



Measuring Disability and Functioning in Studies of Aging

NIMLAS-MiCDA Workshop
October 8, 2026

Agenda for today

12:05-12:50 pm: Disability & functioning as concepts—what are studies of aging trying to measure?

12:50-1:10 pm: Connecting the reason for collecting disability & functioning in studies of aging with measurement decisions

1:10-1:30 pm: Survey design considerations for measuring disability & functioning in studies of aging

1:30-1:45 pm: Break

1:45-2:45 pm: How are disability & functioning currently captured in studies of aging?

2:45-3:15 pm: Novel and ancillary ways to capture disability & functioning in studies of aging

3:15-4:00 pm: Measurement Clinic: Aligning disability & functioning measures to your study purpose

Disability and functioning as concepts—What are studies on aging trying to measure?

Vicki A. Freedman, PhD

Measuring Disability and Functioning in Studies of
Aging NIMLAS-MiCDA Workshop

October 8, 2026

Overview

- History of disability models
- Why these distinctions matter
- Considerations around context and language

History of disability models

Brief History

- Early 1800s: diagnostic tools (e.g. stethoscope) cast physicians as "objective" arbiters of who did and did not have disability



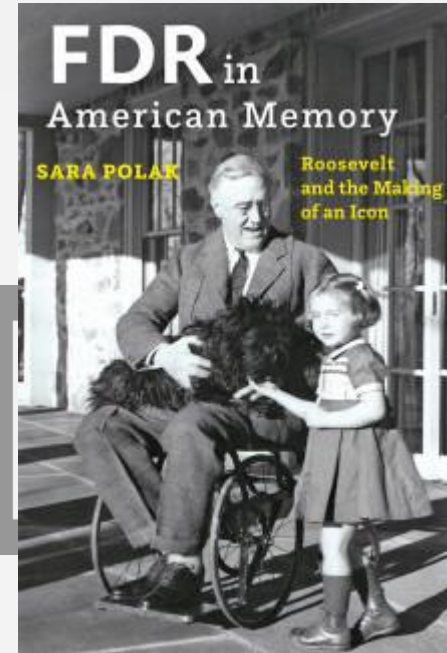
Dr Constantin Paul using the Galante stethoscope, c.1885.
(Science & Society Picture Library)
<https://www.historytoday.com/archive/invention-stethoscope>

Adapted from: lezzoni & Freedman, JAMA, 2008

The Medical Model

- Views disability as a problem of the person, directly caused by disease, trauma or other health condition
- Is aimed at cure or the individual's adjustment and behavior change
- Presumes that physicians know what is best for patients
- Dominant model since 1800s, incorporated into many disability programs
- No environmental role

Adapted from: lezzoni & Freedman, JAMA, 2008



Picture of Franklin D. Roosevelt in a wheelchair, 1941.

The Social Model

- Views the issue mainly as a socially created problem
- Is aimed at the full integration of individuals into an accessible society
- Recognizes that disability is not an attribute of an individual, but created by the social environment
- Came about in the 1970s and 1980s
- Complete focus on environment

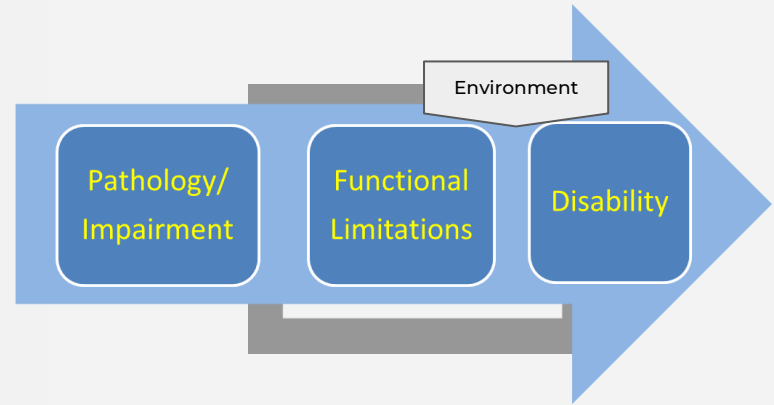


Time magazine cover featuring Judith Heumann, Fighting for Access, Women of the Year for 1977 (selected in 2020)

Adapted from: lezzoni & Freedman, JAMA, 2008

Nagi/IOM Model of Disability

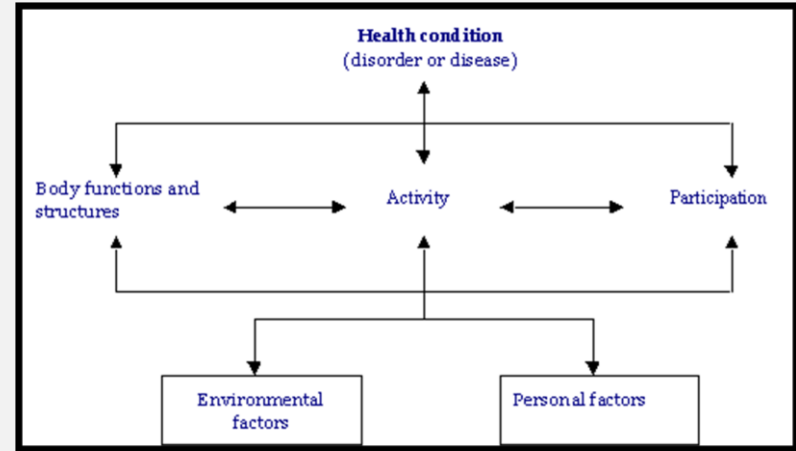
- Pathology/impairment occurs at the level of an organ or system (arthritis of the knee)
- Functional limitations are restrictions or lack of abilities assessed in a manner to eliminate environmental influences. (inability to kneel)
- Disability is any restriction or lack of ability to perform an activity in the individual's environment (inability to work at a job requiring kneeling)
- Dominated geriatric research 1980s, 1990s
- Environment distinguishes functional limitations from disability



Nagi/IOM Model of Disability has three stages of progression: Pathology/impairment, functional limitations and disability.

