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Current State of Disability Status Collection in Health Settings

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Background

People with disabilities experience barriers in health settings that lead to worse health outcomes. Though defining 'disability' is nuanced, identifying populations with disabilities by **collecting disability status data is the first step to understanding the extent of health disparities faced by individuals with disabilities and operationalizing data for driving equity.** Prominent disability researchers and advocates published a roadmap for disability status measures that urges the implementation of existing disability measures and working towards more-inclusive measurement practices to ensure appropriate allocation of resources and disability programming.[1] The National Committee for Quality Assurance (NCQA) distributed a virtual survey on disability status collection practices in health settings to understand the current state of disability status collection and to inform development of measures and standards for disability equity.

Landscape of Disability Status Data Collection

Organizational Approach to Collecting Data on Disability Status

NCQA acknowledges that there are varying definitions for disability used by organizations for different purposes. Through this survey, NCQA is requesting additional information about your organization's efforts to understand 1) if and/or how functional aspects of disability (e.g., hearing, seeing, walking) are documented for members, 2) how your organization is currently collecting data on disability, and 3) if there are any opportunities for your organization's members to self-report their disability status. Please proceed to answer the next set of questions on your organization's approach to collecting data on disability status.

* 4. Does your organization have any ongoing efforts to collect data on disability status directly from members/patients?

○ Yes, across all populations.

○ Yes, for specific sub-populations (e.g., by product line, age range, risk group).

○ No, there are no organizational initiatives for collecting disability status data.

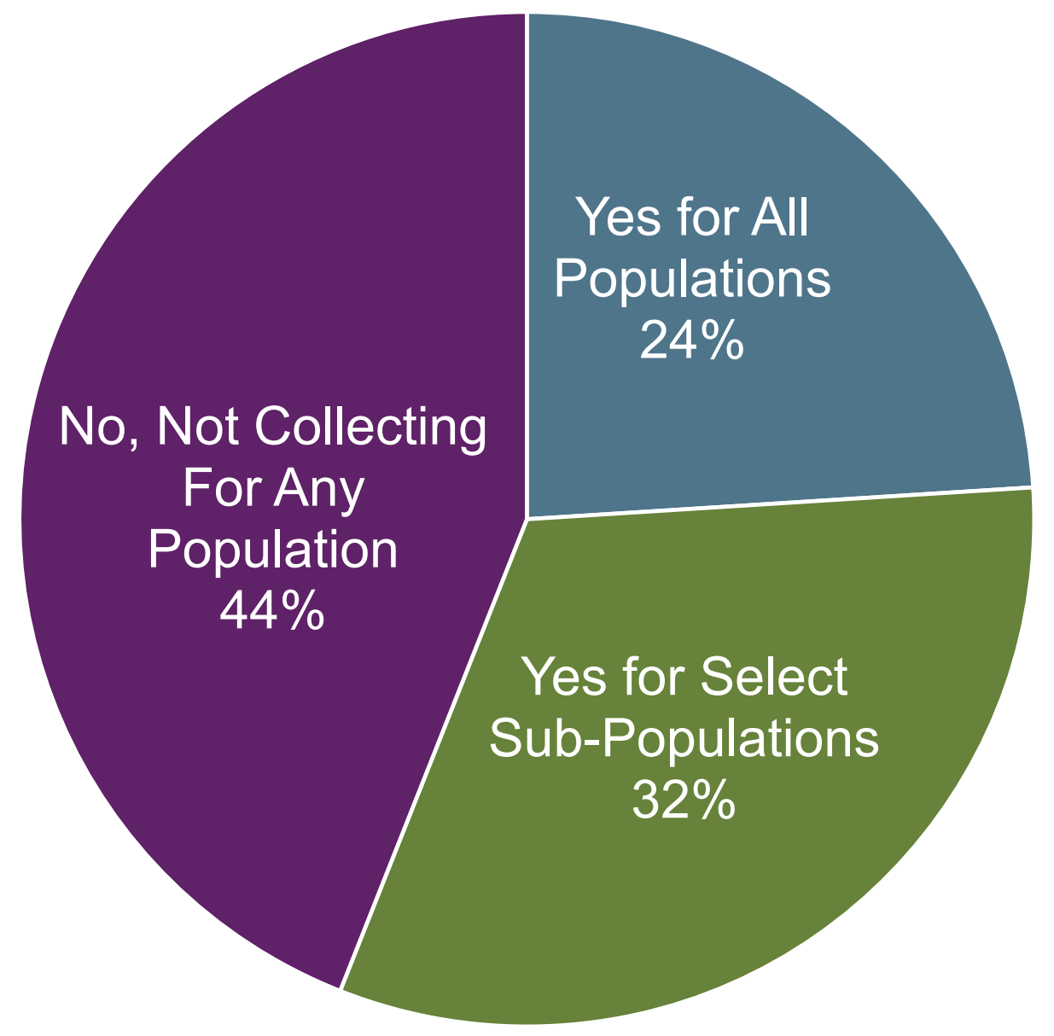
Results

Are health organizations collecting disability information?

