCD, 2020).

In 2009, the NCD released a report, [The Current State of Health Care for People with Disabilities](#), which provides an overview of issues with access to health care for people with disabilities at the federal level. The report also discusses deficiencies in the roles of key non-federal stakeholders and provides ideas for future reforms to increase health care access for people with disabilities. The NCD offers

recommendations in the following areas: (1) research; (2) professional education, training, and technical assistance; (3) monitoring, oversight, and accountability; and (4) improving systemic access to health care services and programs. This report identifies specific, key recommendations for a wide range of federal agencies to improve the health of people with disabilities.

The NCD released the [Bioethics and Disability Report Series](#) in 2019, exploring many of the biases and assumptions that people with disabilities face in a variety of critical health care issues. The reports cover the following topics: (1) organ transplantation; (2) physician-assisted suicide; (3) genetic testing; (4) quality-adjusted life years; and (5) medical futility. This series draws from original research, interviews, literature reviews, media reports, and legal analysis for each topic and makes recommendations for lawmakers and policymakers.

U.S. Access Board

The U.S. Access Board is an independent federal agency that creates accessibility guidelines on a variety of issues. The concept of universal design is incorporated into their accessibility guidance. The Access Board was originally created in 1973 to ensure people with disabilities had access to federally funded facilities, but it now creates and maintains information on design criteria for the physical environment, vehicles, telecommunications equipment, medical equipment, and information technology. It also provides training resources on accessibility and enforces the accessibility standards for federally funded facilities. The U.S. Access Board maintains the [Medical Diagnostic Equipment Accessibility Standards](#) and has led efforts to develop standards for [prescription drug container labels](#).

U.S. Department of Health & Human Services

ADMINISTRATION FOR COMMUNITY LIVING

The [Administration for Community Living \(ACL\)](#) aims to help older adults and people of all ages with disabilities to “live where they choose, with the people they choose, and with the ability to fully participate in their communities” (ACL, 2020a). ACL funds a variety of community-level targeted programs for older adults and people with disabilities, as well as research and education efforts.

In 2020, ACL announced a funding opportunity to develop efforts to educate medical and allied health professionals on intellectual and developmental disabilities. The goal of this grant is to increase the intellectual and developmental disability-specific knowledge, skills, attitudes, and competence of health care professionals by incorporating this into education programs. Ultimately, ACL aims to improve health equity for people with disabilities and as a result increase their life expectancy. More information is available about this project [here](#).

National Institute of Disability, Independent Living, & Rehabilitation Research

The National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) is the primary disability research agency in the federal government. NIDILRR’s aim is to produce new knowledge and promote its effective use to improve the abilities of people with disabilities to perform their daily activities (ACL, 2020b). In addition, NIDILRR’s research hopes to expand the capacity for society to provide opportunities and accommodations for people with disabilities. NIDILRR examines a wide range of disabilities across the lifespan, including all aspects of a living with a disability. The following are a selection of recent and ongoing NIDILRR-funded grantee projects related to aging with disability.

Americans with Disabilities Act National Network

The [ADA National Network](#) offers information, guidance, and training on ADA implementation to fulfill its mission to “assure equality of opportunity, full participation, independent living, and economic self-sufficiency for individuals with disabilities.” The Network consists of 10 regional ADA Centers and one collaborative research grant, the ADA Participatory Action Research Consortium. The Network focuses on accessibility in a variety of fields, including health care. NIDILRR funding for these Centers has led to a variety of research on health care accessibility. A [study](#) in 2020 examined the inclusion of accessibility information for patients in electronic health records. A 2019 [study](#) examined the accessibility of primary care offices and their medical equipment. The ADA National Network also develops fact sheets and other educational tools about accessibility, including ones on [health care and the ADA](#), [accessible medical examination equipment](#), and [accessible medical diagnostic equipment](#). In light of the COVID-19 pandemic, the Pacific ADA Center released a brief on [accessibility at drive-thru medical sites](#).

Collaborative on Health Reform & Independent Living

The NIDILRR-funded [Collaborative on Health Reform and Independent Living](#) investigates a wide range of issues related to health care, health insurance, and health outcomes for people with disabilities. It is comprised of a group of academic researchers and disability advocates committed to creating public policies that address the needs of people with disabilities. The Collaborative’s mission is “to provide disability stakeholders with accurate, current, accessible and actionable information on how changes in the US federal health policy, such as the Affordable Care Act of 2010, affect community living and participation for working-age adults with disabilities.” The [Disability Stories Project](#) is a video interview series released by the Collaborative to highlight the struggles of people with disabilities with the U.S. health care system and advice for how to reform it.

Rehabilitation Engineering Research Center (RERC) on Technologies to Support Aging-in-Place for People with Long-Term Disabilities (TechSAge RERC II) (2018 – 2023)

TechSAge RERC II is a NIDILRR-funded project that seeks to advance technology-based interventions to facilitate aging-in-place and reduce secondary conditions among people aging with long-term disabilities. This Center’s work includes research, as well as training and dissemination activities to promote this mission. In 2020, TechSAge RERC II released a [study](#) on access to daily activities for adults aging with long-term physical disabilities, to include health management activities such as accessing health information, attending health care appointments, and monitoring health.

Rehabilitation Research & Training Center (RRTC) on Community Living Policy (2013 – 2018)

The **RRTC on Community Living Policy** at the University of California San Francisco investigated and identified ways to improve long-term services and supports (LTSS) and improve data collection on community living policy. The RRTC on Community Living Policy worked to develop a strategic plan for research on LTSS and community living. The RRTC also implemented the College of Personal Assistance and Caregiving, an online training program for both paid and family caregivers. As part of this RRTC’s research, the Center released a [paper](#) examining disability health disparities before and after ACA implementation. This study found that the ACA improved overall access to health care and reduced several disparities, yet many disparities still persist. One of the major disparities for people with disabilities post-ACA that this study found is a higher risk of delaying or foregoing care.