The World Health Organization (WHO) ICF Model

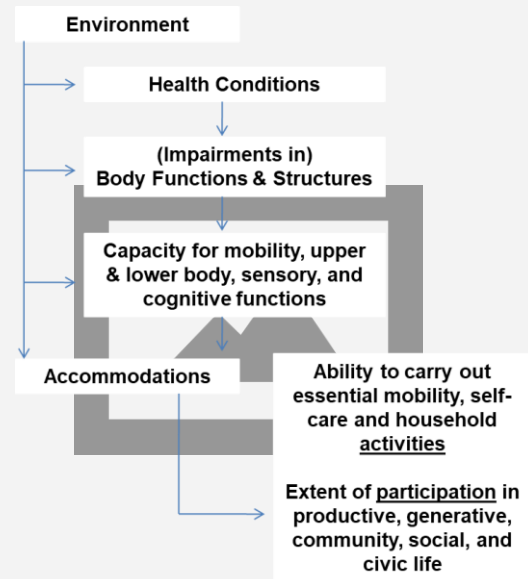
- International Classification of Functioning, Disability and Health (ICF) is a classification scheme that integrates both medical and social perspectives
- Emphasizes positive language
- Defines disability as an umbrella term for "impairments, activity limitations or participation restrictions"
- Functioning is positive analogue
- 2000s, especially outside US
- Environment influences main path



ICF Model of Disability. Classification scheme that defines disability as an umbrella term that includes impairments in body functions, activity limitations, and participation restrictions.

The National Health and Aging Trends Study (NHATS) Disability Model

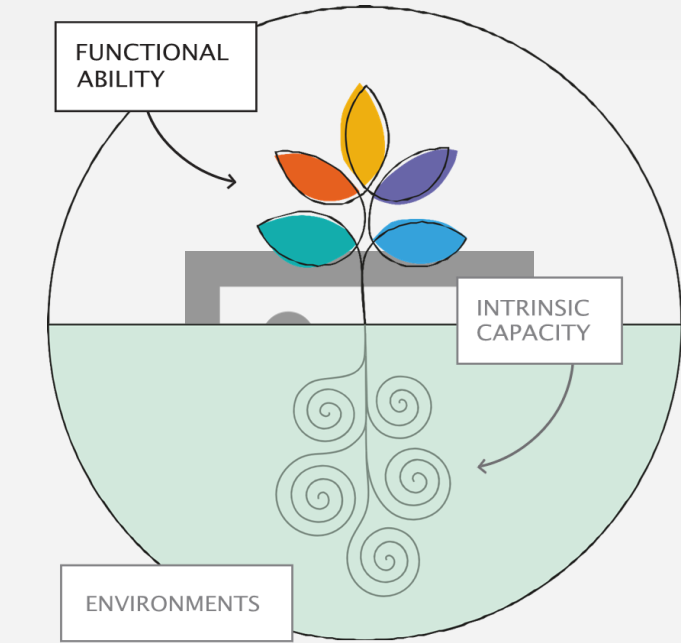
- Builds on Nagi/IOM using ICF language
- Distinguishes capacity (without accommodations in a controlled environment), from accommodations that are put into place (e.g., devices, environment changes, behavior change, help from another person), from the ability to carry out essential activities and to participate in valued activities
- Environment influences entire process



NHATS Disablement Framework blends elements of the ICF language with the Nagi/IOM disablement model.

World Health Organization's Healthy Aging Model

- The process of developing and maintaining the functional ability that enables wellbeing in older age
- Includes: 1) ability to meet one's basic needs; 2) ability to learn, grow and make decisions; 3) mobility; 4) ability to build and maintain relationships; and 5) ability to contribute.
- Functional ability reflects both intrinsic capacity and the environments in which people live.



All Models: Disability is Not Poor Health

- **Disability**

- Refers to how a person interacts with their environment
- Physical, sensory, or cognitive differences are not necessarily treated; they may be accommodated
- Can have a disability and be in excellent health

- **Poor Health**

- Refers to absence of physiological or psychological well-being
- Conditions underlie poor health are typically treated
- Can be in poor health and not have a disability



Why these distinctions matter

Disability models have evolved

- Newer models recognize the environment and how accommodations improve older adults lives



Nuance is needed to understand older adults' daily lives

- Recognition of environmental component and its intersection with individual abilities can facilitate participation in valued activities
- Distinctions help focus on how well accommodations enable older adult to carry out activities independently – helpful for targeting interventions
- Durable medical equipment, assistive devices, and environmental changes matter in the lives of older adults



Nuance is needed to understand older adults' daily lives (continued)

- Behavior changes are important because they may signal impending difficulties (preclinical disability)
- Self-care and mobility are critical daily activities, but quality of life more affected by other kinds of elective (valued) activities – e.g. participation in productive, generative, community, social, and civic life



Disability is a disparity group

- Adults with disabilities
 - Experience higher rates of chronic illness and mortality
 - Are much more likely to delay or not receive essential medical care
- Poor health outcomes faced by people with disabilities may stem from inaccessible environments—not the disability itself
- NIH formally designated people with disabilities as a health disparity population in 2024
- Need to be able to identify



Considerations around context and language

Context Matters

- Environments vary by state, country, urban/rural settings
- Culture affects how concepts are perceived and questions about difficulty/ability are answered



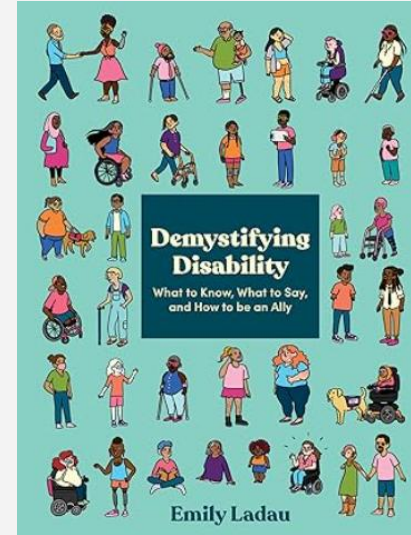
Photo source: Farmer with disability using accessible tractor.
<https://news.clemson.edu/clemson-and-s-c-state-collaborate-to-bring-agrability-to-south-carolina/>



