



Using Data from the National Survey on Health and Disability (NSHD)

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Institute for Health and
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Funding Statement

The National Survey on Health and Disability (NSHD) is administered by the University of Kansas Institute for Health & Disability Policy Studies (KU-IHDPS) and funded by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR, project #s 90DP0075 and 90IFRE0050). The contents of this presentation do not necessarily represent the policy of NIDILRR, ACL, or HHS and you should not assume endorsement by the federal government.

NSHD Overview

- 18+ years of age and living in the U.S.
- On-line survey (phone, ASL, alt formats) first administered in 2018 to measure the impact of the Affordable Care Act (ACA) on adults (18+) with disabilities – **Wave 1** (n=1,246)
- **Wave 2** contained social determinants of health domains that became core domains for future administrations. Administration ended right before the COVID-19 pandemic began (n=2,175)
- **Wave 3** included a COVID-19 Supplement and was fielded in 2021 (n=1,648)
- **Wave 4** fielded in Summer of 2022 added items related to Long COVID and items from other NIDILRR researchers per an RFP process (n=2,725)
- **Wave 5** fielded October 2023 – January 2024 (n=1,919)
- **Wave 6** contained two new domains on medical ableism and those who identify as LGBTQ+ (n=2,506)
- **Wave 7** scheduled for Winter 2026/27

NSHD Sample

- Convenience sample with outreach to those who had completed the survey in previous years and said they would like to be contacted about future administrations
- Recruitment via 80+ national and state disability, condition-specific and advocacy organizations (e.g., NCIL, MS Society, The Arc, NAMI, AWN)
- Not nationally representative
 - over-representation of females, employed, college-educated and respondents with income over 200% of FPL
 - weighting conducted by The Urban Institute can be used
- Sample size each wave has varied due to our recruitment methods changing over time to overcome bots/scammers and recently, the national climate and uneasiness in providing data
- Repeat responders allow for longitudinal analyses
- Broad definition and multiple measures of disability

NSHD Domains

Included in all waves	SDOH	Special Topics
Demographics	Transportation	Reproductive Health*
Health status	Housing	Mattering*
Unmet health care needs/services	Quality of Life	Employment Quality & Satisfaction*
Multiple measures of disability	Loneliness	Medical Ableism
Insurance Coverage (public, private and none)	Resiliency	Preventive Testing
Personal Assistance Services (PAS)	Community Participation	Internet Access
SSI, SSDI and other benefits		Emergency Preparedness Plans*
Employment and Household Income		TBI*
Proxy items		Cannabis Use*

Multiple Measure of Disability

- Single item:

Do you have any type of physical or mental health condition or illness, impairment or disability that has lasted or is expected to last for 12 months or more?

Screeners



- ACS-6

- WG-SS (Waves 2 & 6)

- Open-ended:

What is your disability and/or health condition(s)? *If you have more than one, please list them starting with the disability or health condition that affects you the most.*

- Self-categorization:

Of the options below, which ONE category would you use to describe the disability or health condition you listed first? **AND** Please select the category(ies) below of any other or additional disabilities or health conditions you have. *Mark all that apply.*

Chronic illness/disease; communication-related; developmental; intellectual/cognitive; mental health/emotional or psychiatric; neurological; physical/mobility disability; sensory

Obtaining NSHD Data

- De-identified limited datasets for all waves are available
- Completion of data use agreement - including acknowledgement of data source and NIDILRR funding
- 30-minute Zoom meeting to provide overview and orientation to the data
- On-going technical assistance provided to all data users, as needed
- On-going knowledge translation work with advocacy organizations
- Contact Noelle Kurth (pixie@ku.edu) to start the process
- Inclusion in the NSHD Data Analysis Team (DAT)

NSHD Data Analysis Team (DAT)

- Comprised of all who are using the data. Currently, 94 people from 59 organizations/institutions
- Multi-disciplinary
- Used by graduate and doctoral students for their theses and dissertations
- Monthly meetings to discuss analyses and findings, get feedback and collaborate
- Has led to numerous collaborations across institutions
 - 50+ presentations at national and regional conferences
 - 39 peer-reviewed publications with 6 more currently under review
 - <https://ihdps.ku.edu/nshd-publications>

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General information on the NSHD: <http://ihdps.ku.edu/nshd>

We would like to gratefully acknowledge our colleague, Dr. Jean Hall, who worked diligently to establish the NSHD. Its existence and widespread use is her research and advocacy legacy since retirement in 2025.