RRTC on Disability Statistics & Demographics (StatsRRTC) (2018 – 2023)

The **StatsRRTC** aims to bridge the divide between producers and end users of statistics related to disability. The RRTC’s projects focus on the collection of disability statistics and seek to (1) develop recommendations and tools to improve the identification of the population with disabilities and measurement of services

and (2) conduct experiments to test alternative survey methods. Improvements to collecting disability statistics and demographics have implications for examining access to health care for people with disabilities.

AGENCY FOR HEALTHCARE RESEARCH & QUALITY

The [Agency for Healthcare Research and Quality \(AHRQ\)](#) is a federal agency mandated to improve the safety and quality of health care in the United States. AHRQ develops knowledge, tools, and data necessary to initiate improvements in health care that benefit Americans, health care professionals, and policymakers (AHRQ, 2018). The AHRQ website offers several research-based tools and a variety of datasets. AHRQ hosts information on quality measures for home health agencies, nursing homes, and hospices. Additionally, AHRQ provides patient safety resources to help prevent avoidable complications in hospitals, emergency departments, long-term care facilities, and ambulatory settings. On AHRQ's website, it has a [page](#) dedicated to resources for addressing health disparities and improving quality. It lists resources both by federal agency and by specific population group, including people with disabilities. In 2012, AHRQ published a report, *Quality Improvement Measurement of Outcomes for People with Disabilities*, detailing known evidence for health plans, providers, and policymakers to make the necessary changes to close the quality gap for people with disabilities. This report gathers information on what occurs in clinical practices for people with disabilities on a day-to-day basis and how reforms can be made to address quality gaps.

Each year AHRQ releases the National Healthcare Quality and Disparities Report, which assesses the health care system in the United States on over 250 measures of quality and disparities. This report describes six main aspects of quality: patient safety, person-centered care, care coordination, effective treatment, healthy living, and care affordability. While the report does not focus specifically on people with disabilities, it includes a section on beneficiaries dually eligible for Medicare and Medicaid. The 2019 version of the report is available on the [AHRQ website](#).

CENTERS FOR DISEASE CONTROL & PREVENTION

The CDC works to protect the health and safety of Americans from diseases both foreign and domestic (CDC, 2019). It supports increasing the health security of the country through critical research and health information. The CDC has been involved in promoting health care access for people with disabilities across the lifespan since 1988 (CDC, 2020). Its site on [Disability and Health](#) hosts a variety of resources for people with disabilities and health care providers on inclusion, research, grants, and resources. In addition, the CDC outlines [common barriers](#) that people with disabilities face when accessing health care and provides a [comprehensive list of resources](#) for facilitating inclusion in health care access. The CDC published a [paper](#) on the prevalence of disabilities and health care access by disability type in 2018. It also supported a paper in 2020 on educating health professionals on disability, *[A Call to Action: Preparing a Disability-Competent Health Care Workforce](#)*.

National Center on Birth Defects & Developmental Disabilities

The National Center on Birth Defects and Developmental Disabilities (NCBDDD) aims to improve the health and well-being of the country's most vulnerable populations (NCBDDD, 2021). The NCBDDD's mission focuses on four main themes: (1) saving babies through surveillance, research, and prevention of birth defects and infant disorders; (2) helping children live to the fullest by understanding developmental disabilities; (3) protecting people by preventing the complications of blood disorders; and (4) improving the health of people living with disabilities (NCBDDD, 2021). The following is an example of a project funded by this Center related to health care access and quality for people with disabilities.

Review of Oral Health Interventions for People with Intellectual Disabilities (2012 – 2015)

A project funded by the NCBDDD at the University of Massachusetts Medical School partnered with the American Academy of Developmental Medicine and Dentistry

to investigate interventions that address oral health disparities for people with intellectual disability. This project built upon the knowledge that people with intellectual disability are at greater risk for tooth decay and other oral health complications and face barriers such as a lack of trained clinicians and attitudes that diminish importance of oral health for this population. This project assembled a panel of experts to identify and review a range of interventions to increase access to oral health care for people with intellectual disabilities. A publication from this grantee's work is available [here](#).

CENTERS FOR MEDICARE & MEDICAID SERVICES

The Centers for Medicare & Medicaid Services (CMS) is a federal agency in HHS that administers the Medicare program and partners with states to administer Medicaid, the Children's Health Insurance Program, and health insurance standards (CMS, 2020). CMS is also responsible for ensuring quality standards in health care facilities, oversight of the HealthCare.gov platform, and clinical laboratory quality standards. With the Medicare and Medicaid programs serving a significant percentage of people with disabilities, CMS recognizes the issues that people with disabilities may face when seeking medical care. CMS released *Getting the Care You Need: A Guide for People with Disabilities*, which offers a quick and easy reference tool for patients to understand their right to accessible health care. It includes important phone numbers, checklists, and worksheets.

In 2017 CMS released *Increasing Physical Accessibility of Health Care Facilities*, which provides an overview of accessibility laws and regulations and discusses mechanisms for increasing accessibility. The report *Modernizing Health Care to Improve Physical Accessibility* builds on this, offering resources on regulations and guidelines, assessment tools, and methods to support improvements for use by health care providers to improve the accessibility of their programs and facilities. For information on Medicaid enrollees with disabilities, CMS released an [analytic brief](#) detailing these enrollees' health care experiences.

CMS Videos on Navigating Health Care with a Disability

To accompany *Getting the Care You Need*, CMS also released two videos on navigating health care with a disability. The [first video](#) focuses on people with disabilities and includes several personal experiences with the health care system. The [second video](#) focuses on the perspectives of health care providers, offering recommendations for how to improve quality of care for patients with disabilities.