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The Language of Disability

- Language evolves
 - Person-first language: people with disabilities
 - Identity-first language: disabled people
- *Demystifying Disability*, by Emily Ladau



Examples of Disability Terminology

Terms to use

- Disability
- Disabled
- Person who uses a wheelchair
- Person w/high support needs
- Has a disability

Terms to avoid

- Handicapped
- Differently abled
- Wheelchair-bound/confined to a wheelchair
- Low functioning
- Suffering from/with

Source: *Demystifying Disability*, by Emily Ladau



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Connecting the reason for collecting disability/functioning in studies of aging with measurement decisions

Jody Schimmel Hyde, PhD

Measuring Disability and Functioning in Studies of Aging

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Connecting purpose to measurement

- Reasons to measure disability
- Considerations for measuring disability
- Why can measuring disability be political?

Reasons to measure disability

Why measure disability in an aging population?

- Determine program eligibility
- Capture daily living
 - Point-in-time measurement
 - Assess unmet need for care, supports, accommodations, assistive tech
 - Understand environmental barriers and participation limitations
 - Track population-level changes as population ages and individual-level changes with age
- Identify disparity population
 - Document prevalence, measure disparities

What do *you* need to know about disability/functioning for your study?

- Overall or in activity domains
- Context(s) in which disability occurs
- Assistance needs, using assistance
- Severity
- Timing, onset, duration
- Self-reported versus performance-based



Photo credit: Disability:IN



Disability with aging vs. aging with disability

- Disability with aging: Prevalence and incidence of activity limitations and participation restrictions within and across cohorts; unmet care needs; use of assistance, accommodations, and technology
 - Many/most longitudinal surveys of aging focus on disability with aging
- Aging with disability: Exposure to disability earlier in the life course □ cumulative disadvantage, accumulated experience with systems
 - Left censoring (lacking information before a certain age) can make it difficult to identify this group—lacking disability onset date, but also who participates in survey

Considerations for measuring disability

The disability experience is not binary

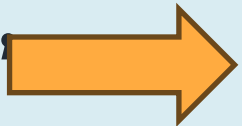
- Disability crosses sex, race, ethnicity, education, income, geography...and culture matters
- Can happen at any time from birth to death—length of exposure varies
- Varies in severity—across people and time
- Varies across body system affected—and based on environment
- Visible or invisible, or both



Photo credit: Disabled and Here



**Disability is multifaceted,
across people and time**



**There is no single, one-size-fits-
all, survey measure of disability**



Federal programs measure disability differently (1)

- About 70 different definitions in federal programs!
- Americans with Disabilities Act (ADA) definition, also adopted by NIH

A person who has a physical or mental impairment that substantially limits one or more major life activities, a person who has a history or record of such an impairment, or a person who is perceived by others as having such an impairment.

Federal programs measure disability differently (2)

- Social Security (and Medicaid, in most cases) definition

A medically determinable physical or mental disability(ies) that is long-lasting or will result in death and makes a person not be able to engage in any substantial gainful activity (SGA).

- Older Americans Act definition

Mental or physical impairment, or a combination of mental and physical impairments, that results in substantial functional limitations in at least one area of major life activity ***including self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, economic self-sufficiency, cognitive functioning, and emotional adjustment.***

For more examples: New Editions Consulting Inc. (2024). Federal statutory definitions of disability. Washington, DC: Interagency Committee on Disability Research.

Why can measuring disability be political?



Why is disability measurement political?

- Strength in numbers: Showing the importance of programs to support people with disabilities (VR, Medicaid, transportation, personal assistance, special education)
- Social services grant funding tied to number of people with disabilities
 - E.g. Enhanced Mobility of Seniors and Individuals with Disabilities (FTA Section 5310)
 - Protection and advocacy funding allocated across states based on #s



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Survey design considerations for measuring disability and functioning in studies of aging

Vicki A. Freedman, PhD

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Inclusion of individuals with disability in national surveys is incomplete

- Cirilli et al. 2024 surveyed 30 national federal surveys of adults conducted by HHS or Census from 2018-2023
- Found that strategies to include individuals with disabilities not systematic or in widespread use
- Can lead to under-representation of individuals with disabilities



Design decisions matter

Survey design considerations

- Sample of interest
- Mode & related considerations
- Other design considerations

Sample of interest

Sample of interest: considerations (1)

- Are you studying
 - disability with aging (start older, typically 65+), or
 - adults aging with disability (start younger)

Sample of interest: considerations (2)

- Is sampling based on residential status?
 - Does the study include only the community?
 - Are residential care settings (assisted living, nursing homes) included?



Sample of interest: considerations (3)

- Does the frame consist of beneficiaries, residents, patients or some other group?



Mode & related considerations

Mode: In Person (1)

- Interviewers need to be trained to work with older adults who have impairments
- Training may include:
 - how to identify cognitive impairment that may require a proxy/assistant
 - how to adjust the interview to accommodate hearing or vision impairments
 - how to handle slow responses or the need to take breaks



Mode: In Person (2)

- Lab-based studies may bias participation toward those able to access transportation and/or living nearby
- Home-based studies less likely to introduce this bias but measurement options may be more limited



Mode: Telephone

- Design so that those with hearing impairments can participate (e.g., captioning, text technology)
- Severe cognitive impairments may preclude telephone interviewing
- If interview is long, design so that respondents can take breaks (modular design)



Mode: Online

- Access increasing among older adults, but still lower among those with activity limitations or cognitive limitations
- Severe cognitive impairments may preclude online interviewing
- Design so that online instruments are accessible to those with low vision
- Reading should be at 8th grade level
- If interview is long, design so that respondents can take breaks (modular design)



