IMPROVING HEALTH CARE FOR ADULTS WITH DISABILITIES

AN OVERVIEW OF FEDERAL DATA SOURCES

December 2020

CMS

CENTERS FOR MEDICARE & MEDICAID SERVICES

Table of Contents

List of Tables

Introduction

Health disparities among people with disabilities are well documented.[1,2,3] Approximately 61 million adults in the United States are living with a disability.[4] Research suggests that having a physical disability increases the likelihood of having unmet health needs and, in many cases, poor health outcomes.[5] Adults with disabilities are almost twice as likely to report unmet health care needs due to barriers they face in accessing care.[6] Health disparities may result from multiple factors, such as a lack of physically accessible medical equipment and health care facilities. In addition, social determinants of health such as unemployment, poverty, and lack of access to transportation have an impact on health outcomes for people with disabilities.[7]

Understanding patients' needs and experiences is essential to increasing access to care, improving quality of care, and addressing health disparities for people with disabilities. Health care organizations, researchers, and policymakers can draw on existing data sources and opportunities to collect additional data to identify individuals with disabilities, better understand barriers they face when seeking care, and assess where there are unmet needs. For example, Medicare/Medicaid claims data, enrollment data, state waiver records, and other administrative data may allow us to identify Medicare and dual-eligible beneficiaries with disabilities.[8] From there, Medicare and/or Medicaid claims would enable examination of health service cost and utilization patterns for individuals with disabilities.[9] Electronic health records (EHRs) provide more opportunities to collect data about individuals at the point of care. This brief focuses on examples of publicly available population-level surveys sponsored by the U.S. Department of Health and Human Services (HHS) that provide information on disability, access to care, experience of care, and social determinants of health.[i]

Getting the Care You Need: A Guide for People with Disabilities

This guide highlighs best practices and protections for people with disabilities who are accessing health care. It is available in Braille, **Arabic / العربية** (PDF), **Chinese / 中文** (PDF), **Korean / 한국어** (PDF), **Russian / Русский** (PDF), **Spanish / Español** (PDF), **Vietnamese / TIẾNG VIỆT** (PDF), and **Haitian Creole / Kreyòl Ayisyen** (PDF). To request a physical copy, email the Health Equity Technical Assistance Program at HealthEquityTA@cms.hhs.gov.

Data Sources

The population-level survey instruments described below are intended to highlight examples of data sources that provide information about the experience of people with disabilities in health

---

[i] For additional sources of federal disability data see the Interagency Committee on Disability Research website: https://icdr.acl.gov/resources/disability-data. For a comprehensive compilation of datasets and data-related resources developed, maintained, or funded by federal agencies on socioeconomic factors and social determinants of health, see the Compendium of Federal Datasets Addressing Health Disparities, available at: https://www.minorityhealth.hhs.gov/assets/pdf/2019%20IHEC%20Data%20Compendium_FullDocument_RegularFormat%20-%207-20-20.pdf.

care settings; this brief does not provide an exhaustive list or a complete representation of all available disability data sources. Tables for each data source provide information on target population, frequency of data collection, and reach, as well as relevant survey content on disability, access, patient experience, and social determinants of health. Table 1 provides an overview of how the highlighted surveys capture information on these topics.

While the highlighted data sources include questions to identify people with disabilities and, to some extent, the type of disability individuals experience, there are differences in how disability is defined. However, many population-based surveys use the U.S. Census Bureau six-item question set from the American Community Survey, which were incorporated into the HHS Data Collection Standards established in 2011, to assess disability status.[10] These questions represent the minimum standard for federal population-based surveys and provide some guidance for a set of uniform data collection standards in surveys that HHS conducts or sponsors.[11]

Table 1. Select Measures of Disability, Access, Patient Experience, and Social Determinants of Health

Disability	► Measures of disability in reviewed surveys include but are not limited to: • Deafness or serious difficulty hearing • Blindness or difficulty seeing • Difficulty concentrating, remembering, or decision making, particularly due to a physical, mental, or emotional condition • Difficulty walking or climbing stairs • Difficulty dressing or bathing • Difficulty doing errands alone, including visiting a doctor’s office • Activities of daily living (ADLs) • Instrumental activities of daily living (IADLs) • Specific disability types or limitations • Aspects of health status that could relate to or be the result of a disability
Access	► Measures of access in reviewed surveys include but are not limited to: • Usual source of care • Receipt of preventative health services • Preventable hospitalizations • Unmet needs and barriers to care • Care-seeking behaviors • Health insurance coverage • Physical accessibility of a facility or the equipment used in a visit
Patient experience	► Measures of patient experience in reviewed surveys include but are not limited to: • Satisfaction with care • Ease of communication with providers • Difficulty obtaining needed care (including from specialists) • Wait time for appointments and providers