Office of Minority Health

The CMS Office of Minority Health is one of the eight offices within HHS that works to eliminate health disparities for minority populations. One of the minority populations this office focuses on is people with disabilities. The Office of Minority Health ensures that people with disabilities have equal access to health care by providing tools and resources for patients to understand their rights and access services. This office updates a [webpage](#) with resources and tools including videos, issue briefs, and studies for health care providers to learn how to improve accessibility in their practices. One of its [briefs](#) provides an overview of how disability affects access to care for beneficiaries dually eligible for Medicare and Medicaid.

NATIONAL INSTITUTES OF HEALTH

The National Institutes of Health (NIH) is the country's main medical research agency. The NIH works to pursue "fundamental knowledge about the nature and behavior of living systems and the application of the knowledge to enhance health, lengthen life, and reduce illness and disability" (NIH, 2017). The NIH develops and maintains resources to help the nation prevent disease and improve health.

Additionally, promoting scientific integrity, public accountability, and social responsibility are other integral parts of the NIH’s mission.

All of Us Research Program

The [All of Us Research Program](#) is an NIH initiative that began in 2018 to build one of the most diverse health databases in history. The program is recruiting one million participants from a wide range of backgrounds and will use the data to improve treatments and prevent disease for the U.S. population. Participants will share health information about themselves over many years to improve the precision of treatment. This initiative includes people with disabilities and is working to improve the health of people with disabilities in the U.S. The All of Us program partners with the American Association on Health and Disability (AAHD) to work on the data related to disability. Webinars and additional information about this program can be found on the AAHD [website](#).

National Institute of Child Health & Human Development

The Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD) began in 1962 to examine human development during the life course, with a focus on understanding disabilities and events that occur during pregnancy. NICHD funds research efforts that work to save lives, improve wellbeing, and reduce societal costs associated with illness and disability. NICHD’s mission is “to lead research and training to understand human development, improve reproductive health, enhance the lives of children and adolescents, and optimize abilities for all” (NICHD, 2019).

Surveying Physicians to Understand Health Care Disparities Affecting Persons with Disability & Identify Approaches to Improve Their Care (2018 – 2021)

An NICHD-funded [project](#) examined the factors that contribute to health care disparities for persons with disabilities by determining the perspective of physicians in outpatient settings. The goal of this project was to develop feasible

recommendations to improve health care delivery to people with disabilities. This study was the first to examine the perspective of physicians nationwide on caring for people with disabilities and to provide suggestions to close the gap of health disparities for people with disabilities. This grantee released a [paper](#) in 2019 examining the knowledge of practicing physicians about their legal obligations when caring for patients with disabilities. Interviewees in this study reported having minimal training about disability and demonstrated superficial or incorrect understanding of legal responsibilities related to treating patients with disability, indicating further education for health care providers on disability is needed.

National Institute on Deafness & Other Communication Disorders

The National Institute on Deafness and Other Communication Disorders (NIDCD) conducts and supports research on normal and disordered processes of hearing, balance, taste, smell, voice, speech, and language (NIDCD, n.d.). The goal of the NIDCD is to improve the quality of life for people with hearing loss and other communication disorders. Over the past 10 years, the NIDCD has prioritized research on improving access and affordability of hearing health and released [this statement](#) about its research. The NIDCD currently supports [19 projects on accessible and affordable hearing health care](#).

National Library of Medicine

The National Library of Medicine (NLM) within NIH was founded in 1836 and is the world's largest biomedical library (NLM, 2021). NLM maintains a vast amount of information and resources in both electronic and print format. Additionally, NLM conducts research, development, and training related to biomedical informatics and health information technology.

Partnering with Women with Disabilities to Develop a Health Information Website (2017 – 2021)

This project is a partnership between NLM and the Center for Research on Women with Disabilities (CROWD) at the Baylor College of Medicine. As women with disabilities are living longer with a better quality of life due to medical advances, issues persist with disseminating life-saving information about women’s health to women and their families. CROWD has documented information about disparities in access to health care for women with disabilities for the past 25 years; however, this project aims to expand access to this information and disseminate it widely. This grantee partners with consumers, clinicians, researchers, and librarians to develop an online information resource on women’s health in the context of disability. The goal is to advance the reproductive and pelvic health of women with disabilities through a website that is fully interactive and searchable by women with disabilities. It will also include an accompanying training program to increase health literacy, improve health outcomes, and reduce health disparities for women with disabilities. More about this project is available [here](#).

OFFICE OF DISEASE PREVENTION & HEALTH PROMOTION

The Office of Disease Prevention and Health Promotion (ODPHP) in HHS was created in 1976 and assists with setting the nation’s public health objectives, programs, services, and education activities to improve the health of all Americans (ODPHP, 2020). ODPHP hosts information about Healthy People 2030, discussed below, and [MyHealthfinder](#), which helps consumers find important health information.

Healthy People Initiative

The Healthy People initiative began in 1979 to address the nation’s public health priorities. Its goal is to help individuals, organizations, and communities improve overall health and well-being. The Healthy People 2020 initiative identified that people with disabilities are more likely than people without disabilities to experience difficulties or delays in care. The disability-related objectives for Healthy

People 2020 can be viewed [here](#). Healthy People 2030 builds on what was learned in the last iteration of this initiative and expands objectives on disability, including mental health, intellectual disability, traumatic brain injury, arthritis, and sensory and communication disorders. The disability-related objectives for Healthy People 2030 are available [here](#).