Mixed Mode

- Consider offering multiple modes to maximize participation
- For instance, offer interview online, by phone, and if needed in person
- Important to design questionnaires to minimize mode effects and/or maximize quality in each mode



Other design considerations

Study recruitment

- Think about inclusively designed materials
 - Reading level
 - Large print
 - Online accessibility



Advisory Boards and Community Partnerships

- Consider including an Advisory Board that has older adults with disabilities
 - May result in improved survey clarity, accessibility, and relevance
- Consider letters of support from community partners to facilitate recruitment
 - May enhance trust

Cristensen et al. 2025
<https://doi.org/10.1016/j.trip.2025.101702>



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Proxy interviews

- ~7%-8% of older adults unable to be interviewed in face-to-face interview; higher if survey is only online
- Need to identify a close contact, familiar with daily routine
- Questionnaire needs to be designed for proxies (e.g., Are you/Is {name of sample person})
- Literature suggests that a proxy respondents is more likely than the older adult to report that the sample person has difficulty



How are disability and functioning currently captured in studies of aging?

Jody Schimmel Hyde, PhD

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Existing measures of functioning and disability

- Capturing daily living
- Counting/identifying disparity populations
 - Domain-focused
 - Global self-identification



Capturing daily living

Overview of session

- To capture the dynamic age-related disablement process, and what is driving late-life disability trends, researchers need to know:
 - Which activities are limited, and in what ways
 - Including how the activity is carried out
 - How the environment affects activity completion
 - Physical modifications & devices
 - Human support

What activities might disability affect?

- **Mobility:** Walking across room, getting outside, walking distances, stairs, getting in/out of bed
- **Self-care:** Bathing/showering, dressing, eating/drinking, toileting
- **Household:** Cooking/meal prep, managing finances, managing medication, housekeeping/laundry, phone/computer/email, driving/transit
- **Participation:** Work, social engagement, other valued activities

How are activities completed?

- Use of devices, other technology
- Receipt of help from others / level of independence
- Level of difficulty: Not at all, a little, somewhat, very difficult, can't do, don't do
 - Under what circumstances? With or without devices/independently (or ambiguous)
 - Attribution of difficulty: Because of a physical, mental, emotional condition?
- Duration, frequency



Photo credit: In-Press Photography via Age Without Limits



Survey design considerations

- Question ordering to learn about role of environment
- Question wording
- Response categories
- Skip logic/survey flow
- Temporal patterns

The next slides walk through some examples of these considerations using the HRS and NHATS.

Crimmins EM, et al. Documentation of Physical Measures, Anthropometrics and Blood Pressure in the Health and Retirement Study. Ann Arbor, Michigan: ISR, UM; 2008.

Freedman VA, et al. Validation of new measures of disability and functioning in the National Health and Aging Trends Study. Journal of Gerontology, Series A, 2011, 66(9):1013-21. doi: 10.1093/gerona/glr087.



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Question ordering: Activity assistance

- Ask about help/devices only after difficulty reported (HRS)
- Ask about difficulty after asking about devices/help used to complete activity (NHATS)
 - Activity carried out with devices? With help (because of health or functioning)?
 - If did not receive help all the time, difficulty carrying out activity independently (with devices)
 - Changes in behavior (doing activity less often)

Question wording primes respondents

- **HRS:** “...difficulty dressing, including putting on shoes and socks?”
- **NHATS:**
 - “By getting dressed we mean changing out of the clothes you slept in.”
 - “Did you use any special items to get dressed, such as a button hook, reacher or grabber, or clothes that are designed to get on and off easily?”
 - In the last month, did anyone ever help you get dressed, for instance, by getting clothing over your head, helping with clothing behind your back like a belt {or bra}, or helping you put on socks or shoes?

Response categories to differentiate difficulty

- Binary yes/no difficulty (HRS)
 - Options for can't do/don't do
- None, a little, some, a lot of difficulty (NHATS)
 - Only asked if done by self in the last month
 - Difficulty with devices (if reported that devices used)

Temporal details about activities

- Limited, without specifying period (HRS)
- Last month (NHATS)