Social determinants of health	▶ Measures that address social determinants of health in reviewed surveys may include but are not limited to: • Limited English Proficiency and language preferences • Transportation barriers • Food insecurity • Housing insecurity • Utility access

BEHAVIORAL RISK FACTOR SURVEILLANCE SYSTEM

The Centers for Disease Control and Prevention (CDC)'s Behavioral Risk Factor Surveillance System (BRFSS) consists of health-related telephone surveys conducted by state health departments in 50 states as well as the District of Columbia, American Samoa, Palau, Puerto Rico, the U.S. Virgin Islands, and Guam. BRFSS is the largest continuously conducted health survey system in the world.[12] It includes questions about health risk behaviors, chronic health conditions, preventive health practices, and access to health care (see Table 2).[13,14] It includes the HHS data standard for disability status.[15] It does not include specific questions on the physical accessibility of the provider facilities or equipment during the visit, although some states may add more questions to their state's BRFSS. Results for all questions, including those specific to disability, are available by state on the CDC website; for the disability questions, tables are available that show results by gender, age, race, income, and education.[16] Disability estimates and demographic data at the state and national level are also available on the CDC Disability and Health Data System (DHDS), an interactive tool that uses BRFSS data.[17] BRFSS data may be useful for a health care organization looking to identify community needs, tailor health messages, or improve health care services that are specific to the needs of people with disabilities.

Table 2. Behavioral Risk Factor Surveillance System (BRFSS)

Target population		Non-institutionalized adults
Frequency of data collection		Administered continuously
Data years available		Annual data from 1991; provided on the CDC BRFSS website
Sample size		Approximately 400,000 people annually
Relevant survey content	**Disability**	▶ Uses the HHS data standard for disability status
	Access	▶ Specific topics covered: • Cost-related barriers • Timeliness of care
	Patient experience	▶ Specific topics covered: • General satisfaction with care received
	Social determinants of health	▶ Food insecurity ▶ Housing insecurity

Source: "Behavioral Risk Factor Surveillance System," CDC, last modified May 16, 2014, https://www.cdc.gov/brfss/about/index.htm.

CONSUMER ASSESSMENT OF HEALTHCARE PROVIDERS AND SYSTEMS

The Consumer Assessment of Healthcare Providers and Systems (CAHPS®) family of surveys ask patients about their experiences with, and ratings of, their health care providers and plans (see Table 3).[18,19] CAHPS surveys are an integral part of Centers for Medicare & Medicaid Services (CMS) efforts to improve health care in the United States.[20] Some CAHPS surveys are used in value-based purchasing (pay for performance) initiatives like the Hospital Value-Based Purchasing Program and the Medicare Advantage Quality Bonus Payments.[21] Health care providers and health plans contract with approved vendors to administer the surveys. CAHPS surveys can be repeated continuously, quarterly, or annually. Health care organizations use CAHPS data to identify areas where patients have negative and positive patient experiences. These insights can inform initiatives and help with tracking progress over time.[22,23] Researchers use CAHPS data to evaluate efforts to improve patient experience, though only some CAHPS surveys are available for research purposes.[24]

CMS CAHPS surveys fall into three broad categories:[25]

- **Patient experience with providers.** This includes CAHPS for Accountable Care Organizations (ACOs) participating in Medicare initiatives and the CAHPS for Merit-based Incentive Payment System (MIPS CAHPS); Home Health CAHPS (HHCAHPS); and Hospice CAHPS. Both the ACO CAHPS and MIPS CAHPS are based on the CAHPS Clinician & Group Survey.
- **Enrollee experience with health plans and related programs.** This includes the Medicare Fee-for-Service CAHPS (FFS CAHPS); the Medicare Advantage and Prescription Drug Plan CAHPS (MA and PDP CAHPS); the Nationwide Adult Medicaid CAHPS (NAM CAHPS); and the CAHPS Home and Community-Based Services (HCBS CAHPS). The FFS CAHPS, MA and PDP CAHPS, and NAM CAHPS are based on the CAHPS Health Plan Survey.
- **Patient experience with facility-based care.** These include Emergency Department CAHPS (ED CAHPS); Hospital CAHPS (HCAHPS); In-Center Hemodialysis CAHPS (ICH CAHPS); and Outpatient and Ambulatory Surgery CAHPS (OAS CAHPS).