U.S. Department of Justice

DOJ is a federal executive agency responsible for enforcing the law and defending the interests of the United States based upon the law. DOJ is responsible for enforcing the ADA, a leading piece of legislation on accessibility standards. In 2010, DOJ revised the ADA standards and released the *2010 ADA Standards for Accessible Design*. These standards outline the minimum requirements that state and local government facilities, public accommodations, and commercial facilities must follow when constructing and designing buildings and other types of facilities. When buildings, including health care facilities, do not comply with these minimum standards, DOJ's role is to investigate and enforce the law.

In 2014, DOJ released a publication, *Effective Communication*, which provides information on how Title II entities (state and local governments) and Title III entities (businesses and nonprofit organizations serving the public) can effectively communicate with people who have communication disabilities. This publication is designed to help these entities understand how the rules of the ADA apply to them. Health care providers can use this guide to assist with communicating with patients with communication disabilities.

BARRIER-FREE HEALTH CARE INITIATIVE

In 2012, DOJ announced the *Barrier-Free Health Care* Initiative, a partnership between the U.S. Attorney's offices and the Civil Rights Division to address enforcement of the ADA in the health care sector. This initiative was announced

on the 22nd anniversary of the ADA and seeks to ensure people with disabilities, especially those who are deaf or hard of hearing, have equal access to medical information in a way that is understandable to them. A main issue this initiative focused on is ensuring physical access to medical buildings. A list of settlements related to this initiative can be found [here](#). DOJ also has a [blog post](#) with more information about this initiative and how it is making an impact.

U.S. Department of Veterans Affairs

The U.S. Department of Veterans Affairs (VA) is a federal executive agency responsible for administering benefits and services earned by veterans of the U.S. military. The VA operates in four main areas: (1) veteran health care; (2) veteran benefits administration; (3) national cemeteries; and (4) preparation for war, emergencies, and disasters (VA, 2020). The VA works to improve access to health care for veterans with a variety of needs, including disability. Some of the [main programs](#) the VA has to increase health care access include: (1) the Veterans Transportation Service; (2) its telehealth program; and (3) specialized groups to study, understand, and improve care for subgroups of veterans.

Best Practices to Address Health Care Access & Quality Disparities for People with Disabilities

Research in the field of health care access for people with disabilities is still emerging, meaning few evidence-based practices are available. Researchers and disability organizations are working to develop best practices in this field. Several initial recommendations from researchers and federal organizations are presented in the following section regarding how to improve health care access for people with disabilities.

Three Ways to Improve Health Care Quality for People with Disabilities

Reynolds and Wieseler (2019) highlight three main ways that health care quality can be improved for patients with disabilities: **(1) connections with disability communities; (2) collaboration in care; and (3) disability humility.** Forming connections with disability communities is an important way for health care providers to improve outcomes for patients with disabilities. The authors highlight the Centers for Independent Living as important resources to draw from, offering a wide range of services, equipment recycling programs, and a variety of other programs at no cost to participants. Making referrals to a local Center for Independent Living can significantly benefit patients. For health care professionals caring for people with disabilities, collaboration with the patient is another essential way to improve health outcomes for this population. While health care providers may not be used to partnering with patients in such a way, it can be a valuable way to discover relevant information or best ways of communicating with the patient. Reynolds and Weisler (2019) also emphasize that providers should make sure they are not over-emphasizing or underemphasizing the patient's disability when providing care.

CMS Recommendations to Increase Physical Accessibility across the Health Care Sector

In a 2017 brief on physical accessibility in health care, CMS makes the following recommendations for increasing accessibility across the health care sector: **(1) understand the needs of people with disabilities; (2) monitor and report information on accessibility; (3) reduce financial barriers for providers; and (4) increase provider awareness and training** (Singer et al., 2017). CMS describes the opportunity to collect data on patient needs, including collecting additional information on functional limitations and accessibility in electronic health records. This can help providers get a better sense of the needs of people with disabilities. There are currently no national-level data on physical accessibility; however, CMS provides an overview of several states that collect this data as part of their Medicaid program. CMS recommends an increase in monitoring and reporting on accessibility for people with disabilities. To address the financial barriers many providers face with increasing their practice's accessibility, CMS describes several federal and state-level efforts to offset the cost of accessibility modifications. Lastly, the brief describes the pressing need to increase education and training for medical providers on disability and accessibility.

Best Practices from the ADA National Network

In 2019 the ADA released a brief on health care access and the ADA, detailing several examples of best practices and education activities the ADA centers engage in. The three best practices this brief includes are: **(1) responsibilities for effective communication; (2) generating solutions to accommodate all; and (3) training on accessibility standards.** Defining responsibilities related to effective communication mandated by the ADA can help health providers to better understand their obligation and available resources. One ADA Center provided information about the definition of a qualified interpreter, the definition of undue burden for an accommodation, and the specific language from Title III of the ADA relating to effective

communication. Another ADA assisted a health care provider with ensuring that their accommodation policy included all patients. The Center helped the practice determine ADA standards for service dogs while brainstorming ways to reduce exposure to pet dander for patients who might have allergies, such as alternative scheduling or waiting areas. Lastly, the brief describes an ADA Center contracted by a metropolitan city hospital to provide 5 days of training on the ADA Standards of Accessible Design. These examples illustrate just a few of the numerous ways providers and ADA Centers can partner to improve access to health care for people with disabilities.

Recommendations for Future Research on Health Care Access & Quality for People with Disabilities

Past and current research on health care access and quality for people with disabilities sheds light on areas that warrant further exploration. In 2015, the ICDR Working Group on Health, Functioning, and Wellness developed a list of problem statements for future research in this field. One problem statement specifically addresses health care access: “There is ample evidence of the barriers to health care and quality care, experienced by persons with disability. In general, interventions addressing disparities in health care and quality for persons with disabilities, fall short of environmental and contextual factors, makes unrealistic assumptions about equity in structural accessibility, access to resources, and cultural sensitivity. This results in reduced participation among persons with disabilities, especially those with multiple chronic conditions.”