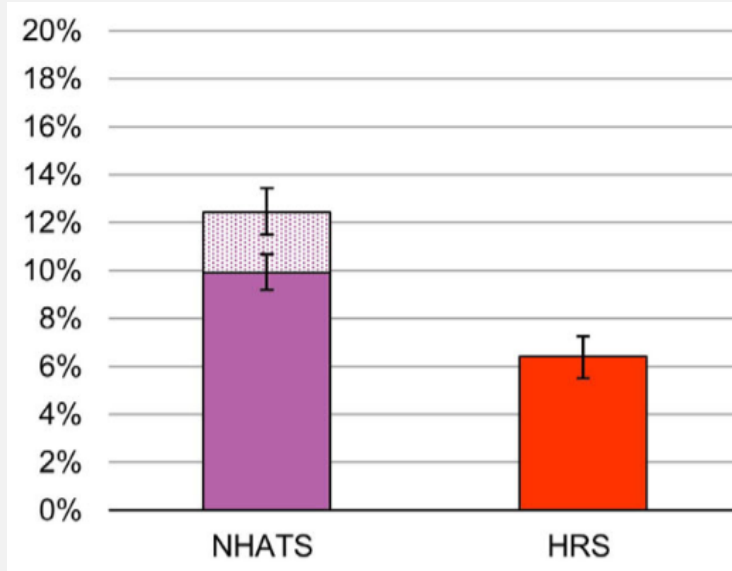


Skip logic considerations

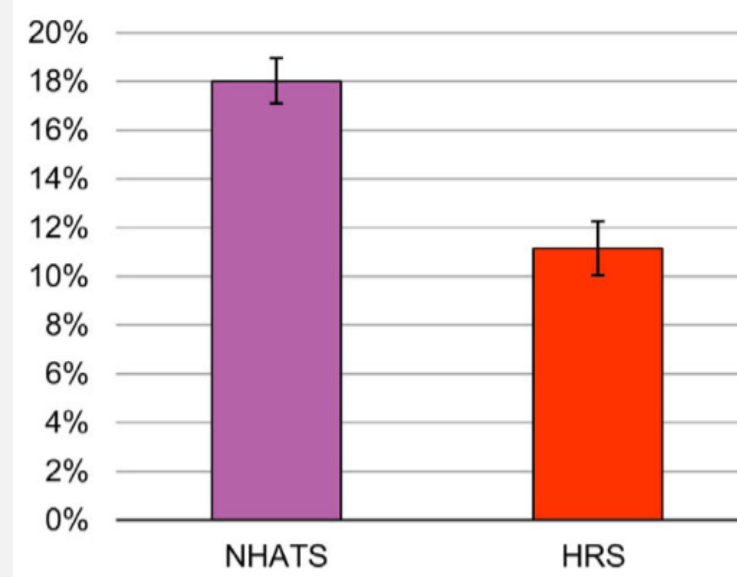
- Skip over additional activities based on earlier responses?
 - E.g. only ask about bathing, toileting if reported difficulty with dressing or other activities (HRS)
- Pro: Shortens survey length
- Con: May miss important details about other activities

How do NHATS and HRS compare?

Receives help with dressing



Reports difficulty dressing



Ankuda CK, Covinsky K, Freedman VA, Langa K, Aldridge MD, Yee C, Kelley AS. The devil's in the details: Variation in estimates of late-life activity limitations across national cohort studies. *J Am Geriatr Soc.* 2023 Mar;71(3):858-868. doi: 10.1111/jgs.18158.

Counting/identifying disparity populations: Domain-focused measures

Measures of functioning to span age groups

- Daily living difficulties represent significant challenges that are common with age-related disablement
- Do not capture all aspects of disability
- May miss people at risk of experiencing disability



Photo credit: The Ability Ministry

Domain-focused measures of disability

- Aligned to the biopsychosocial (ICF) model
- Two “main” versions today (ACS 6QS and WG-SS)
- Both are designed to quickly identify respondents with disabilities
 - For surveys with limited space, where disability measure needed to disparity group
 - Also used to track trends in population disability prevalence over time

Impetus for the ACS 6QS and WG-SS

- **American Community Survey (ACS) six-question series (6QS)**
 - Designed to “(1) monitor whether people with disabilities are prevented from full participation in society and (2) to estimate the number eligible for state and federal government programs”
- **Washington Group Short Set (WG-SS)**
 - Designed to “identify those at risk of participation restrictions due to the presence of difficulties in core functional domains”

What is the 6QS?

- Developed by an Office of Management and Budget (OMB)-convened interagency committee, led by the National Center on Health Statistics (NCHS)
 - Aimed to overcome problems with existing measures and operationalize the 2001 WHO ICF
- Mandated as the minimum survey-based [disability measure](#) in federally administered surveys as part of the Affordable Care Act

Brault, M. [Reliability and stability of the 6-question disability measure in the Survey of Income and Program Participation](#). 2013 Joint Statistical Meetings.

Altman BM, Madans J, Weeks JD. An evaluation of the American Community Survey indicators of disability. Disability and Health Journal, 2017, 10(4):485-491. doi: 10.1016/j.dhjo.2017.03.002.

Which national surveys use the 6QS?

- Census Bureau surveys since 2008
 - ACS
 - Current Population Survey (CPS)
 - Survey of Income and Program Participation (SIPP)
- Behavioral Risk Factor Surveillance Survey (BRFSS) since 2016 (*did not include hearing disability 2013-2015)
- National Health Interview Survey (NHIS) in the past (not currently)

What is included in the 6QS?

Domain	Question
Seeing	Are you blind or do you have serious difficulty seeing even when wearing glasses?
Hearing	Are you deaf or do you have serious difficulty hearing? (5+ years old)
Mobility	Do you have serious difficulty walking or climbing stairs? (5+ years old)
Cognition	Because of a physical, mental, or emotional condition, do you have serious difficulty concentrating, remembering, or making decisions? (5+ years old)
Self care	Do you have difficulty dressing or bathing? (5+ years old)
Independence	Because of a physical, mental, or emotional condition, do you have difficulty doing errands alone, such as visiting a doctor's office or shopping? (15+ years old)

Note: 6QS response categories are yes/no. Disabled=yes if at least one of the responses is yes.

What is the WG-SS?

- Washington Group (WG) on Disability Statistics aimed to harmonize disability measurement across countries
- Multiple versions:
 - WG Short Series ([WG-SS](#)) Non-disability-focused surveys
 - [WG-SS Enhanced](#): Population health studies
 - WG Extended Series ([WG-ES](#)): Disability-focused surveys
- Cognitive testing in the U.S. and fifteen other countries; field testing in the U.S., Argentina, Brazil, Gambia, Paraguay, and Vietnam

Mont, DJ, et al. Commentary: Harmonizing Disability Data to Improve Disability Research and Policy. Health Affairs, 2022, 41(10): 1442–1448.

Madans JH, Loeb ME, Altman BM. Measuring disability and monitoring the UN Convention on the Rights of Persons with Disabilities: the work of the Washington Group on Disability Statistics. BMC Public Health., 2011;11(4):S4.

Which national surveys use the WG-SS?

- NHIS began using the WG-SS starting in 2011, fully starting in 2018
 - Phased out 6QS fully in 2019 (asked of selected respondents after 2011)
 - Also asked additional questions related to disability
- Nutrition Examination Survey (NHANES)
- National Study of Family Growth (NSFG)
- Census Bureau's Household Pulse Survey
- In 2023, WG-SS named by Census Bureau as a potential 6QS replacement for other agency surveys¹

¹ US Census Bureau. American Community Survey 2025 Content Changes Federal Register Notice, Docket USBC-2023-0009. 2023; <https://www.regulations.gov/document/USBC-2023-0009-0001>.

What is included in the WG-SS?

