Future Directions of Functioning Measures in the U.S. National Health Interview Survey

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A number of functioning measurement developments...

National Health Interview Survey (NHIS)

- Content redesign for 2019
- Extensive changes to functioning content
- Changes to structure and periodicity of measures

Washington Group measures for adults and children
Disability statistics: implications to consider
Why redesign?
  • Most recent major content redesign occurred in 1997
  • Respondent burden increasing and response rates decreasing

Why now?
  • Reduce respondent burden and improve data quality
  • Necessary sampling frame redesign in 2016 introduced additional complexity
  • Final measurements for Healthy People 2020 objectives can be completed in 2016 and 2017
  • Conceptual changes dictate measurement changes
  • Long-term planning can help sponsors target content
Length of Completed Interviews, by Quarter: NHIS, 2006-2015

![Graph showing Length of Completed Interviews, by Quarter: NHIS, 2006-2015]
NHIS Family, Child, and Adult Response Rates, NHIS 1997-2015
Criteria for Prioritizing Content

- **Strong link to public health:** Leading causes of morbidity/mortality, known risk or protective factors, priority populations at risk, intermediate outcomes
- **Relevant to HHS agency goals:** Part of HHS strategic plan, HHS initiatives
- **Relevant to international standards reporting:** where applicable
- **Needed for long-term monitoring:** Leading health indicators
- **High quality measurement:** Content can be measured well in household interviews
- **Consistent with other federal surveys:** Measure is used by others for calibration, does not duplicate detail collected by targeted HHS surveys
- **Can be estimated reliably with one or two years of data:** Less focus on rare conditions or behaviors
NHIS Functioning Content

Before redesign:

- Work Limitation
- Activity Limitation (any way, any activity)
- Social Activity Limitation
- Participation Limitation
- ADLs
- IADLs
- Basic Actions Difficulties
- Complex Activity Limitations
- Personal Care
- ACS Set
- WG Short Set
- WG Extended Set
- Age of onset
NHIS Functioning Variable Count

Functioning variables on the core section NHIS – approximately 170 functioning variables:
- 36 asked on the Family section
- 100 asked of the Sample Child
- 33 asked of the Sample Adult

ACS variables:
- 6 asked on the Family section
- 6 asked of the Sample Child
- 6 asked of the Sample Adult

WG variables
- 63 asked of Sample Adult

** This is a total of roughly 250 disability variables to program, administer, clean, weight, etc. per year. **
Redesign NHIS Functioning Content

Before redesign:

- Work Limitation
- Activity Limitation (any way, any activity)
- Social Activity Limitation
- Participation (IADL) Limitation
- ADLs
- IADLs
- Basic Actions Difficulties
- Complex Activity Limitations
- Personal Care
- ACS Set
- WG Short Set
- WG Extended Set
- Condition Causing (problem)
- Age-of-onset

After redesign:

- Work Limitation
- Social Activity Limitation
- Participation (IADL) Limitation
- WG Short Set
- WG Extended Set
- WG-UNICEF Child Module
WG Short Set on Functioning

1-5. How much difficulty do you have:

- seeing even if wearing glasses?
- hearing even if using a hearing aid?
- remembering or concentrating?
- walking or climbing stairs?
- with self-care, such as washing all over or dressing?

6. Because of a physical, mental or health condition, how much difficulty do you have communicating, for example understanding or being understood by others?

Response:

- a) No, no difficulty
- b) Yes – some difficulty
- c) Yes – a lot of difficulty
- d) Cannot do at all
## Comparison of ACS vs. WG-SS

<table>
<thead>
<tr>
<th>Functioning Domain</th>
<th>ACS Question Text</th>
<th>WG-SS Question Text</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hearing</td>
<td>Are you deaf or do you have serious difficulty hearing?</td>
<td>Do you have difficulty seeing, even when wearing glasses?</td>
</tr>
<tr>
<td>Vision</td>
<td>Are you blind or do you have serious difficulty seeing even when wearing glasses?</td>
<td>Do you have difficulty hearing, even when using a hearing aid?</td>
</tr>
<tr>
<td>Cognition</td>
<td>Because of a physical, mental, or emotional condition, do you have serious</td>
<td>Do you have difficulty remembering or concentrating?</td>
</tr>
<tr>
<td></td>
<td>difficulty concentrating, remembering, or making decisions?</td>
<td></td>
</tr>
<tr>
<td>Mobility</td>
<td>Do you have serious difficulty walking or climbing stairs?</td>
<td>Do you have difficulty walking or climbing stairs?</td>
</tr>
<tr>
<td>Self-Care</td>
<td>Do you have difficulty dressing or bathing?</td>
<td>Do you have difficulty (with self-care such as) washing all over or dressing?</td>
</tr>
<tr>
<td>Independence</td>
<td>Because of a physical, mental, or emotional condition, do you have difficulty</td>
<td>n/a</td>
</tr>
<tr>
<td>(IADLs)</td>
<td>doing errands alone such as visiting a doctor’s office or shopping?</td>
<td></td>
</tr>
<tr>
<td>Communication</td>
<td>n/a</td>
<td>Using your usual (customary) language, do you have difficulty communicating, for example understanding or being understood?</td>
</tr>
</tbody>
</table>
WG Extended Set on Functioning

Additional questions in these domains:
- Hearing
- Cognition
- Mobility

Additional functional domains:
- Communication
- Upper body
- Affect (anxiety and depression)
- Pain
- Fatigue

Four-category response options
WG-UNICEF
Child Functioning Module

A survey module specifically designed to capture functioning for children 2-4 and 5-17 years.

