

Proposed New Measure for HEDIS^{®1} MY 2026: *Disability Description of Membership (DDM)*

NCQA seeks comments on a proposed new measure for inclusion in HEDIS Measurement Year 2026.

Disability Description of Membership: Describes the disability status of members 15 years of age and older enrolled any time during the measurement year, including information by data source and disability type.

The measure includes two tables for reporting:

- *Table 1* Disability Status by Data Source: Yes Disability, No Disability, Missing
- *Table 1* Data Source: Self-Reported Questionnaire, Self-Reported Accommodations, Enrollment Status, Unknown, No Data.
- *Table 2* Disability Type: Hearing, Seeing, Concentrating, Walking, Dressing or Bathing, Completing Errands, Communicating, Other Disability Type, Asked but No Answer, Not Disabled, and Disabled, No Disability Type Data.

Members may be included in multiple Disability Type categories.

It is estimated that one in four adults in the United States lives with a disability.² Persons with disabilities are more likely to report poorer overall health and have less access to adequate health care.³ In recognition of the need to advance equitable care and outcomes for persons with disabilities, NCQA conducted an environmental scan and developed the proposed *Disability Description of Membership (DDM)* measure as a potentially valuable tool to improve care for this population.

Throughout 2024, NCQA executed a comprehensive literature review of 1,400 articles, conducted 23 stakeholder interviews (with advocates, policymakers, payers, long-term services and supports providers, state agencies, disability community members), and convened a focus group of experts that provided feedback on the proposed concept over the course of three sessions between April and December 2024.

The DDM measure intends to promote collection and documentation of disability data that will be used for quality improvement efforts. Better disability data will allow identification of care disparities through stratification of quality measures; improved risk adjustment for strengthening the accuracy of quality measures and addressing problematic incentive structures; and development of targeted quality measures that address care gaps experienced by persons with disabilities.

The proposed measure would be in line with existing NCQA measures and programs regarding health plan demographic data. Since 2013, NCQA has developed and implemented measures that require health plans to report the completeness of race/ethnicity and preferred language data for their member populations. The *Language Diversity of Membership (LDM)* and *Race/Ethnicity Diversity of Membership (RDM)* measures provide valuable insight into the completeness of these data across product lines. Data from the RDM measure has been instrumental in implementing the race and ethnicity stratification in HEDIS.

Table 1 of the measure will include three data sources to identify populations with disability:

- *Questionnaire.* The best practice for collecting disability status data from members is administration of a self-reported questionnaire. Questionnaires may include, but are not limited to, the American

¹ HEDIS[®] is a registered trademark of the National Committee for Quality Assurance (NCQA).

² Centers for Disease Control and Prevention. 2021. *Prevalence of Disability and Disability Types.*
<https://www.cdc.gov/ncbddd/disabilityandhealth/features/disability-prevalence-rural-urban.html>

³ Centers for Disease Control and Prevention. 2020. *Disability and Health Information for Healthcare Providers.*
<https://www.cdc.gov/ncbddd/disabilityandhealth/hcp.html>

Community Survey Six-item (ACS-6) Disability Questions and the Washington Group Short Set (WG-SS) on Disability, which align with the current federal standard for disability data.

- *Accommodations*: Documentation of self-reported accommodation requests provides another pathway for identifying disability status. NCQA welcomes feedback on the list of accommodations in the measure specifications.
- *Enrollment Status*: Enrollment in health coverage programs based on eligibility due to disability is the least preferable method for collecting disability status, but is more valuable than not identifying any populations with disabilities. Disability status via enrollment may be furnished by state Medicaid agencies or patient enrollment information in claims.

Table 2 of the measure includes different types of functional disabilities, informed by two common standardized tools: the ACS-6 and WG-SS questionnaires. These include difficulty in performing the following functions: hearing, seeing, concentrating, walking, dressing/bathing, completing errands and communicating. NCQA acknowledges the limitations of identifying individuals with disabilities with these survey tools, and is prepared to update the measure upon release of more comprehensive tools in federal standards and definitions.

The measure includes a proposed restriction of age 15 and older. This is because age restrictions are included in the ACS-6 questionnaire for certain functional activities (e.g., difficulty in completing errands). Thus, an age limitation of members 15 years and older is included in the measure to standardize reporting across all disability types. Future efforts from NCQA will aim to include children and adolescents in the collection of disability data.