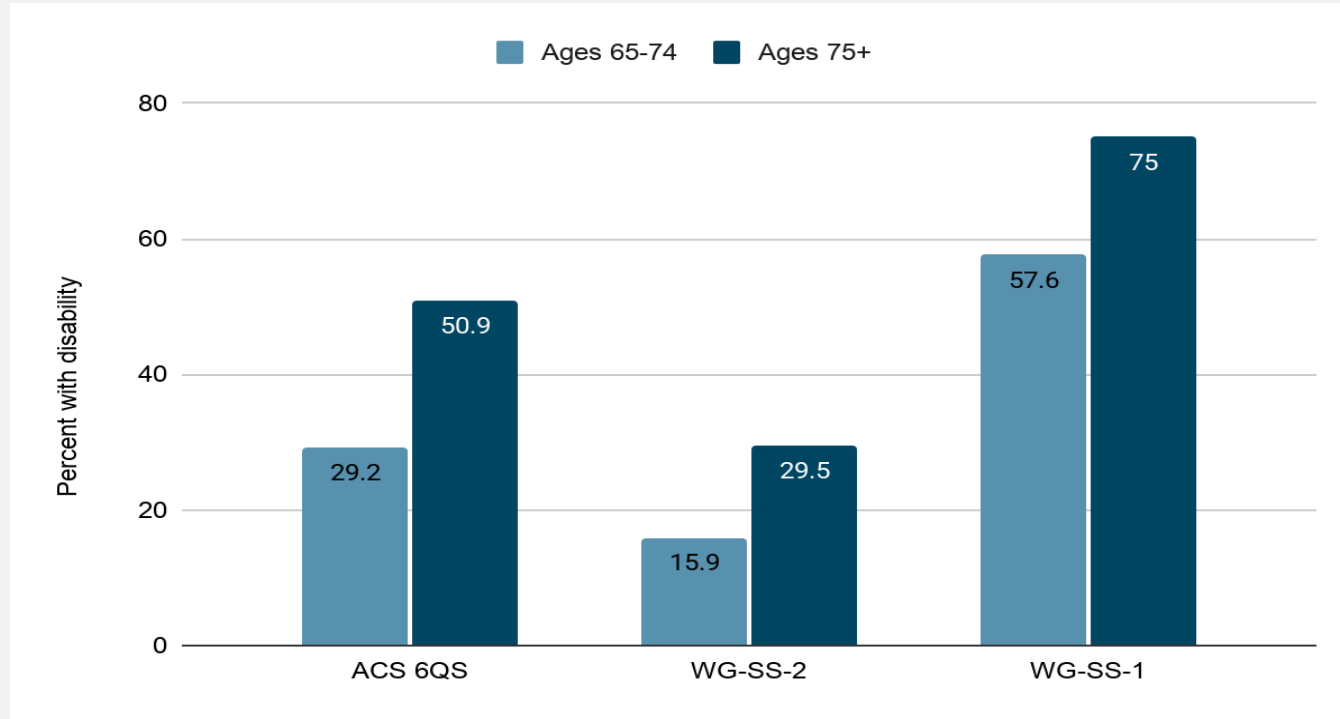
Domain	WG-SS
Seeing	Do you have difficulty seeing, even when wearing glasses?
Hearing	Do you have difficulty hearing, even when using a hearing aid?
Mobility	Do you have difficulty walking or climbing stairs?
Cognition	Do you have difficulty remembering or concentrating?
Self care	Do you have difficulty (with self care such as) washing all over or dressing?
Communication	Using your usual (customary) language, do you have difficulty communicating, for example, understanding or being understood?

Note: WG-SS response categories are no difficulty, some difficulty, a lot of difficulty, cannot do.

How does the WG-SS differ from the 6QS?

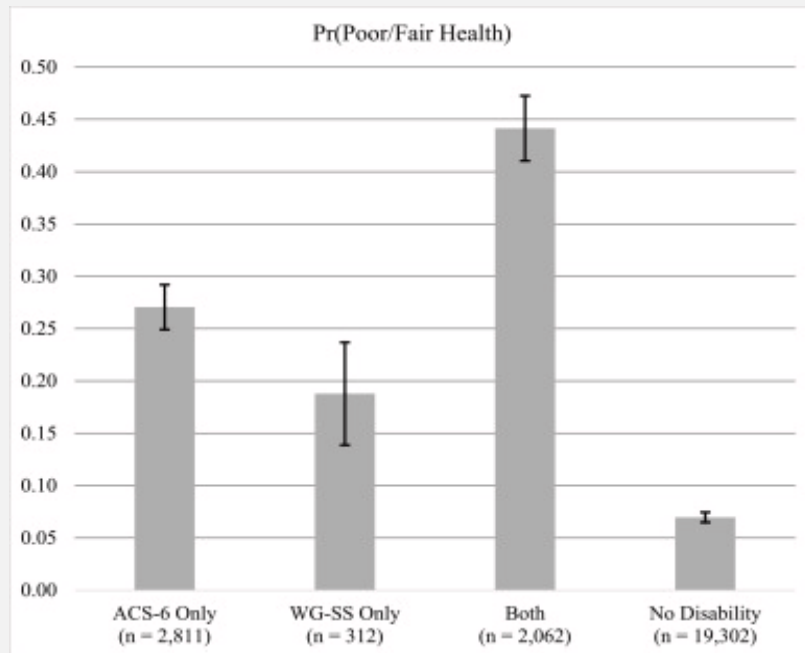
- Domains: Includes communication, excludes independence
- Wording differences: Difficulty vs. serious difficulty
- Four categories vs. binary measure for each domain: No difficulty, some difficulty, a lot of difficulty, cannot do
- WG-SS-2: Disabled is yes if at least one of the responses is a lot of difficulty or cannot do
 - Recommended by the Washington Group to measure disability prevalence

Disability prevalence using WG-SS & 6QS



Source: Lauer EA, Henly M, Coleman R, Comparing estimates of disability prevalence using federal and international disability measures in national surveillance. Disability and Health Journal, 2019, 12(2):195-202. doi: 10.1016/j.dhjo.2018.08.008.