The CAHPS surveys also include an optional item set focused on people with mobility impairments (PWMI), which can be added either to the CAHPS Health Plan Survey or the CAHPS Clinician & Group Survey. The PWMI item set for both surveys contains questions that cover many topics relating to physical disabilities, including difficulty moving around the restroom, pain, fatigue, being weighed at the doctor's office, and being examined on the examination table. Also, the PWMI set includes questions about getting physical/occupational/speech therapy and mobility equipment. The PWMI set is unique in that it focuses specifically on the patient experiences of care for persons with physical disabilities, setting it and CAHPS more generally apart from other available data sources.

Table 3. Consumer Assessment of Healthcare Providers and Systems (CAHPS®)

Target population		Consumers of health plan, provider, and health care facility services
Frequency of data collection		Administered continuously, quarterly, or annually
Data years available		Data years available vary by survey; information on data availability is posted on the CMS CAHPS website.
Sample size		CMS requires health care organizations to participate in CAHPS surveys as part of some public reporting or reimbursement programs. For example, hospitals subject to the Inpatient Prospective Payment System (IPPS) annual payment update provisions must collect and submit HCAHPS data to receive their full annual payment update (APU). Similarly, all Medicare-certified hospices must participate in the Hospice CAHPS Survey to receive their full APU.
Relevant survey content	**Disability**	► Some CAHPS surveys use the HHS data standard for disability status. The HCBS CAHPS addresses five disability populations, including frail elderly, individuals with physical disabilities, persons with developmental or intellectual disabilities, those with acquired brain injury, and persons with severe mental illness. ► Specific topics covered by the PWMI supplement for certain CAHPS surveys: • Getting physical, occupational, or speech therapy • Use of mobility equipment • Ability to walk and/or difficulty in walking a quarter-mile • Getting or replacing mobility equipment and/or having it repaired • Getting weighed at the doctor’s office • Being examined on the examination table • Difficulty moving around the restroom • Pain • Fatigue
	Access	► Specific topics covered: • General access to health care services • Ease of communication • Timeliness • Medical equipment
	Patient experience	► Getting timely appointments, care, and information ► How well providers communicate with patients ► Providers’ use of information to coordinate patient care ► Helpful, courteous, and respectful providers and staff ► Patients’ rating of the provider ► Customer service
	Social determinants of health	► Limited English Proficiency and language preferences ► Transportation barriers ► Employment services

Sources: Review of CAHPS surveys; “Consumer Assessment of Healthcare Providers & Systems (CAHPS),” CMS, last modified July 16, 2020, https://www.cms.gov/Research-Statistics-Data-and-Systems/Research/CAHPS; “HCAHPS: Patients’ Perspectives of Care Survey, CMS, last modified February 11, 2020, https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/HospitalQualityInits/HospitalHCAHPS; CAHPS® Hospice Survey, CMS, last modified June 10, 2020, https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/Hospice-Quality-Reporting/CAHPS%C2%AE-Hospice-Survey; “CAHPS Item Sets for People with Mobility Impairments,” Agency for

Healthcare Research and Quality (AHRQ), last modified April 2020, http://www.ahrq.gov/cahps/surveys-guidance/item-sets/mobility/index.html.

HEALTH AND RETIREMENT STUDY

The Health and Retirement Study (HRS) is a nationally representative survey focused on workforce and health transitions among the aging population (see Table 4). HRS covers several topics related to disability and health, including cognitive function and memory, physical and functional limitations, use of assistive equipment and technology, and health care utilization and costs. The survey is sponsored by the National Institutes of Health (NIH), National Institute on Aging (NIA), and the Social Security Administration (SSA) through a cooperative agreement with the University of Michigan, who administers the survey.

Table 4. Health and Retirement Study (HRS)

Target population		Adults over 50
Frequency of data collection		Administered by a core interview with follow up every two years
Data years available		Biennial, off-year, and cross-year data from 1992; available from the HRS Data Products website
Sample size		Longitudinal sample of approximately 20,000 people
Relevant survey content	**Disability**	► Does not use the HHS data standard for disability status ► Specific topics covered: • Functional limitations • Role of caregivers • Difficulty with movement and daily activities due to a health or memory problem • Assistive aids used[26]
	Access	► Specific topics covered: • Health insurance coverage • Occurrences navigating and receiving health care • Cost for coverage • Length of time without coverage • Reasons for lack of coverage • Frequency of hospital, doctor, and dental visits • Medication use and costs • Delays taking medication
	Patient experience	► Specific topics covered: • Experience with current health plan • Satisfaction with quality and cost • Convenience
	Social determinants of health	► Housing insecurity

Source: “Health and Retirement Study,” University of Michigan Institute for Social Research, last modified 2019, https://hrs.isr.umich.edu/about.