In fall 2024, NCQA surveyed organizations to gather preliminary information about disability data collection practices; 21 organizations responded. Results indicate that around half of respondents have ongoing efforts to collect data on disability directly from members, and around one third collect information on disability-related accommodations. The most commonly collected functional areas are vision difficulty and speech-related disability, followed by hearing difficulty, cognitive difficulty and physical disability. About half of organizations cited uncertainty on best practices and internal organization priorities as barriers to collecting the data. These findings suggest that a disability data collection measure could be feasible to implement, and useful for improving completeness of disability data across the health care system.

NCQA seeks general feedback on the measure, and specific feedback on the following:

1. Appropriateness of data sources in the measure.
2. Accommodations to include in measure specification.
3. Inclusion of disability type reporting in the measure.
4. Age restrictions in the eligible population.

NCQA expert panel members support the proposed measure, and believe it is an important step forward toward better disability data in health care.

Supporting documents include the draft measure specifications and measure workup.

NCQA acknowledges the contributions of the Health Equity Expert Work Group, the Technical Measurement Advisory Panel and the Disability Equity Focus Group.

Disability Description of Membership (DDM)

Description

Describes the disability status of members 15 years of age and older enrolled any time during the measurement year, including information by data source and disability type.

Calculations

Product lines	Commercial, Medicaid, Medicare (report each product line separately).
Age	15 years and older as of January 1 of the measurement year.
Table instructions	<p>Table DDM-A-1/2/3</p> <p>Enter the number of members by disability status and by data source, including reporting disability status information sourced from:</p> <ul style="list-style-type: none"> • Self-reported questionnaires. • Self-reported accommodations. • Obtained enrollment status/eligibility criteria. <p>For members whose disability status is not collected or not documented, include in “Missing” under <i>Disability Status</i> and “No Data” under <i>Source</i>.</p> <p>For members whose disability status is known, but the source is not traceable, include under the appropriate <i>Disability Status</i> and “Unknown” under <i>Source</i>.</p> <p>Table DDM-B-1/2/3</p> <p>Enter the number of members in each disability status category. Include members in “Other Disability Type” under <i>Disability Type</i> if their disability is not related to hearing, seeing, concentrating, walking, dressing/bathing, completing errands or communicating.</p> <p>Report members as “Disabled, No Disability Type Data” under <i>Disability Type</i> if their disability status is “Disabled” in Table DDM-A-1/2/3, but there is no documented disability type.</p> <p>Report members as “Not Disabled” under <i>Disability Type</i> if their disability status is “Not Disabled” in Table DDM-A-1/2/3.</p>
Data source	<p>Report the number of members for whom data has been collected from each data source for disability status. Data sources must fall into one of the following types: self-reported questionnaire, self-reported accommodations, enrollment status, unknown, no data.</p> <ul style="list-style-type: none"> • <i>Self-Reported Questionnaire</i>. Includes data the organization has collected directly from members; for example, through surveys, health risk assessments or case management systems. Questionnaires may include, but are not limited to, the American Community Survey Six-item (ACS-6) Disability Questions and the Washington Group Short Set (WG-SS) on Disability. LOINC codes may be used to report this source category and disability type.

- **Self-Reported Accommodations.** Organizations may collect information on accommodations requested by members. These may include, but are not limited to: wheelchair access, braille materials, text magnifiers, materials in large print, audio recordings of materials, sign language interpreters, audio described content, communication cards/boards, alternative communication devices, text-to-speech or speech-to-text applications, voice amplifiers, Communication Access Real Time Translation (CART), low stimulation environments, sensory fidgets, appointment time accommodations.
- **Enrollment Status:** Enrollment information furnished by state Medicaid agencies, patient enrollment information in claims.
- **Unknown:** When the reported disability status value is known, but the source is unknown (i.e., there is a disability status value on file from a legacy system, but the organization does not know the source).

Disability Type Definitions

Hearing	Member is deaf or has serious difficulty hearing.
Seeing	Member is blind or has serious difficulty seeing, even when wearing glasses.
Concentrating	Because of a physical, mental or emotional condition, member has serious difficulty concentrating, remembering or making decisions.
Walking	Member has serious difficulty walking or climbing stairs.
Dressing/Bathing	Member has difficulty dressing or bathing.
Completing Errands	Because of a physical, mental or emotional condition, member has difficulty doing errands alone such as visiting a doctor’s office or shopping.
Communicating	Using their usual language, the member has difficulty communicating; for example, understanding or being understood.
Other Disability	Member has another type of disability not captured above.
Asked But No Answer	Information was sought but not found (i.e., member was asked but didn’t know).