Over half (56%) of the 21 participating health organizations reported that they have some ongoing efforts to collect disability information from their members. Some respondents indicated which sub-populations they collected disability information on, which included

- children with special needs
- pregnant people
- individuals with complex conditions

Figure 1. Proportion of Health Organizations Collecting Disability Data



***How* are health organizations collecting disability information?**

Ten organizations (48%) reported having ongoing efforts to collect disability status directly from members.

- Few utilized standard questionnaires such as the American Community Survey six questions on disability (ACS-6) or the Washington Group Short Set on Functioning (WG-SS).

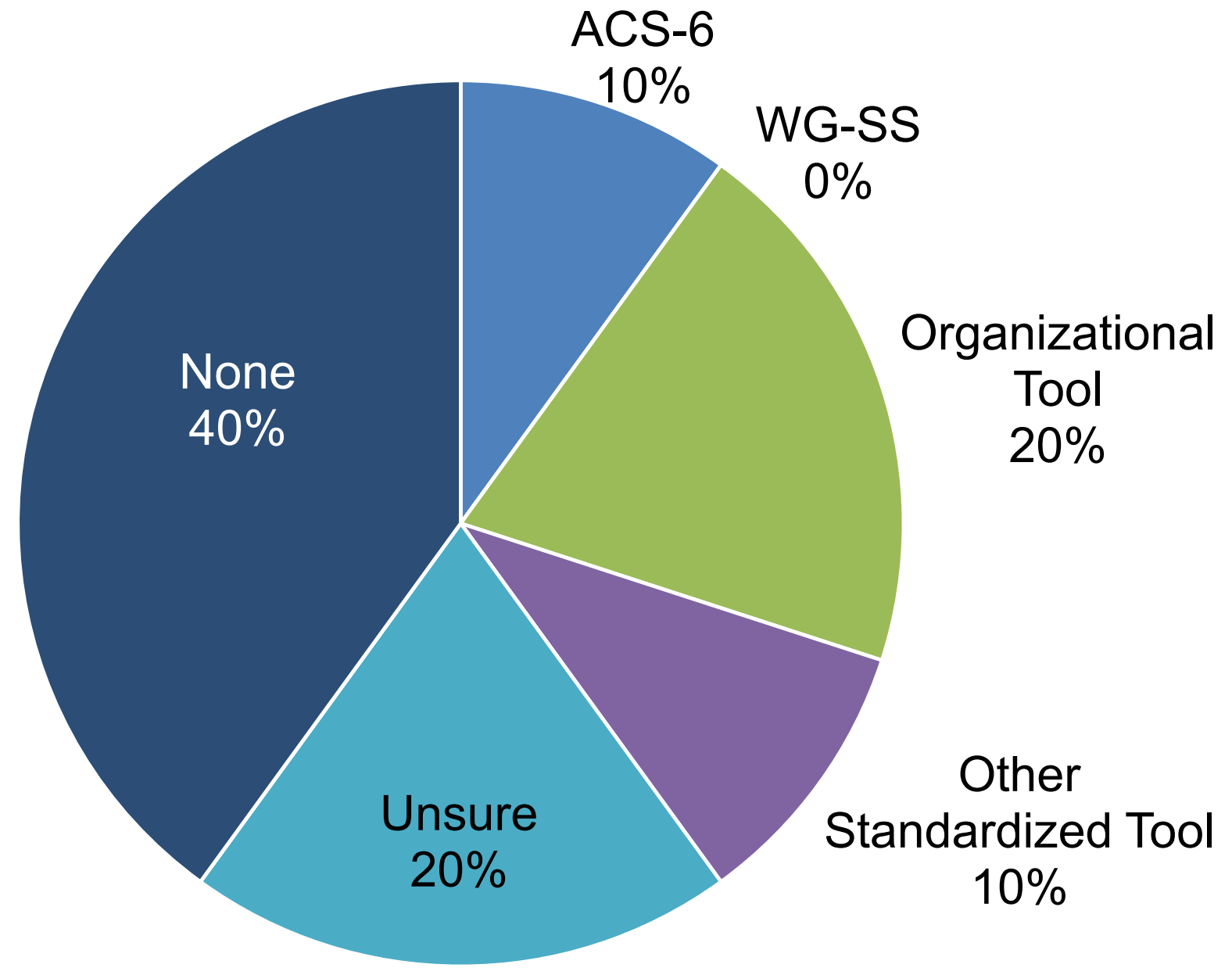
Seven organizations (33%) responded that they make note of disability-related accommodation requests.