This ICDR Working Group listed the following examples of areas for future research related to health care access:

- Access to adaptive equipment (wheelchair, accessible technology devices);
- Delaying medical care because of cost;
- Local approaches to resolving access problems;
- Developing a cultural competency model for addressing health care; and
- Measuring the cost as a nation not to successfully care for people with disabilities.

Since the development of these problem statements, research has been conducted in a few of these areas, yet additional research and data is needed. The sections below outline four important health care access areas to focus future research efforts on for people with disabilities.

Data Collection on Disability & Health Care Access

The key to understanding any research topic is the collection and synthesis of data. However, data on disability, especially in the health care system, is not routinely collected in most settings. While progress has been made on including disability as a variable in federal surveys, there is still a lack of data on health access for people with disabilities. Routinely collecting data by disability status across public health research could greatly impact the knowledge about health care access issues for people with disabilities and effective interventions (Krahn et al., 2015). Additionally, a report from CMS recommends that health care providers use the same six disability questions used in federal surveys to help with consistency in data collection (CMS, 2020). CMS also suggests that providers record information on functional limitations, activities of daily living, and instrumental activities of daily living in the patient record.

Inclusion of Disability in Cultural Competence Education for Health Care Professionals

Another important topic to address is incorporating education on disability into existing curriculum for health care professionals. It is essential that health care providers receive adequate training about how to best communicate with patients with disabilities. As the importance of cultural competence for physicians is gaining awareness, it is important to include disability culture as part of this education (Crossley, 2015). Physicians should be educated on the common social history of exclusion, stigmatization, and oppression that people with disabilities share. The traditionally used “medical model” of disability views the impairment as the

cause of any disadvantages experienced in society by people with disabilities and has been rejected by the disability community (Goering, 2015). This view focuses on a treatment or cure being the only way to rectify these societal disadvantages. Therefore, there is an understandable distrust of the medical community that must be understood by medical professionals treating people with disabilities. Medical professionals should learn about the social model of disability, which views disability as contextual, with the focus on the social and physical environments that cause disabling interactions for individuals (Berridge & Martinson, 2018). The ADA National Network recommended provider education as a key area for future research, stating that research should focus on how to build in education on disability into requirements and accreditation for medical programs (Gould et al., 2019). While some momentum has been building in this field, it is important that researchers continue to investigate how to translate best practices in disability etiquette and communication to health care providers with the goal of improving access to quality health care.

Political Engagement for People with Disabilities in Advocating for Health Reform

Another area that has been overlooked in research on health care access and disability is the role of people with disabilities engaging in self-advocacy for health reform. A study of people with disabilities, people without disabilities, and medical providers found that participants discussed political empowerment and engagement as being central elements to achieving health care reform (McClintock et al., 2018). They discussed the need to modify current paradigms, practices, and approaches to improve the quality of health care received by people with disabilities. To address the multifaceted issues with access to health care for this population, engagement with the community infrastructure and people with disabilities is necessary (Sabat et al., 2017). This type of engagement assists with identifying needs and increasing the awareness of health care access issues.

Standards & Enforcement of Accessible Medical Equipment

One topic that warrants additional research is standards and enforcement of accessible medical equipment. Highlighted at the beginning of the toolkit, several measures and studies have assessed the accessibility of health care facilities; however, future efforts should call for the systematic collection of data on accessibility of medical offices and equipment (Krahn et al., 2015). Disparities in access to health care can be addressed by future efforts to monitor compliance with the ADA and ACA and track how providers are implementing standards for accessible equipment and facilities. In 2019, a brief from the ADA National Network highlighted accessible equipment as a key area for future research related to health care access (Gould et al., 2019). This brief discusses how physical and architectural barriers continue to be a major barrier to health care access for people with disabilities. Therefore, it is essential that more research is conducted on increasing accessible medical equipment across all types of health care providers.

Resources

The following are both federal and non-federal resources related to health care access and quality for people with disabilities to encourage collaboration among federal agency staff, researchers, advocacy organizations, and people aging with disability and their caregivers. The resources are organized by type and include: (1) associations and organizations; (2) case studies and patient stories; (3) data and research tools; (4) fact sheets; (5) policy briefs; (6) provider education and guidelines; (7) research papers and reports; (8) toolkits; and (9) webinars.

Associations & Organizations

- **Achieva Disability Healthcare Initiative**

The Achieva Disability Healthcare Initiative (DHI) provides statewide leadership in Pennsylvania for improving health care access for people with disabilities. DHI engages in education, public policy, and advocacy activities, including a program for self-advocates. DHI focuses on issues related to physical and programmatic access, medical workforce development, and education. DHI's website hosts a resource center and information on their events and programs.

<https://www.achieva.info/disability-healthcare-initiative>

- **American Association on Health and Disability**

AAHD works to ensure health equity for children and adults with disabilities. AAHD engages in a variety of policy, research, education, and dissemination activities at the federal, state, and local levels. The goal of AAHD is to support full community inclusion and reduce health disparities for people with disabilities.

<https://aahd.us/>

- **Center for Research on Women with Disabilities**

CROWD works to improve the health and expand the life choices of women with disabilities. CROWD does this through promoting, developing, and disseminating health information for women with disabilities and providers. There are a wide variety of resources on CROWD's website, including an [A to Z Directory](#) on health topics affecting women with disabilities, personal stories, information on CROWD studies, and publications.

<https://www.bcm.edu/research/labs-and-centers/research-centers/center-for-research-on-women-with-disabilities>

- **Disability Rights Education and Defense Fund**

The Disability Rights Education and Defense Fund (DREDF) is a policy and civil rights law center directed by people with disabilities and parents who have children with disabilities. DREDF's mission is to advance the civil and human rights of people with disabilities through legal advocacy, training, education, and public policy and legislative development. DREDF's website offers a page on health care access, with a variety of highlights on DREDF's work in this field.