Notes

- *It is considered “best practice” to collect data directly from members, because this method reflects members’ self-identification. If self-reported data from a questionnaire is not available, disability status may be identified by the proxy of accommodation requests. If self-reported accommodations are not available, third-party data collected directly by another entity, such as the state or CMS, are desired. If multiple disability statuses are identified for a single member, report data source according to the following hierarchy: self-reported questionnaire, self-reported accommodations, enrollment status.*
- *When multiple sources of data are used, there may be disagreements in the data collected. To resolve a disagreement, the organization should use a logical process that considers the relative accuracy of each data source. One way to use a stepwise logic for a data disagreement is:*
 - *Select self-reported categories (questionnaire, accommodations) over indirectly measured categories (disability based on enrollment status).*

– If there is documentation that a member has a disability, include it in Table DDM-B-1/2/3.
The plan might also prioritize data sources based on analysis of the reliability of data sources.

Table DDM-A-1/2/3: Percentage of Members for Whom the Organization Has Disability Status Information by Data Source

Metric	DisabilityStatus	Source	Data Element	Reporting Instructions
DisabilityAndSource	Disabled	SelfReportedQuestionnaire	MemberCount***	For each Stratification
	NotDisabled	SelfReportedAccommodations	Rate	(Percent)
	Missing	EnrollmentStatus		
	Total	Unknown*		
		NoData**		
		Total		

* Source = "Unknown" is only reported for members who have DisabilityStatus = "Disabled" or DisabilityStatus = "NotDisabled," but the data source is unknown.

** DisabilityStatus = "Missing" is only reported for members with Source = "NoData" and Source = "NoData" is only reported for DisabilityStatus = "Missing"

*** MemberCount numbers in Table DDM-A-1/2/3 are mutually exclusive and will add up to 100% of the health plan population.

Table DDM-B-1/2/3: Disability Types Reported

Metric	Disability Type	Data Element	Reporting Instructions
DisabilityType	Hearing	MemberCount*	For each Type
	Seeing	Rate	(Percent)
	Concentrating		
	Walking		
	DressingBathing		
	CompletingErrands		
	Communicating		
	OtherDisabilityType		
	AskedButNoAnswer		
	NotDisabled		
	Disabled,NoDisabilityTypeData		
	Total		

*MemberCount numbers in Table DDM-B-1/2/3 are not mutually exclusive. Members can be included in multiple Disability Type categories.

Disability Description of Membership (DDM)

Measure Workup

Executive Summary

This workup focuses on identifying barriers and current quality measures in health care for persons with disabilities. Research questions regarding barriers, intersectionality considerations, policy implications and existing frameworks for quality measurement are assessed across three key populations in disability, aligned with the Biopsychosocial Model:

1. Individuals with visual, hearing or ambulatory disabilities as captured by the American Community Survey (ACS) questions.
2. Individuals with intellectual or developmental disabilities.
3. Individuals with chronic conditions that result in a disabling or potentially disabling condition.

Barriers range from systemic or population level (e.g., structural ableism, along with other intersecting identities and experiences of discrimination) to interpersonal (e.g., provider stigma, communication challenges) and individual levels (e.g., internalized stigma, fear of disclosure to providers, limited structural access). Gaps in maternal and reproductive health, care coordination and provider education can also perpetuate worse clinical and social outcomes in this population.

Organizations have made efforts to capture disability information through data collection and measurement, but existing quality measures for disability and care needs are limited due to their reliance on patient-reported indicators, underutilized measurement tools and restricted data collection and reporting on disability.

Based on the findings gathered through the environmental scan, the National Committee for Quality Assurance (NCQA) is considering these gaps, and recommendations for improvement, as we identify opportunities to leverage HEDIS^{®1} measures and standards to address disability equity.

Environmental Scan Methods

Literature Review

NCQA conducted a literature review from February–July 2024 to gain an understanding of health care quality for individuals with disabilities. Key areas of interest were identified based on the following research questions, grounded in the Biopsychosocial Model:²

1. What systemic barriers have been identified for people with disabilities? What unique challenges are experienced by persons with disabilities through an intersectional lens?
2. Have best practices or interventions been identified for supporting inclusion and improving health outcomes for persons with disabilities?
3. Are there frameworks or indicators for monitoring the progress of disability initiatives over time (nationally, state level or within organizations)?

¹ HEDIS[®] is a registered trademark of the National Committee for Quality Assurance (NCQA).