MEDICARE CURRENT BENEFICIARY SURVEY

CMS conducts the Medicare Current Beneficiary Survey (MCBS), which includes a nationally representative sample of the Medicare population (see Table 5). The survey is conducted among a sample of Medicare beneficiaries within the 48 contiguous states, the District of Columbia, and beginning in 2017, Puerto Rico. MCBS identifies persons with disabilities through the HHS data standard for disability status, as well as a variety of questions focused on functional limitations (ADLs/IADLs). It does not ask specific questions about the physical accessibility of the provider or equipment available or used during a visit. One goal of MCBS is to assess satisfaction with care; as such, it includes a number of questions focused on access to care that are relevant to patient experiences with physical accessibility.

Table 5. Medicare Current Beneficiary Survey (MCBS)

Target population		Medicare beneficiaries
Frequency of data collection		Administered continuously
Data years available		Annual public use data from 2013; available from the CMS MCBS website
Sample size		Annually surveys 15,000 people
Relevant survey content	**Disability**	► Uses the HHS data standard for disability status ► Specific topics covered: • Functional limitations (ADLs/IADLs)
	Access	► Specific topics covered: • Ease of getting to the doctor from home • Usual source of care • Delays due to cost
	Patient experience	► Specific topics covered: • Satisfaction with care • Wait times for appointments and at the office • Difficulty in obtaining referrals for services of specialists or other doctors • Difficulties with managed care plans paying for treatment
	Social determinants of health	► Limited English Proficiency and language preferences

Sources: CMS, Medicare Current Beneficiary Survey (MCBS) 2017 Methodology Report, https://www.cms.gov/Research-Statistics-Data-and-Systems/Research/MCBS/Downloads/MCBS2017MethodReport508.pdf; “Medicare Current Beneficiary Survey,” CMS, last modified June 10, 2020, https://www.cms.gov/Research-Statistics-Data-and-Systems/Research/MCBS; “Medicare Current Beneficiary Survey (MCBS): Differences between the Cost and Use and Access to Care Modules,” Research Data Assistance Center (ResDAC), last modified June 2, 2017, https://www.resdac.org/articles/medicare-current-beneficiary-survey-mcbs-differences-between-cost-and-use-and-access-care.

MEDICAL EXPENDITURE PANEL SURVEY

The Medical Expenditure Panel Survey (MEPS) is a large-scale survey administered by the Agency for Healthcare Research and Quality (AHRQ) focusing on cost and use of health care and insurance (see Table 6).[27] The survey contains over 50 topics, including disability, health status, and access to health care. Topics are contained throughout three components:

- Household Component surveys individuals and members of their households.
- Insurance Component surveys employers about employer-based health insurance.
- Medical Provider Component surveys providers who provide medical care to Household Component respondents.

MEPS examines how people use health services and collects data on which specific services are used, frequency, cost, and method of payment. MEPS includes questions relating to ADL/IADL limitations and mobility impairment, and questions about vision and hearing ability and cognitive limitations. Despite its focus on how people use health services, MEPS does not ask specific questions about the physical accessibility of the providers' facilities or equipment during visits.

Table 6. Medical Expenditure Panel Survey (MEPS)

Target population		Non-institutionalized children and adults
Frequency of data collection		Administered continuously
Data years available		Annual data from 1996; available from the ARHQ MEPS website
Sample size		Annually surveys approximately 15,000 households, which may include 35,000 people
Relevant survey content	**Disability**	► Uses the HHS data standard for disability status ► Specific topics covered: • IADLs • ADLs • Cognition • Days missed from work/school due to physical illness or injury, or a mental or emotional problem
	Access	► Specific topics covered: • Usual source of care • Difficulties accessing regular care • Delays due to cost • Ease of communication
	Patient experience	► Specific topics covered: • Provider availability
	Social determinants of health	► Limited English Proficiency and language preferences

Sources: "MEPS-HC Sample Sizes," AHRQ, last modified August 30, 2019, https://meps.ahrq.gov/survey_comp/hc_sample_size.jsp; "MEPS-HC Panel Design and Data Collection Process," AHRQ, https://meps.ahrq.gov/mepsweb/survey_comp/hc_data_collection.jsp; "HC Questionnaire Sections for Rounds 1-5," AHRQ, last modified November 2019, https://meps.ahrq.gov/mepsweb/survey_comp/hc_ques_sections.jsp.