<https://dredf.org/healthcare-access/>

- **National Disability Navigator Resource Collaborative**

The National Disability Navigator Resource Collaborative (NDNRC) is part of the AAHD and offers cross-disability information and support for navigators and other ACA Marketplace enrollment specialists. It offers numerous disability and health resources on its website, with many focused on health insurance, including topical fact sheets, webinars, and links to resources on health insurance and the ACA.

<https://nationaldisabilitynavigator.org/about/>

- **National Center on Disability in Public Health**

The National Center on Disability in Public Health works to foster collaboration between public health partners and the Association of University Centers

on Disabilities' Network Centers across all states and territories. Its focus areas include health care access, developmental monitoring and screening, vaccinations, emergency preparedness, nutrition and healthy weight, sexual and reproductive health, and wellness and mental health. The National Center hosts information on these topics on its website in addition to inclusion tools and its Prepared4All training to ensure emergency preparedness planning is inclusive.

<https://nationalcenterdph.org/>

- **National Health Council**

The National Health Council, founded in 1920, is an organization that brings a diverse group of stakeholders together to drive patient-centered health policy. Information on health access and quality by topic area is available on their website, including webinars, education materials, and resources.

<https://nationalhealthcouncil.org/>

Case Studies & Patient Stories

Autistic Self Advocacy Network & Office of Developmental Primary Care—Our Lives, Our Health Care: Self Advocates Speaking Out About Our Experiences with the Medical System

This document, developed by the Autistic Self Advocacy Network in conjunction with the Office of Developmental Primary Care, provides an overview of interviews with self-advocates about their experiences with the health care system and corresponding recommendations. The goal is to provide health care professionals with the resources and policies to provide people with disabilities with quality care. This document is a resource that self-advocacy organizations, policymakers, and health care professionals can use to advance access to health care for people with disabilities.

<https://autisticadvocacy.org/wp-content/uploads/2014/04/>

[OurLivesOurHealthCare-revision-2014-04_15_DRAFT.pdf](#)

- **Centers for Disease Control and Prevention—Mark’s Story**
This video from the CDC showcases a man’s role assisting future health care providers with improving the quality of care they provide to people with disabilities. Medical students provide feedback on how they have learned from this experience.
<https://www.youtube.com/watch?v=KKyzZVpWezw>
- **Disability Rights Education and Defense Fund—*Health Care Stories***
DREDF hosts a video advocacy tool to promote health care justice for people with disabilities. These stories collected by the Special Hope Foundation and the Manuel D. and Rhoda Mayerson Foundation provide insight into the experience of people with disabilities in the health care system. DREDF has a [set of three videos](#) on common barriers to health care for people with disabilities and potential solutions.
<https://dredf.org/healthcare-stories/>
- **The Commonwealth Fund—*Creating Better Systems of Care for Adults with Disabilities: Lessons for Policy and Practice***
This publication from the Commonwealth Fund examines health plans and clinics that have created a custom model for people with disabilities. The models in this study include disabilities that are physical, intellectual and developmental, and related to serious mental illnesses. The programs selected focus on: (1) prevention and proactive identification of secondary conditions; (2) engagement with patients and efforts to build trust; and (3) integration of LTSS to improve health and promote independence and social inclusion.
<https://www.commonwealthfund.org/publications/case-study/2018/sep/systems-care-adults-disabilities>
- **The Independence Center—*Improving Health Care Access for People with Disabilities***
This video from the Independence Center in Missouri includes several interviews

from people with a variety of disabilities. They discuss the lack of health care accessibility for people with disabilities and how this impacts the quality of their health care experiences.

<https://www.youtube.com/watch?v=KKyzZVpWezw>

Data & Research Tools

- **Centers for Medicare & Medicaid Service—*Improving Health Care for Adults with Disabilities***

This report from CMS provides an overview of federal data sources on health care access for people with disabilities. CMS highlights how researchers have used these data sources to better understand access to health care for people with disabilities and identifies opportunities to build upon this work and enhance data collection efforts.

<https://www.cms.gov/files/document/federaldatadisability508.pdf>

- **Disability Rights Education and Defense Fund—*Research and Data Collection***
DREDF hosts a list of research and data collection on disability and health. The list includes information about the prevalence of inaccessible medical equipment and barriers in medical offices, identification of people with disabilities in the health care context, and health disparities for people with disabilities.

<https://dredf.org/healthcare-access/research-and-data-collection-on-disability/>

- **Institute on Disability—*Health Disparities Chartbook on Disability and Racial and Ethnic Status in the United States***

The Institute on Disability released a chart book in 2011 to answer the question of whether working-age people with disabilities in the U.S. experience health disparities similar to those experienced by racial and ethnic minority groups in the United States. This chart book has a specific chapter on health care access. It provides an overview of data on disability and health indicators, people of color

with disabilities, and children with disabilities and health disparities. The purpose of this chart book is to illustrate the need for careful planning on a national level for how to address the health disparities people with disabilities face.

https://iod.unh.edu/sites/default/files/media/Project_Page_Resources/HealthDisparities/health_disparities_chart_book_o8o411.pdf

Fact Sheets

- **ADA National Network—*Accessible Health Care***

The ADA National Network’s fact sheet on accessible health care discusses the number of people with disabilities affected by inaccessible medical services. The fact sheet provides questions for health providers to consider related to the accessibility of medical facilities and equipment. Suggested accommodations are outlined in the fact sheet by type of disability.