² Wade, D.T., & P.W. Halligan. 2017. "The Biopsychosocial Model of Illness: A Model Whose Time Has Come." *Clinical Rehabilitation* 31(8), 995–1004. <https://doi.org/10.1177/0269215517709890>

4. What measures exist for assessing the quality of care for populations with disabilities? What gaps exist? Could these measures create unintentional consequences that might harm persons with disabilities?

The review evaluated literature published in the US between January 1, 2018, and February 1, 2024. The literature search was conducted through PubMed. Over 10,000 articles were screened, resulting in 1,400 articles undergoing final review. The team subsequently conducted an abstract extraction to compile major resulting themes, findings and populations of study.

Stakeholder Interviews

NCQA conducted 23 semi-structured interviews with stakeholders across perspective groups, including advocates, policymakers, payers, long-term services and supports providers, state agencies and disability community members. Contacts were identified through existing organizational relationships, web search and stakeholder recommendations. Outreach was conducted through email, and 1-hour interviews were held with each individual/organization between April and July 2024.

NCQA created an interview guide for consistency that included discussion questions about the representative and/or their organization; motivations for engaging in the disability space; organizational use of data (as relevant); goals for the disability community; potential challenges/barriers to these goals; and NCQA's opportunities for involvement.

Findings

Environmental scan results are summarized in several themes, listed below. While priorities, experiences, concerns, challenges and successes shared during the interviews were consistent with the literature review, they also contributed valuable insights about the opportunities for measures and standards concepts.

Ableism and Stigma, Bias and Discrimination Toward People With Disabilities. The literature review identified that stigma, bias and discrimination experienced by this population in medical and societal settings lead to depressive symptoms and stress, heightened effect of negative environmental factors and decreased social function. Explicit/implicit provider bias against treating persons with disabilities negatively impacts patient-provider relationships, reduces patient engagement in clinical care and potentially induces fear. Stigma and bias rooted in ableism prevent this population from receiving comprehensive care from providers, who may feel inexperienced in caring for persons with disabilities. Providers may also take an “over-medicalized” approach to treatment, highlighted as a concern in interviews. Ableism reduces the number of clinicians with disabilities in the field due to prominent cultural and structural barriers to attending medical school. The intersection of marginalized identities and disability can result in disproportionately worse health and social outcomes for persons with disabilities.

Accessibility of Care. Environmental scan findings emphasized that the lack of accessibility, especially for medical diagnostic equipment (e.g., patient exam tables, scales), and accommodations for people with intellectual and developmental disabilities (e.g., autism) can result in delayed or foregone care, and reduce patient engagement. Outside medical settings, many persons with disabilities rely on public and other transportation to travel to appointments. Difficulties or delays with transportation, particularly for those who need assistance with mobility, can result in missed or rescheduled appointments. Minimal compliance with the Americans with Disabilities Act (ADA) and the potential high financial cost of implementing accessible medical equipment impede access to health settings and worsen health for this population.

Communication Challenges: Challenges in communication can affect the patient-provider relationship and result in decreased patient understanding, lower rates of appropriate response to patient accommodation requests, growing patient frustration and potential mistrust of providers. These can reduce coordination and quality of patient-centered care and deviate from expected compliance with ADA accommodations.

Maternal and Reproductive Health. Environmental scan findings stated that barriers faced by persons with disabilities range from discussing contraceptive care with clinicians to receiving adequate and comprehensive care during pregnancy. Some persistent challenges include limited adoption by providers of communication modification requests, lack of provider awareness or accommodations during pregnancy, lack of access to reproductive health and contraception education, stigma and ableism resulting in persons with disabilities not being offered reproductive care and reduced screening rates for breast and cervical cancer. The end result can be significantly worse clinical outcomes, including higher likelihood of ED visits during pregnancy or postpartum hospitalization, and increased concerns about judgment, discrimination and intrusive provider surveillance.

Disability Data Collection and Measurement. Stakeholder interviews highlighted the limited standardization in data collection and use, although there has been movement toward inclusiveness and urgency in data collection. The ACS-6 and Washington Group Short Set on Functioning (WG-SS) are the most widely used methods to measure disability, despite severely undercounting populations and failing to capture the type and extent of disability among persons with disabilities. The ACA mandates collection of data on disabilities, and the HHS employs the ACS-6 questions in data standards.³ More recently, the NIH designation of persons with disabilities as a population that experiences disparities, re-evaluation of disability data collection methods by the Census Bureau and development of a roadmap outlining immediate, mid- and long-term goals for disability status data collection bring needed attention to measurement and equity for this population.⁴

Although the landscape for disability quality measurement lacks systemic accountability, some measurement programs—the National Core Indicators for Intellectual and Developmental Disabilities Surveys, the National Core Indicators for Aging and Disabilities, The Consumer Assessment of Healthcare Providers and Systems (CAHPS), Personal Outcome Measures by the Council on Quality and Leadership, and others—act as frameworks or tools for assessing the quality of care for persons with disabilities. These programs rely on patient reporting and voluntary reporting, which highlights the need for disability measurement in accountability programs. Further use for disability data in quality measurement includes stratification and risk adjustment—two approaches that would illuminate disparities and equip health systems with tools to address them.