NATIONAL HEALTH AND NUTRITION EXAMINATION SURVEY

Administered by CDC's National Center for Health Statistics (NCHS), the National Health and Nutrition Examination Survey (NHANES) collects information on the health and nutritional status of the U.S. population (see Table 7). In addition to questions on physical and mental functioning, NHANES provides results of physical examinations administered to survey respondents. Thus, NHANES includes information on individuals' health and functioning that is both self-reported and assessed by health professionals.

Table 7. National Health and Nutrition Examination Survey (NHANES)

Target population		Non-institutionalized children and adults
Frequency of data collection		Continuous
Data years available		Annual data from 2000; available from the CDC NHANES website
Sample size		Annually surveys 5,000 people
Relevant survey content	**Disability**	► Uses the HHS data standard for disability status ► Includes questions that cover: • Health problems that limit ability to play, walk, or run • Mental health • Medication use • Some elements from IADLs • Some elements from ADLs • Use of special equipment • Early interventions
	Access	► Specific topics covered: • Usual source of care • Frequency of medical care • Hospitalized overnight • Care-seeking behavior • Proximity to grocery stores
	Patient experience	► No questions about patient experience
	Social determinants of health	► Limited English Proficiency and language preferences ► Food insecurity

Source: "About NHANES," CDC, last modified September 15, 2017, https://www.cdc.gov/nchs/nhanes/about_nhanes.htm.

NATIONAL HEALTH INTERVIEW SURVEY

The National Health Interview Survey (NHIS), administered by the CDC NCHS, serves as a primary source of information on the health of the civilian/non-institutionalized population within the 50 United States and the District of Columbia. HHS uses NHIS data to monitor trends in illness and disability.[28] As such, it contains numerous questions relevant to disability and physical accessibility (see Table 8). NHIS contains core questions and supplemental questions. The core questions are divided into four components—Household, Family, Sample Adult, and

Sample Child—and do not change from year to year, while the supplements are developed as new data needs arise. In 1994 and 1995, after the passage of the Americans with Disabilities Act (ADA), NHIS conducted a disability supplement survey to better understand disability data.[29]

Table 8. National Health Interview Survey (NHIS)

Target population		Non-institutionalized adults
Frequency of data collection		Administered continuously
Data years available		Annual data from 1963; the instrument was redesigned in 1997 and 2019. Data are available from the CDC NHIS website.
Sample size		Expected sample size is 35,000 households or about 87,500 people annually
Relevant survey content	**Disability**	► Uses the HHS data standard for disability status ► Specific topics covered: • Difficulty concentrating, remembering, or making decisions • Assistive aids used • Difficulty with tasks even when using assistive aids
	Access	► Specific topics covered: • Usual source of care • Frequency of medical care, including emergency services
	Patient experience	► No questions about patient satisfaction
	Social determinants of health	► Food insecurity ► Housing insecurity

Source: "National Health Interview Survey," CDC, last modified January 16, 2019, https://www.cdc.gov/nchs/nhis/about_nhis.htm.

Opportunities

While none of the data sources comprehensively captures information on patient needs, these data sources may still provide some insight on patient experiences with accessibility in health care settings. Researchers have used many of the data sources highlighted in this brief to better understand access to care for people with disabilities.[30-44] Next, we identify opportunities to build on this work, leverage existing data sources, and enhance data collection efforts to better understand and meet the needs of people with disabilities.

Understand barriers to accessing care and use relevant research for continuous quality improvement efforts. Health plans, health systems, and individual providers can use research findings, existing data sources, and/or primary data collection to drive quality improvement efforts in individual practice and system-wide settings, address the most common barriers to care, and anticipate challenges their patients with disabilities may face in accessing needed services. Data can also be used to tailor communication campaigns for enrollees and patients. This may increase rates of preventive services, address overutilization, and identify training opportunities for providers. Hospital administrators can analyze BRFSS data as part of their community health needs assessments[45] and use what they learn to strengthen existing quality improvement efforts (e.g., drive improvements in their Overall Hospital Quality Star Rating).

Modernizing Health Care to Improve Physical Accessibility - Resources Inventory

The resources in this inventory include guidance on how to increase physical accessibility of medical services, tools to assess a practice or facility's accessibility, and tips and training materials to support efforts to reduce barriers and improve quality of care for individuals with disabilities.

Use multiple data sources to gain insight into health care utilization and needs of people with disabilities. Data linkages provide powerful opportunities to address questions on disability, utilization, usual sources of care, access to care, quality of care, and social determinants of health. Claims data on the Medicare and Medicare-Medicaid dually enrolled populations can be linked to several national surveys, including the MCBS, NHIS, HRS, and Medicare FFS CAHPS. The NCHS Data Linkage Program connects data from CDC population surveys, including the NHIS and NHANES, with Medicare and Medicaid data.[46] Health care organizations can also assess whether their quality improvement efforts include linking their claims data with survey data.[47] Similarly, CAHPS and the Medicare Health Outcomes Survey data may be used together to guide the design of quality improvement efforts.[48] Health plans could also identify people with disabilities through their health risk assessments and match these responses with their claims and/or HEDIS® data to explore ways to improve health care quality and patient experience. Quality improvement networks, coalitions, and other partners across the health care system can use public claims data to understand community-level needs and challenges, allowing them to identify and engage with people with disabilities and the organizations that serve them.