<https://adata.org/factsheet/accessible-health-care>

- **Healthy Aging and Physical Disability RRTC—*How to Make Healthcare Accessible for All***

As part of the Healthy Aging and Physical Disability RRTC’s Aging with a Disability Factsheet Series, it released this fact sheet on common barriers people with disabilities experience when accessing health care. This fact sheet discusses ways to remove barriers and improve access for this population, including changes in design, training, and policy.

<http://agerrtc.washington.edu/info/factsheets/healthaccess>

- **National Center on Disability in Public Health—*Health Care Access***

This fact sheet from the National Center on Disability in Public Health provides reflection on ways health care providers can include people with disabilities in their practices. It offers ways practices can engage in training and partnerships to strengthen their knowledge of health care accessibility. Additionally, the

National Center on Disability in Public Health has a resource list for providers.
<https://nationalcenterdph.org/health-care-access-fact-sheet/>

Policy Briefs

- **Administration for Community Living—*Wheelchair-Accessible Medical Diagnostic Equipment: Cutting Edge Technology, Cost-Effective for Health Care Providers, and Consumer-Friendly***

ACL's policy brief on wheelchair-accessible medical diagnostic equipment provides an overview of what constitutes accessible equipment and how using accessible equipment can reduce health care worker and patient injuries and related costs. This brief presents information on how health providers can use existing incentives and resources to integrate accessible equipment into their practice. Overall, the brief presents accessible medical diagnostic equipment as essential to health care providers' overall strategy to improve quality and address health disparities. Resources for free technical assistance are provided at the end of the brief.

<https://acl.gov/ada/accessibility-standards-medical-diagnostic-equipment>

- **Association of State and Territorial Health Officials—*Access to Preventive Healthcare Services for Women with Disabilities***

This policy brief by the Association of State and Territorial Health Officials details the public health issue of access to preventive health care services for women with disabilities. It provides information on major barriers that women with disabilities face when trying to access preventive services and describes solutions that state public health agencies can implement to address these barriers.

<https://www.astho.org/Access-to-Preventive-Healthcare-Services-for-Women-with-Disabilities-Fact-Sheet/>

Provider Education & Guidelines

- **Alliance for Disability in Health Care Education—*Core Competencies on Disability for Health Care Education***

The Alliance for Disability in Health Care Education published core competencies in 2019 to establish the required expertise for providing quality health care to patients with disabilities. They partnered with the Ohio Disability and Health Program at the Ohio State University Nisonger Center to establish these core competencies through the efforts of people with disabilities, disability experts, health educators, and health care providers. These competencies are designed to be integrated into existing curricula to ensure patients with disabilities are included as a member of the care team and receive quality care.

https://nisonger.osu.edu/wp-content/uploads/2019/08/post-consensus-Core-Competencies-on-Disability_8.5.19.pdf

- **Champaign County Health Care Consumers—*Advice from People with Disabilities on Providing Quality Health Care: What Health Care Providers Really Need to Know***

This document from the Champaign County Health Care Consumers provides advice for providers based on the experiences of people with disabilities. This handout describes these experiences to offer providers concrete and helpful examples of how to provide quality health care to people with disabilities. The advice spans the following categories: (1) communicating with people with various disabilities; (2) basic sensitivity; (3) transfers; (4) health care providers' equipment; (5) environment; (6) architecture; (7) common areas; and (8) staff training tips for managers and trainers.

<https://www.healthcareconsumers.org/advice-from-people-with-disabilities-on-providing-quality-health-care-what-health-care-providers-really-need-to-know/>

- **Disability Rights Texas— *Access to Health Care for People with Disabilities: Know Your Right***

This video from Disability Rights Texas provides an overview of the rights of people with disabilities when accessing health care services. It outlines the right to access facilities, services, and information at medical offices and hospitals. This video can also be helpful for providers, as it provides a clear discussion of the variety of ways access must be provided and ways providers are prohibited from discriminating against people with disabilities.

<https://www.youtube.com/watch?v=ETf4JfAl3kl>

- **National Association of the Deaf—*Position Statement on Health Care Access for Deaf Patients***

The National Association of the Deaf, the premier civil rights organization of, by, and for the deaf and hard of hearing, advocates for a broad array of issues including early intervention, education, employment, technology, and health care. It has a position statement on health care access for deaf patients, with a list of guidelines for health care providers.

https://www.nad.org/about-us/position-statements/position-statement-on-health-care-access-for-deaf-patients/#_edn1

- **RRTC on Independent Living—*Disability Resources for Healthcare Providers***

The RRTC on Independent Living released a list of resources with information on making medical offices more accessible to people with disabilities. This resource list also includes information on tax incentives for making physical accommodations, accommodations for sensory disabilities, and disability etiquette guidance.

<https://rtcil.org/healthcare-access-products>

Research Papers & Reports

- ***Disability-Related Disparities in Access to Health Care Before (2008–2010) and After (2015–2017) the Affordable Care Act (2019)***

This paper examines the effect of the ACA on disparities in access to health care based on disability status and several other variables. This study found that the large health disparities for people with disabilities were reduced during the period when the ACA was implemented for people of certain disability types. The author discusses how disability status is still associated with a much greater risk of delayed or forgone care despite passage of the ACA.