Opportunities for Measurement

There are several potential routes for utilizing plan-level quality measurement to equip health systems with tools for quality improvement and disability equity:

Disability Data Collection. Methods for collecting and documenting disability status data are not standardized, and the ACS-6 and WG-SS do not comprehensively capture data from this population. Survey tools with self-reported disability, and efforts to incorporate disability status collection in health systems, aim to address gaps in availability of disability data. NCQA has the opportunity to elevate a standard for inclusive and equitable collection of disability status and promote collection and documentation activities across health plans.

³ U.S. Department of Health & Human Services, Office of Minority Health. (n.d.). Data Collection Standards for Race, Ethnicity, Sex, Primary Language, and Disability Status." <https://minorityhealth.hhs.gov/data-collection-standards-race-ethnicity-sex-primary-language-and-disability-status>

⁴ Landes, S.D., B.K. Swenor, M.A. Clark, K.S. Goddard, J.P. Hall, A. Hermans, C. Ipsen, M. Karpman, N.K. Kurth, A. Myers, S.J. Popkin, M.R. Salinger, & Vaitsiakhovich, N. (n.d.). *A Research Roadmap Toward Improved Measures Of Disability*. Retrieved July 17, 2024, from <https://www.healthaffairs.org/doi/10.1377/forefront.20240708.306851/full/>

Measure Stratification. Stratification of performance measures increases understanding of the extent of disparities. Stratification has been implemented in key demographic populations, and provides tools for quality improvement programming. Insights from stratification by disability using dual eligibility status show that disparities exist.⁵ Given the limited portion of the disability population captured through this approach, it might not accurately describe the extent of disparities experienced by persons with disabilities. Efforts to stratify performance with complete disability status information, and by disability type, will produce better opportunities for addressing disparities—these would require complete, comprehensive data on disability status.

Risk Adjustment. Risk adjustment models in quality measurement are a tool for accounting for factors which may play into measure scores, and allow for the development of measures that more accurately capture quality and improve fairness in comparing performance. Disability is included as a minimum set of variables for risk adjustment, according to a technical guidance report by the National Quality Forum (NQF) that outlines data availability and development considerations regarding disability as a social risk factor, and a functional status factor in risk adjustment models.⁶ Work to risk-adjust for disability status has been potentially effective for improving accuracy of quality measures and alleviating incentives for providers to avoid caring for more challenging patient populations.⁷ Risk adjustment has potential for addressing problematic incentives in reimbursement structures; ameliorating disability status data collection and documentation would allow for improvements to risk-adjustment models.

Targeted Measures. Several aspects of quality in care for disability subpopulations are particularly lacking. To address these, NCQA could develop targeted measures focused on maternal and reproductive health access for persons with disabilities or care for persons with intellectual disabilities, given the gap in data and literature regarding care and outcome disparities for this population. There are opportunities to collaborate with initiatives across NCQA that focus on equity measurement for birth equity and behavioral health.

⁵ Center for Medicare & Medicaid Services. (2023, May). *Disparities in Health Care in Medicare Advantage Associated with Dual Eligibility or Eligibility for Low-Income Subsidy and Disability*. CMS.Gov.

<https://www.cms.gov/files/document/2023-disparities-health-care-medicare-advantage-associated-dual-eligibility-or-eligibility-low.pdf>

⁶ National Quality Forum. (2022, December 21). *NQF: Risk Adjustment Technical Guidance Final Report—Phase 2*.

https://www.qualityforum.org/Publications/2022/12/Risk_Adjustment_Technical_Guidance_Final_Report_-_Phase_2.aspx

⁷ Sorbero, M., Susan M. Paddock, P., Damberg, C., Ann Haas, M. S., Mallika Kommareddi, M. P. H., Tolpadi, A., Megan Mathews, M. A., & Elliott, M. (2018). *Adjusting Medicare Advantage Star Ratings for Socioeconomic Status and Disability*. 24. <https://www.ajmc.com/view/adjusting-medicare-advantage-star-ratings-for-socioeconomic-status-and-disability>