- Level of standardization of accommodations list or accommodation request details varied.

Health organizations estimated the completeness of documented disability status across their populations.

- Equal distributions across the estimate categories, ranging from no access to disability data to disability documented for >75% of population.

Figure 2. Standardized Tools Used by Health Organizations to Collect Data on Disability



***What* disability information are health organizations collecting?**

Most commonly collected functional areas:

- vision difficulty
- speech-related disability,
- hearing difficulty
- cognitive difficulty
- physical disability

Least commonly collected functional areas:

- independent living difficulty
- attention-deficit disorder (ADD) or attention-deficit/hyperactivity disorder (ADHD)
- immunology related disability
- traumatic brain injuries (TBI)

What *prevents* organizations from collecting disability data?

Most commonly selected barriers to disability data collection:

- Uncertainty on the best practices or best approach
- Internal organization priorities

Other commonly selected barriers:

- Lack of staffing resources
- Lack of standardized tools or IT resources

Figure 3. Barriers to Implementation of Disability Data Collection

Study Design

Study Population

Total of 21 respondents

- 10 health plans
- 6 health systems
- 5 integrated organizations
- Geographically diverse regions (including Midwest, West, Mid-Atlantic, and national networks)
- 14 served commercial populations,16 served Medicaid populations, and 18 served Medicare populations

Table A. Study Population Attributes

RECRUITMENT AND METHODS

- Survey disseminated to health organizations in NCQA's network via newsletters, direct outreach, and social media. Survey was open October to November 2024.
- Survey asked 20 multiple choice and free-text questions on organization demographics, approaches to collecting data on disability, sources and storage of disability data, and completeness of disability data for their membership.

Functional Areas	Percent of Health Orgs Collecting Disability Data
Hearing difficulty	60%
Vision difficulty	70%
Cognitive difficulty	60%
Ambulatory difficulty	40%
Self-care difficulty	30%
Independent living difficulty	20%
Communication difficulty	50%
Walking difficulty	50%
ADD or ADHD	20%
Autism/autism spectrum disorder	40%
Chemical dependency	30%
Health-related disability	50%
Intellectual disability	50%
Immunology related disability	20%
Learning disability	40%
Mental health condition	30%
Mobility-related disability	50%
Physical disability	60%
Speech-related disability	70%
Traumatic brain injury	20%

Legend:
Green = Collected by >50% of plans which collect disability data
Yellow = Collected by 20-50% of plans which collect disability data
Red = Collected by <20% of plans which collect disability data

Table B. Disability-Related Functional Areas Collected by Health Organizations Which Have Disability Data Collection Practices Implemented

Conclusion

Variation across health organizations on their disability data collection practices suggests that there are **substantial opportunities for improving consistency and standardization of disability data collection practices.** Health organizations will benefit from stronger standards and clarity on best practices. With improved disability data collection, the health industry will be better equipped to advance health equity for individuals with disabilities.

Implications for Policy

Improving disability data collection will require a concerted effort throughout the industry. Better disability information of populations relies on policy initiatives which incentivize the documentation and use of standardized disability data. For example, America's Health Insurance Plans (AHIP), in collaboration with Civitas Networks for Health and Health Level Seven® International, have established an initiative to improve demographic data standards, including for disability.[2]

Health organizations will be equipped with important information regarding the demographics and needs of the populations they serve.

AHIP + CIVITAS Networks for Health + HL7 International

Health researchers will have better data to inform disparities research, including stratification of quality metrics and risk adjustment modeling.

People with disabilities will benefit from targeted quality + care experience improvement and more equitable resource distribution.

References

1. "A Research Roadmap Toward Improved Measures Of Disability", Health Affairs Forefront, (2024) DOI: 10.1377/forefront.20240708.306851
2. *Demographic Data Element Modernization (DEMo) Initiative*. Civitas Networks for Health. (2025). https://www.civitasforhealth.org/demographic-data-standards/

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