Data Highlights and Reports from the CMS Office of Minority Health

- How Does Disability Affect Access to Health Care for Dual Eligible Beneficiaries?
- Medicare Fee-For-Service Beneficiaries with Disabilities, by End Stage Renal Disease Status, 2014
- Does Disability Affect Receipt of Preventive Care Services among Older Medicare Beneficiaries?
- Toward the Creation of a Patient-Reported Disability Index

Collect disability information consistently at the point of care. Some surveys discussed in this issue brief do not include the HHS data standard for disability status,[49] which may offer an opportunity to improve data collection alignment in survey instruments. Also, health care organizations and providers could consider using the same six disability questions in their data collection efforts (e.g., health risk assessment, intake forms, surveys) to work towards consistency of data collection. For example, the care team can add functional limitation information to the patient record when making appointments, and verify functional limitations during the appointment with the patient's provider.[50] This would help prepare providers and their staff to better meet patients' needs and improve the quality of care provided to people with disabilities.[51] Questions on ADLs and IADLs may also provide important details.

Navigating Health Care with a Disability: Our Stories

Learn how health care organizations and providers can improve accessibility and care for people with disabilities.

Collect additional data to shed light on the challenges individuals in a local community may face. Additionally, while data from surveys and claims can be helpful, they sometimes unintentionally ignore the unique experiences faced by people with disabilities. To assess disparities, health care organizations should consider soliciting feedback directly from people with disabilities. Some ways to collect this feedback is through interviews, listening sessions, focus groups, and advisory panels that may uncover new issues and help with interpreting findings from health care data. Gathering feedback from diverse stakeholders is key because experiences may vary based on a person's disabilities, race and ethnicity, language preference, gender, sexual orientation, and geography. Priorities and initiatives informed directly by a diverse group of people with disabilities may identify practical and sustainable solutions that improve care and satisfaction for everyone.

Conclusion

This issue brief highlights several data sources that can help the health care community, researchers, and policymakers better understand disparities related to access to care and patient experience that affect people with disabilities. Although existing research and data sources provide some insight into the experiences of people with disabilities in health care, additional exploration could support organizations working toward continuous quality improvement. The CMS Office of Minority Health (OMH) offers Health Equity Technical Assistance for health care organizations needing assistance with these or other quality improvement efforts.

The CMS Office of Minority Health (OMH) offers technical assistance for health care organizations working to advance health equity. For help or for more information about available resources, visit go.cms.gov/OMH or email the Health Equity Technical Assistance Program at HealthEquityTA@cms.hhs.gov.

---

[1] Amanda Reichard, Hayley Stolzle, and Michael H. Fox, “Health Disparities among Adults with Physical Disabilities or Cognitive Limitations Compared to Individuals with No Disabilities in the United States,” *Disability and Health Journal* 4, no. 2 (April 1, 2015): 59-67, https://doi.org/10.1016/j.dhjo.2010.05.003.

[2] HHS Office of Disease Prevention and Health Promotion, “Disability and Health,” Healthy People 2020, https://www.healthypeople.gov/2020/topics-objectives/topic/disability-and-health.

[3] H. Stephen Kaye, “Disability-Related Disparities in Access to Health Care Before (2008-2010) and After (2015-2017) the Affordable Care Act,” *American Journal of Public Health* 109 (2019): 1015-1021, https://ajph.aphapublications.org/doi/abs/10.2105/AJPH.2019.305056.

[4] Catherine A. Okoro et al., “Prevalence of Disabilities and Health Care Access by Disability Status and Type among Adults — United States, 2016,” *MMWR. Morbidity and Mortality Weekly Report* 67 (2018), https://doi.org/10.15585/mmwr.mm6732a3.

[5] Elham Mahmoudi and Michelle A. Meade, “Disparities in Access to Health Care among Adults with Physical Disabilities: Analysis of a Representative National Sample for a Ten-Year Period,” *Disability and Health Journal* 8, no. 2 (April 1, 2015): 182–90, https://doi.org/10.1016/j.dhjo.2014.08.007.