- Seeing
- Hearing
- Mobility
- Self-care*
- Fine Motor*
- Communication
- Learning (and Remembering+)
- Emotions (Anxiety and Depression)+
- Controlling Behaviour
- Focusing Attention / Concentrating+
- Coping with Change+
- Relationships+
- Playing*

* Domains specific to those 2-4 years of age
+ Domains specific to those 5-17 years of age
The Quilt

**Annual core**
- Key measures
- Sociodemographics

**Rotating core**
- Newer topic areas
- Expanded detail
- Varying periodicity

**Sponsored supplements**
- “Sustaining” sponsors
- 1- or 2-year modules
- 5 min or less
2019 NHIS: Proposed Core Modules

**Sample Adult Core**
- Self-response (unless unable)
- Relevant family-level data
- Fielded with fixed periodicity

**Sample Child Core**
- Knowledgeable adult responds for child
- Relevant family-level data
- Fielded with fixed periodicity

Demographics, some family relationships, and family income; Health insurance, utilization, conditions, and behaviors
Rotating Content

How to balance the collection of relevant health content and crucial covariates with respondent burden and funding constraints?

Some questions will appear with fixed periodicity, not annually

Pros:

• Less time intensive than asking all questions every year
• Can still monitor changes in trends with periodic data

Cons:

• Data will not be available annually for all topics
Adult Functioning Content Periodicity

**Annual Core:**
- WG Short Set
- WG Extended Set (almost*)

**Social functioning:**
- Social Activity Limitation
- Participation (ACS IADL)
- Limitation
- Work Limitation`
- Anxiety
- Depression

**Rotating Core Content:**
- 2-years on and 1-year off (2019, 2020, 2022, 2023, 2025, 2026):
  - Mental health care (MHC)
  - Pain*
- 2-year Rotation (2020, 2022, 2024, 2026):
  - Fatigue*
- 3-year Rotation (2019, 2022, 2025):
  - GAD-7 (diagnostic tool for anxiety)
  - PHQ-8 (diagnostic tool for depression)
- 3-year Rotation (2021, 2024, 2027):
  - Serious Psychological Distress
  - Hearing Detail*
Child Functioning Content Periodicity

Annual Core:
WG-UNICEF Child Module (vision, hearing, mobility, motor skills and self-care, communication, cognition, affect, behavior)

Social / emotional screening for very young children

2-years on and 1-year off (2019, 2020, 2022, 2023, 2025, 2026):
Mental health care (MHC)

3-year Rotation (2019, 2022, 2025):
SDQ (Strengths and Difficulties Questionnaire)
SDQ-Impact (Strengths and Difficulties Questionnaire – Impact Suppl.)
WG Question Sets Milestones

Short Set on Functioning (6 questions):
- Adopted in 2006
- Added to 2009 NHIS
- Admitted as the international standard for disability measurement for the 2020 Round of Censuses by UN and UNECE
- Implemented in surveys and censuses internationally, including DHS
- Used to monitor the CRPD and the SDGs

Extended Set on Functioning (additional functional domains):
- Adopted in 2010
- Added to 2010 NHIS

Module on Child Functioning and Disability
- Developed in collaboration with UNICEF
- Adopted in 2016
- Added to 2019 NHIS
- Implemented on MICS
WG Questions Adopted Widely

• Used in censuses or surveys in over 78 countries.
• Has been promoted by international aid programs, (DFID/UK and DFAT/Australia), as the means to collect disability data in all programs and projects.
• Has been introduced as the means for collecting disability data by the UN Statistical Division (UNSD) and the UN Economic Commission for Europe for the 2020 round of censuses.
• Adopted as the way to disaggregate data for the Incheon Strategy on Making the Right Real in Asia.
• Recommended by UN DESA’s Disability Data Experts Group as way of disaggregating the Sustainable Development Goals (SDGs) by disability.
Disability Statistics from the NHIS

Inform Departmental and Federal disability-related activities.

*Health, U.S.:
- Historically, used “limitation of activity due to a chronic condition”
- In 2009, moved to Basic Actions Difficulties and Complex Activity Limitation
- In 2017, disability based on the WG Short Set on Functioning (WG-SS)

*Healthy People
Include in the core of all applicable Healthy People population data systems a standardized set of questions that identify “people with disabilities.”
- HP2020: Adopted ACS as the standard measure of disability
- HP2030: WG-SS used as the standard measure of disability from NHIS

*OMB Reporting
- WG-SS used for Social Indicators, Analytical Perspectives: Budget of the U.S. Government (http://www.whitehouse.gov/omb/budget/Analytical_Perspectives/)
Disability Statistics from the NHIS

Other NCHS data collections
• NHANES
• NSFG

Forthcoming Publications to Inform Change
• Transition from ACS to WG
• Comparison of ADLs and WG
• Identification of special populations (e.g., I/DD, program eligibility/receipt)
Thank You