6QS and WG-SS to identify health disparities



- Both the 6QS and WG-SS document worse self-rated health compared to non-disabled adults
- The groups that meet one disability definition but not the other are still in worse health than non-disabled adults

Myers, A. Does who is counted matter? Comparing disability measures and self-rated health. Social Science & Medicine, 2026, 405: 119590. doi: 10.1016/j.socscimed.2026.119590.

WG-SS: More sensitive to placement than 6QS?

	6QS % (s.e.)	WG-SS-2 % (s.e.)	WG-SS-1 % (s.e.)
6QS first, WG-SS second, beginning of survey	26.25 (0.76)	10.30 (0.53)	44.01 (0.86)
WG-SS first, 6QS second, beginning of survey	28.27 (0.22)	12.48 (0.57)	60.08 (0.85)
6QS first, WG-SS second, end of survey	28.36 (0.77)	11.60 (0.55)	43.41 (0.85)
WG-SS first, 6QS second, end of survey	28.80 (0.78)	15.16 (0.62)	55.02 (0.86)

Source: Brucker, DL. Comparing effects of question set order and location within a survey instrument of two commonly used disability question sets among a U.S. population of adults. *Disability and Health Journal*, 2023, 16(2). doi: 10.1016/j.dhjo.2022.101424.

Critiques of the 6QS and WG-SS

- Largely focused on disability prevalence and missing disability groups
 - Mental health conditions
 - Chronic disabling health conditions
 - Intellectual and developmental disabilities
 - Upper body mobility limitations
 - Fatigue
 - Pain



Image credit: Designed by pch.vector / Freepik

What is included in other WG batteries?

- Washington Group developed and tested additional questions that could be useful, depending on the purpose
 - **WG-SS Enhanced:** Adds upper body (2 questions), anxiety (2 questions), depression (2 questions)
 - **WG-ES Extended:** Additional questions for each domain (including enhanced), adds pain and fatigue

One other disability domain: Work limitation

- **"Do you have any impairment or health problem that limits the kind or amount of paid work you can do?"**
 - For aging populations, the transition out of paid work is important
- Measures limitation in the work domain, but difficult to ascertain the reason (environment matters!)
 - If you're effectively accommodated, are you still limited?
- Do adults reaching retirement report work limitations to justify no longer working? (Benitez-Silva et al., 2000)

Do disability measures align...should they?

- Federal disability programs have strict eligibility determinations of disability, but:
 - About $\frac{1}{4}$ of disability beneficiaries do not report any ADL difficulties¹
 - 34% of beneficiaries are not disabled based on 6QS²
 - 22% do not report a work limitation²
 - 11% report neither 6QS disability nor work limitation²



¹ Walker E, Roessel E. Social Security Disability Insurance and Supplemental Security Income Beneficiaries with Multiple Impairments. Social Security Bulletin, 2019, 79(3).

² Burkhauser, RV, Fisher TL, Houtenville AJ, Tennant JR. Is the 2010 Affordable Care Act Minimum Standard to Identify Disability in All National Datasets Good Enough for Policy Purposes? Journal of Economic and Social Measurement, 2014, 39(4): 217–245. doi: 10.3233/JEM-150417.

Counting/identifying disparity populations: Global self-identification

Self-reported disability status

- **“Do you have any type of physical or mental health condition or illness, impairment, or disability?”**
 - “Is it expected to last 3 months or more? 12 months or more?”
 - “Do any of your conditions, illnesses, impairments, or disabilities reduce your ability to carry out day-to-day activities?”
- **“Do you consider yourself to be a person with a disability?”**

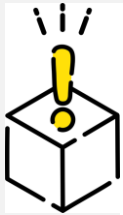
Landes SD, et al. The disability mismatch: the case for a comprehensive disability status measure. Health Affairs Scholar. 2025 4;3(7). doi: 10.1093/haschl/qxaf137.

Hall, JP, et al. Comparing Measures of Functional Difficulty with Self-Identified Disability: Implications for Health Policy. Health Affairs, 2022, 41(10): 1433–1441. doi: 10.1377/hlthaff.2022.00395.

Rennane S, Morris ZA. A comparative analysis of self-identification and functional measures of disability. Disability and Health Journal. 2026;19(2). doi: 10.1016/j.dhjo.2025.101980.

Do older adults self-identify as disabled?

- **6QS:** 28% (ages 50-64), 34% (ages 65-74), 45% (age 75+)
- **ADA:** 51% (ages 50-74), 63% (age 75+)



- Even among those who reported serious functional difficulty and met the ACS definition of someone with a disability, only 41% identified as a person with a disability.
- Moreover, self identification did not have an age gradient.

Gavin, Kara. October 2025. "Disability after 50: Poll looks at self-identity and help with health care."
<https://www.michiganmedicine.org/health-lab/disability-after-50-poll-looks-self-identity-and-help-health-care>



Toward a new survey measure of disability?

- Census Bureau paused plan to move from 6QS to WG-SS-2 in 2024
- Concerns about reductions in prevalence
- Intended to engage the disability community toward a more inclusive measure
- Surprisingly little mention of the need to capture the environment



<https://www.npr.org/2023/12/18/1218954729/census-bureau-survey-disabled-people-with-disabilities>

Santos, Robert L. 2024. "Next Steps on the American Community Survey Disability Questions." Director's Blog. Washington, DC: Census Bureau. <https://www.census.gov/newsroom/blogs/director/2024/02/next-steps-on-ac-s-disability-questions.html>.

Landes SD, Swenor BK, Clark MA, Goddard K S, Hall JP, Hermans A, et al. A Research Roadmap Toward Improved Measures Of Disability. Health Affairs Forefront. 2024 July 9, 2024.