[6] Michael Karpman and Sharon K. Long, “QuickTake: Even with Coverage, Many Adults Have Problems Getting Health Care, with Problems Most Prevalent among Adults with Disabilities,” *Health Reform Monitoring Survey*, September 24, 2015, http://hrms.urban.org/quicktakes/Many-Adults-Have-Problems-Getting-Health-Care.html.

[4] “Disability and Health Data System (DHDS),” Centers for Disease Control and Prevention, last modified May 18, 2020, https://www.cdc.gov/ncbddd/disabilityandhealth/dhds/index.html.

[8] Chronic Conditions Data Warehouse Medicare Administrative Data User Guide. Version 3.1, March 2015, https://www.ccwdata.org/cs/groups/public/documents/document/ccw_userguide.pdf.

[9] Dataset: Medicare-Medicaid Linked Enrollee Analytic Data Source (MMLEADS), 2013, https://www.disabilitystatistics.org/sources-profile.cfm?ID=419.

[10] “U.S. Department of Health and Human Services Implementation Guidance on Data Collection Standards for Race, Ethnicity, Sex, Primary Language, and Disability Status,” U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, published October 31, 2011, https://aspe.hhs.gov/basic-report/hhs-implementation-guidance-data-collection-standards-race-ethnicity-sex-primary-language-and-disability-status.

[11] Ibid.

[12] “Behavioral Risk Factor Surveillance System,” Centers for Disease Control and Prevention, last modified May 16, 2014, https://www.cdc.gov/brfss/about/index.htm.

[13] William A Erickson and Adrien Dumoulin-Smith, “A Guide to Disability Statistics from the Behavioral Risk Factors Surveillance System,” Cornell University Employment and Disability Institute, October 2009, 93.

[14] “Behavioral Risk Factor Surveillance System,” Centers for Disease Control and Prevention.

[15] Okoro et al., “Prevalence of Disabilities and Health Care Access by Disability Status and Type.”

[16] Erickson and Dumoulin-Smith.

[17] “Disability and Health Information for Healthcare Providers,” Centers for Disease Control and Prevention, last modified October 28 2019, https://www.cdc.gov/ncbddd/disabilityandhealth/hcp.html.

[18] “Consumer Assessment of Healthcare Providers and Systems (CAHPS),” Agency for Healthcare Research and Quality, accessed February 18, 2020, http://www.ahrq.gov/cahps/index.html.

[19] Ibid.

---

[20] Ibid.

[21] Ibid.

[22] Agency for Healthcare Research and Quality, “Improving Patient Experience,” last modified April 2020, http://www.ahrq.gov/cahps/quality-improvement/index.html.

[23] Jeana M. Holt, “Patient Experience in Primary Care: A Systematic Review of CG-CAHPS Surveys,” *Journal of Patient Experience* 6, no. 2 (June 2019): 93–102, https://doi.org/10.1177/2374373518793143.

[24] “Consumer Assessment of Healthcare Providers and Systems (CAHPS).” Agency for Healthcare Research and Quality.

[25] “CAHPS Patient Experience Surveys and Guidance,” Agency for Healthcare Research and Quality, last modified August 2019, https://www.ahrq.gov/cahps/surveys-guidance/index.html.

[26] “Health and Retirement Study 2018 | Section G: Functional Limitations and Helpers,” University of Michigan Institute for Social Research, http://hrsonline.isr.umich.edu/modules/meta/2018/core/qnaire/online/07hr18G.pdf?_ga=2.226675935.390572806.

[27] “Medical Expenditure Panel Survey Background,” Agency for Healthcare Research and Quality, https://meps.ahrq.gov/mepsweb/about_meps/survey_back.jsp.

[28] “About the National Health Interview Survey,” Centers for Disease Control and Prevention, last modified January 16, 2019, https://www.cdc.gov/nchs/nhis/about_nhis.htm.

[29] “National Health Interview Survey on Disability,” Centers for Disease Control and Prevention, last modified November 6, 2015, https://www.cdc.gov/nchs/nhis/nhis_disability.htm.

[30] Teresa E. Seeman et al., “Disability Trends among Older Americans: National Health and Nutrition Examination Surveys, 1988-1994 and 1999-2004,” *American Journal of Public Health* 100, no. 1 (January 2010): 100–107, https://doi.org/10.2105/AJPH.2008.157388.

[31] Richard L. Nahin, “Estimates of Pain Prevalence and Severity in Adults: United States, 2012,” *The Journal of Pain: Official Journal of the American Pain Society* 16, no. 8 (August 2015): 769–80, https://doi.org/10.1016/j.jpain.2015.05.002.