Using Machine Learning to Code an Open-Ended Disability Question

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“... we strongly suggest adding... an open-ended question to list disability(ies), similar to questions used for collecting race and ethnicity data in the decennial Census. As the Census Bureau notes, allowing respondents to write-in responses will ‘more accurately illustrate the richness and complexity of how people identify.’ Given the complexity of capturing disability, such options should absolutely be explored.” – Hall et al., 2024

Overview of the ML Program

- ❖ Compares a dictionary to open-ended responses
- ❖ Dictionary is a list of conditions organized by numerical codes
- ❖ Many steps to filter out matches and investigate non-matches

3 | Depression, major depression, major depression disorder, treatment resistant depression, MDD, TRD, seasonal affective disorder, SAD, depressed mood, Postpartum depression, PPD, major depressive disorder, depressive disorder

How it Works

1. Open-ended responses and dictionary are cleaned and tokenized
2. The tokenized responses and conditions are then compared
3. Non-matches undergo fuzzy matching
4. After correcting for non-matches, responses are reconstructed
5. Potential condition matches are compared to responses
6. Positive lookaheads are used to check for unexpected wording
7. Distance between positive lookaheads is checked
8. Unique condition codes are retained and first condition is coded

Example

Response	Code	Potential Matches	Matched
glaucoma corneal disease retinal disease	33	retinal detachment	FALSE
	262	glaucoma	TRUE
	278	retinal disease	TRUE
	341	corneal disease	TRUE
	341	corneal tear	FALSE
	699	central retinal artery occlusion	FALSE
	699	retinal vein occlusion	FALSE
	699	branch retinal vein occlusion	FALSE

Methods - Data

- ▶ NSHD 2020-2023 data
 - ▶ Expand dictionary
 - ▶ Write and test ML code and evaluate fuzzy matching
 - ▶ $n = 6,245$
- ▶ NSHD 2024 Data
 - ▶ $n = 1,919$
 - ▶ 386 responses were hand coded to evaluate performance
 - ▶ Thanks Noelle!

Open-Ended Question

- ▶ “What is your disability and/or health condition(s)? If you have more than one, *please* list them starting with the disability or health condition that affects you the most.”
- ▶ First listed condition is important as it is further coded

Analyses

- ▶ Machine Learning Performance
 - ▶ Completion time
 - ▶ Overall capture rate
 - ▶ First listed classification rate
 - ▶ Overall classification rate
 - ▶ False codes rate

Results – Machine Learning Performance

- ▶ Overall
 - ▶ 1 minute to code all 2024 data
 - ▶ ~ 10 hours to hand code 20%
 - ▶ 99.3% of people were captured
- ▶ Compared to hand coding
 - ▶ 97.4% first condition correct
 - ▶ 98.5% condition codes captured (power)
 - ▶ 1.7% falsely returned (type 1 error)
- ▶ Fuzzy matching and positive lookahead not 100% accurate

Discussion

- ▶ Efficient and effective
- ▶ Address limitations
- ▶ Useful for
 - ▶ Overall prevalence
 - ▶ Capture complexity of how people identify
 - ▶ Empowers to describe in own term
- ▶ Descriptive title ideas?

Contact Information & Funding Statement

- ▶ abeuoy@ku.edu
- ▶ The contents of this presentation were developed under grants from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR grant numbers 90IFRE0050 and 90IFRE0089). NIDILRR is a Center within the Administration for Community Living (ACL), Department of Health and Human Services (HHS). The contents of this article do not necessarily represent the policy of NIDILRR, ACL, or HHS, and you should not assume endorsement by the Federal Government.

Fuzzy Matching (additional info)

- ▶ Hand coded non-matches
- ▶ Evaluated each method's performance

Method	Accuracy	Sensitivity	Specificity
Jaro	0.79	0.58	0.93
Jaro Winkler .1	0.78	0.72	0.82



Using the National Survey on Health and Disability (NSHD) to Advance Longitudinal Methods

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NSHD Administrations

The National Survey on Health and Disability (NSHD) was not originally designed as a longitudinal panel – however, a substantial number of respondents have participated in multiple waves.

This repeat engagement creates opportunities to examine within-person change over time.