<https://ajph.aphapublications.org/doi/10.2105/AJPH.2019.305056>

- ***Health and Health Services Access Among Adults with Disabilities Who Receive Federal Housing Assistance (2017)***

This paper uses data from the U.S. Department of Housing and Urban Development linked with data from the National Health Interview Survey to examine health disparities for people with disabilities receiving federal housing assistance. The study presents information on individual characteristics, self-reported health rating, U.S. Department of Housing and Urban Development program type, chronic conditions, health behaviors, health care use and access, insurance status, and a variety of other variables. The paper discusses the policy implications of these findings, specifically how to address health disparities for this population.

https://nlihc.org/sites/default/files/HHS_Access-Among-Adults-With-Disabilities.pdf

- ***It Takes More Than Ramps to Solve the Crisis of Healthcare for People with Disabilities (2004)***

This report released by the Rehabilitation Institute of Chicago discusses the access issues people with disabilities face in the health care system,

specifically issues with patient safety and patient-centered care. The authors reflect on the moral mandate to ensure people with disabilities have the same access to health care as people without disabilities. It highlights potential solutions to challenges people with disabilities and providers face in the health care system.

https://dredf.org/wp-content/uploads/2012/08/RIC_whitepaperfinal.pdf

- ***Presence of Accessible Equipment and Interior Elements in Primary Care Offices (2019)***

This report provides information on medical office accessibility across 3,993 primary care offices in California from 2013 to 2016. It uses the ADA Accessibility Guidelines and observations of medical examination equipment to determine accessibility. This report offers insight into the status of accessibility in medical offices and offers data for tracking progress on increasing medical office disability access.

<https://dredf.org/wp-content/uploads/2019/10/Presence-of-Accessible-Equipment-and-Interior-Elements-in-Primary-Care-Offices.pdf>

- ***What Should We Teach about Disability? National Consensus on Disability Competencies for Health Care Education (2021)***

This paper discusses what disability competencies should be used for health care education. The authors recognized the lack of consensus regarding what should be taught to medical providers regarding disability and as a result developed six main competencies, 49 sub-competencies, and 10 principles and values in conjunction with a team of people with disabilities, disability experts, and health professionals. The goal of this paper is to establish a set of competencies that will be implemented in education for health professionals to provide information on providing quality health care to patients across all types of disabilities.

<https://www.sciencedirect.com/science/article/pii/S1936657420301217>

Toolkits

- **Academic Autistic Spectrum Partnership in Research and Education (AASPIRE)—*AASPIRE Healthcare Toolkit***

AASPIRE released a toolkit on health care to offer a wide range of resources and worksheets on primary health care and to improve the health of adults on the autism spectrum. The toolkit is divided into two main sections: (1) patients and supporters; and (2) health care providers. AASPIRE compiled this toolkit through research studies funded by the National Institute of Mental Health.

<https://aaspire.org/projects/healthcare-toolkit/>

- **Association of Maternal and Child Health Programs—*TOOLBOX: Improving the Receipt of Clinical Preventive Services among Women with Disabilities***

The Association of Maternal and Child Health Programs developed this online toolkit to provide information on maternal and child health programs that target women with disabilities. The toolkit is designed to centralize resources on this target population and increase the use of preventive services among women with disabilities. Tools are provided in the following goal areas: (1) increase knowledge and use of recommended services; (2) identify service gaps and monitor progress; (3) create or map accessible facilities and transportation in communities; and (4) empower clinicians and women with disabilities to interact effectively.

<http://www.amchp.org/programsandtopics/womens-health/Focus Areas/WomensHealthDisability/Pages/default.aspx>

- **National Disability Navigator Resource Collaborative—*Guide to Disability for Health Insurance Marketplace Navigators***

The NDNRC published a guide to disability for health insurance marketplace navigators that was compiled by DREDF. It provides an overview of information navigators should be familiar with, such as barriers to health care for people with disabilities, disability etiquette, effective communication, types of

accommodations, and many other important topic areas. This guide also lists several population-specific fact sheets that navigators can find on the NDNRC website with more detailed information.

<https://nationaldisabilitynavigator.org/wp-content/uploads/Materials/Disability-Guide.pdf>

- **The Equal Rights Center—*Accessible Health Care Self-Advocacy Toolkit***

The Equal Rights Center published a toolkit on accessible health care self-advocacy for people with disabilities. The goal of the toolkit is to provide people with disabilities information about their right to accessible health care and to provide tools to advocate effectively when experiencing discrimination in the health care system.

https://equalrightscenter.org/wp-content/uploads/accessible_healthcare_toolkit.pdf

- **World Institute on Disability—*Access to Medical Care***

The World Institute on Disability compiled a toolkit on access to medical care for people with disabilities to educate and support practitioners and social service and support staff. It is designed to provide an overview of critical issues that affect access to quality care for patients with physical, sensory, and communication disabilities. This toolkit accompanies two videos that offer perspectives of patients with disabilities and health care providers with expertise in disability.

<https://wid.org/wp-content/uploads/2016/01/access-to-medical-care-curriculum-pdf-format.pdf>

Webinars

- **Disability Rights Education and Defense Fund—*Improving Access to Health Care for People with Disabilities***

This online course from DREDF provides information on ways to increase access to health care for people with disabilities. The modules cover the ADA, an introduction to disability, effective communication, physical access to health care, and policies and procedures. At the end of the course, DREDF compiled a list of resources on improving access to health care and a fact sheet on disability rights and managed care.

<https://dredf.org/2014/11/28/improving-access-health-care-people-disabilities/>

- **Disability Rights Education and Defense Fund—*Promoting Physical and Programmatic Accessibility in Managed LTSS Programs***

In 2019, DREDF hosted this webinar to promote physical and programmatic accessibility in managed LTSS programs. The following four topics are discussed: (1) disability health and health care disparities; (2) physical and programmatic access; (3) federal actions; and (4) promising practices. This webinar also includes a list of related resources.

<https://dredf.org/wp-content/uploads/2019/03/Breslin-Phys-Prog-access-MLTSS-2-2019.pdf>

- **Pacific ADA Center—*Archived Inclusive Healthcare Webinars***

The Pacific ADA Center offers a collection of archived webinars on inclusive health care. Some topics include physical access, vaccine access, and crisis standards. Descriptions of the webinars, presentation slides, and recordings are available for each of the webinars.

<http://adapresentations.org/healthcare/archive-health.php>

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