[32] Benjamin Zablotsky et al., “Estimated Prevalence of Autism and Other Developmental Disabilities Following Questionnaire Changes in the 2014 National Health Interview Survey,” National Vital Statistics Reports, National Health Statistics Report, 67, no. 87 (November 13, 2015), https://stacks.cdc.gov/view/cdc/38790.

[33] Matthew J. Maenner et al., “Prevalence of Cerebral Palsy and Intellectual Disability among Children Identified in Two U.S. National Surveys, 2011–2013,” *Annals of Epidemiology* 26, no. 3 (March 2016): 222–26, https://doi.org/10.1016/j.annepidem.2016.01.001.

[34] Laura A. Schieve et al., “Concurrent Medical Conditions and Health Care Use and Needs among Children with Learning and Behavioral Developmental Disabilities, National Health Interview Survey, 2006–2010,” *Research in Developmental Disabilities* 33, no. 2 (March 1, 2012): 467–76, https://doi.org/10.1016/j.ridd.2011.10.008.

[35] Willi Horner-Johnson et al., “Disparities in Health Care Access and Receipt of Preventive Services by Disability Type: Analysis of the Medical Expenditure Panel Survey,” *Health Services Research* 49, no. 6 (2014): 1980–99, https://doi.org/10.1111/1475-6773.12195.

[36] “Past CMS Health Equity Award Winners,” Centers for Medicare & Medicaid Services, last modified February 21, 2020, https://www.cms.gov/About-CMS/Agency-Information/OMH/equity-initiatives/Past-Health-Equity-Award-Winners.

[37] “Increasing Visibility, Transparency, and Access through the Provider Accessibility Initiative,” Centene Corporation, last modified August 19, 2019, https://www.centene.com/news/provider-accessibility-initiative.html.

---

[38] Mary Elizabeth Bowen and Hector M. González, "Racial/Ethnic Differences in the Relationship between the Use of Health Care Services and Functional Disability: The Health and Retirement Study (1992–2004)," *The Gerontologist* 48, no. 5 (October 2008): 659–67.

[39] Mary Elizabeth Bowen and Hector M. González, "Childhood Socioeconomic Position and Disability in Later Life: Results of the Health and Retirement Study," *American Journal of Public Health* 100, no. S1 (April 1, 2010): S197–203, https://doi.org/10.2105/AJPH.2009.160986.

[40] Ibid.

[41] Ward et al., 1-10.

[42] Elena M. Andresen et al., "Pap, Mammography, and Clinical Breast Examination Screening among Women with Disabilities: A Systematic Review," *Women's Health Issues: Official Publication of the Jacobs Institute of Women's Health* 23, no. 4 (2013): e205–14, https://doi.org/10.1016/j.whi.2013.04.002.

[43] Elizabeth K. Rasch, Stephen P. Gulley, and Leighton Chan, "Use of Emergency Departments among Working Age Adults with Disabilities: A Problem of Access and Service Needs," *Health Services Research* 48, no. 4 (2013): 1334–58, https://doi.org/10.1111/1475-6773.12025.

[44] Mark D. Peterson and Elham Mahmoudi, "Healthcare Utilization Associated with Obesity and Physical Disabilities," *American Journal of Preventive Medicine* 48, no. 4 (April 2015): 426–35, https://doi.org/10.1016/j.amepre.2014.11.007.

[45] Michael A. Stoto, Mary V. Davis, and Abby Atkins, "Making Better Use of Population Health Data for Community Health Needs Assessments," EGEMs 7, no. 1, accessed February 18, 2020, https://doi.org/10.5334/egems.305.

[46] "NCHS Data Linkage," Centers for Disease Control and Prevention, last modified May 2020, https://www.cdc.gov/nchs/data-linkage/.

[47] Hilary Brown et al., "Identifying Reproductive-aged Women with Physical and Sensory Disabilities in Health Administrative Data: A Systematic Review." *Disability and Health Journal* (2020): 100909, https://doi.org/10.1016/j.dhjo.2020.100909.

[48] S. Rae Starr, Grace Kim Crofton, and Asal Sepassi, "Better Together: Examining Interaction between Quality-of-Service and Quality-of-Life Measures Using a Combined CAHPS+HOS-derived Survey of Medicare-Medicaid Patients in a Dual-Eligible Pilot Program, 2016," American Public Health Association, November 5, 2017.

[49] U.S. Department of Health and Human Services, 2011..

[50] Disability Rights Education & Defense Fund, "Health Disparity Research and Data Collection," *Disability Rights Education & Defense Fund* (blog), April 12, 2011, https://dredf.org/2011/04/12/health-disparity-research-and-data-collection/.

[51] Ibid.