Novel and ancillary ways to capture disability and functioning in studies of aging

Vicki A. Freedman, PhD

Measuring Disability and Functioning in Studies of
Aging NIMLAS-MiCDA Workshop

October 8, 2026

Novel and ancillary ways to capture disability and functioning

- Performance-based measures
- Time use & physical activity
- Epigenetic clocks
- Administrative linkages



Performance-based measures

Performance-based measures: details

Source: Kasper JD, Chan KS, Freedman VA. Measuring Physical Capacity. J Aging Health. 2017 Mar;29(2):289-309. doi: 10.1177/0898264316635566.

- Often designed to measure “capacity” in a controlled environment
- Considered “objective” because involve number or timing rather than reports of difficulty or help
- Exclusion criteria, inability to complete may exclude groups of interest
- Typically require in person visit
- Best used in combination with subjective measures

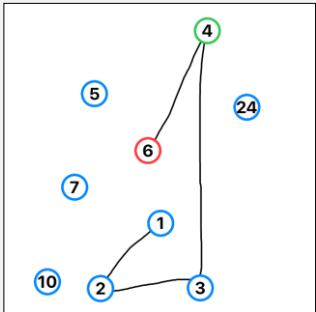


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Examples of performance-based activities measuring physical, cognitive and sensory function (NHATS)



Timer for balance activity, chair stands and walking course activities



Trails activity



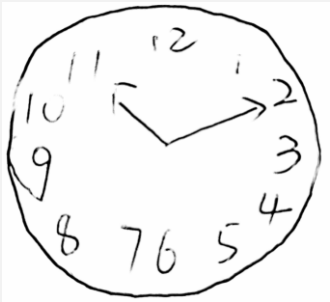
Hearing activity



Grip strength activity



Peak air flow activity



Clock drawing activity



Olfaction activity



Vision activity

Photo Source: NHATS Procedures Manual (Westat)

Time use & physical activity

Time use data

- Refinements in the conceptualization of disability have highlighted the importance of participation in meaningful activities
- Time Use questions ask about time spent on activities in a specified reference period:
 - Now or last few hours
 - Yesterday or current day
 - Last week, month or year
- Have been collected online, on the phone and in person
- Longer reference periods have more error
- Some approaches allow detailed follow-up questions about who is/was there, how they feel/felt, etc.



Types & Sources of Time Use Data

- **Now or last few hours**

- Ecological momentary assessment
- Text messages with brief survey multiple times per day
- Allows follow-up questions
- Does not require reconstructing past
- MIDUS, UAS

- **Yesterday or current day**

- 24-hour time diary or daily diary reconstruct recent periods
- Allows follow-up questions
- 24-hour diary often uses open text and post-codes to highly detailed categories
- ATUS, PSID, NSOC

- **Last week, month or year**

- Stylized questions
- Focus on actual time or time in a typical ref period
- Not conducive to follow-up questions about who was there or how they felt
- Less precision about what is in a category of activities
- PSID, HRS CAMS

Source: Patterson SE, Agree EM, Birditt K, Truskinovsky Y, Freedman VA. A Perspective on Making "Invisible" Care Visible Through Time Use Data. J Aging Soc Policy. 2025 Jul 24:1-16. doi: 10.1080/08959420.2025.2528587.

Physical activity data

- Accelerometry data can assess movement, sedentary behavior, and rest patterns
- Unlike time use data, does not capture what individuals are doing, but captures how much individuals move
- Wrist-worn device (“watch”) commonly used in aging research studies



Types & Sources of Accelerometry Data

- **Research grade vs. commercial watches**
 - Research grade watches provide the underlying data whereas commercial watches generally provide summary measures but not algorithm
- **Measures**
 - Summary of time spent in activity, sedentary behavior over the day
 - With supplemental information can approximate rest in bed (sleep)
 - Researchers also exploring patterns and transitions between rest and activity over the day and variation across days
- **Companies are adding other features to capture:**
 - Heart rate
 - Skin temperature
 - Oxygen saturation
 - Location
 - Etc.
- **Aging studies with accelerometry data**
 - NSHAP (2010 ~800; 2015 ~800; 2021 ~1600; 2027 ~5000)
 - NHATS (2021-2025 ~800; 2026 forward ~6000)
 - UAS (2021-2025; 1000-1500)
 - HRS (2019 pilot)
- **Can be mailed out or added to in-person surveys**

Source: Freedman VA, Friedman EM. 2026. Enhancing the study of chronic disease risk factors across the life course in U.S. population-representative studies. Meeting Summary. Available at micda.isr.umich.edu/wp-content/uploads/2026/02/Chronic-Disease-Risk-Factors-Across-the-Life-Course-Meeting-Summary-.pdf



Epigenetic clocks

Epigenetics

- Behaviors and environment can cause changes that affect how your DNA sequence is read
- Epigenetics turns genes "on" and "off" through DNA methylation / demethylation (adding or removing methyl to the DNA)
- Requires biomarker collection

Source: <https://www.cdc.gov/genomics-and-health/epigenetics/index.html>



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Epigenetic clocks: details

Fuentealba M, Rouch L, Guyonnet S, Lemaitre JM, de Souto Barreto P, Vellas B, Andrieu S, Furman D. A blood-based epigenetic clock for intrinsic capacity predicts mortality and is associated with clinical, immunological and lifestyle factors. Nat Aging. 2025 Jul;5(7):1207-1216. doi: 10.1038/s43587-025-00883-5.

- DNA methylation patterns used to measure biological age are referred to as epigenetic “clocks”
- Many different ways to combine the information so many different clocks
- Recent research suggests an epigenetic clock can be created that captures “intrinsic capacity” defined as the sum of one’s physical and mental capacities
 - Changes may reflect behaviors & environment



Administrative linkages

Administrative linkages: details

- Many aging studies link to administrative data that can provide insight into late-life disability. For example:
 - Social Security: disability applications and benefits (HRS)
 - Medicare and Medicaid (HRS, NHATS, PSID, and others)
 - Veterans administration: benefits (HRS)



Challenges working with administrative linkages

- Resources often restricted; requires secure computing environment
- Matching may require identifiable information like name or SS#
- Matching may be probabilistic, introducing error
- Administrative records can also have errors, may not be salient to respondents