Survey Administrations

- **Wave 1:** February – May 2018 ($n = 1,246$)
- **Wave 2:** October 2019 – January 2020 ($n = 2,175$)
- **Wave 3:** January – April 2021 ($n = 1,648$)
- **Wave 4:** May – August 2022 ($n = 2,725$)
- **Wave 5:** November 2023 – February 2024 ($n = 1,919$)
- **Wave 6:** April – July 2025 ($n = 2,506$)

Repeat Responders Across Waves

Across six survey administrations, 21% of respondents participated in two or more survey waves, creating opportunities for longitudinal analyses.

Total unique respondents: 9,133

Waves Completed	Respondents	Percent
1	7,219	79%
2	1,092	12%
3	473	5%
4	193	2%
5	112	1%
6	44	0.5%

How Respondents Are Matched

Three survey items are used to identify repeat respondents across survey waves:

1. Year of birth
2. What are the first TWO letters of the city where you were born?
 - If unknown: **enter XX**
3. What are the first TWO letters of your middle name?
 - If no middle name: **enter ZZ**

Responses to these items are used to generate KU-derived identifiers.

When the primary identifiers do not produce a clear match, we apply probabilistic matching procedures using demographic characteristics unlikely to change across waves (e.g., race/ethnicity, sex assigned at birth).

Harmonized Measures in the NSHD

- The National Survey on Health and Disability (NSHD) was originally designed as a repeated cross-sectional survey, not a longitudinal panel.
- However, many survey items have been asked using consistent wording and response structures across survey administrations.
- These measures can therefore be harmonized across waves, allowing researchers to examine changes over time among repeat respondents.

Health & Quality of Life Measures

Measure	Item	Waves Available
Self-rated health	In general, would you say your health is...	Waves 1–6
Poor physical health days	Days physical health was not good (past 30 days)	Waves 1–6
Poor mental health days	Days mental health was not good (past 30 days)	Waves 1–6
Activity limitation days	Days poor health limited usual activities	Waves 1–6
Tobacco use	Current cigarette or tobacco use	Waves 1–6

Disability Status Measures (ACS-6)

Measure	Item	Waves Available
Hearing disability	Serious difficulty hearing	Waves 1–6
Vision disability	Serious difficulty seeing	Waves 1–6
Cognitive disability	Serious difficulty concentrating, remembering, or making decisions	Waves 1–6
Mobility disability	Serious difficulty walking or climbing stairs	Waves 1–6
Self-care disability	Difficulty bathing or dressing	Waves 1–6
Independent living disability	Difficulty doing errands alone	Waves 1–6

Health Insurance Coverage

Measure	Example Item	Waves Available
Employer-based insurance	Coverage through employer or union	Waves 1–6
Medicare coverage	Covered by Medicare	Waves 1–6
Military health coverage	TRICARE or other military health care	Waves 1–6
Marketplace coverage	Private insurance purchased through ACA Marketplace	Waves 1–6
Indian Health Services	Coverage through IHS	Waves 1–6
Medicaid coverage	Covered by Medicaid	Waves 1–6
Insurance continuity	Any gaps in insurance coverage in past 12 months	Waves 1–6

Employment & Education

Measure	Example Item	Waves Available
Employment status	Current work status	Waves 1–6
Weekly work hours	Number of hours worked per week	Waves 1–6
Job tenure	Length of time at current job	Waves 1–6
Educational attainment	Highest level of education completed	Waves 1–6

Demographic & Geographic Context

Measure	Example Item	Waves Available
State of residence	State where respondent lives	Waves 1–6
Age	Derived age variable	Waves 1–6
Population density	Metro / micropolitan / non-core classification	Waves 1–6
Marital status	Current marital status	Waves 1–6
Children in household	Number of children under 19 in household	Waves 1–6
Household size	Number of people in household	Waves 1–6

Example Longitudinal Finding

Unmet Healthcare Needs Before and During the Pandemic

N = 185 respondents participating in 2019/2020, 2022, and 2023/2024

Service	2019/20	2022	2023/24
Doctor visits	13.5%	7.4%	5.3%
Mental health care	23.8%	45.9%	40.9%
Prescriptions	15.8%	20.0%	21.2%
Specialists	15.3%	15.2%	16.0%
Dental care	28.3%	36.0%	39.4%
Preventive care	12.3%	17.9%	14.6%
DME / prosthetics	36.1%	42.7%	36.9%

Discussion

- Many opportunities remain for longitudinal analyses using NSHD data that have not yet been explored
- NSHD data are available free of charge to researchers interested in studying disability, health, and policy
- We welcome new collaborators to join the NSHD Data Analysis Team!

Contact Information

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