Disability Statistics at NCHS: A Changing Landscape

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2015 Annual Disability Statistics Compendium
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A number of disability measurement developments…

- ACS Questions
- Washington Group on Disability Statistics
  - Short Set on Functioning
  - Extended Set on Functioning
- National Health Interview Survey
  - Extensive disability content
  - Content redesign for 2018
2010 Patient Protection and Affordable Care Act:
• Mandates the collection of data on disability status
• Requires a standard disability measure
• Acknowledges disability as a *demographic*

ACA Disability Subcommittee:
• Recommended the 6-question ACS measure as the *minimum* standard

Current status:
• 10/31/2011: Secretary announced final standards
• Now collected on multiple federal data collections (NCHS, Census, BLS, HUD, BJS, DOT)
• Standard reporting disaggregated by disability
ACS Set: Health, U.S. and Healthy People

Health, U.S.:
- Historically, used “limitation of activity due to a chronic condition”
- In 2009, moved to Basic Actions Difficulties and Complex Activity Limitation (disability measures consistent with current disability models and legislation)
- Disability now used as a demographic in 20+ tables (pain, SRH, alcohol use, no usual source of care, health care visits, insurance, etc.)

HP Change in Operational Definition:
Include in the core of all applicable Healthy People 2020 population data systems a standardized set of questions that identify “people with disabilities.”
- Adopted ACS as the standard measure of disability for 2020 work
- HP Objectives tables have disability as a demographic
- Where possible ACS set used
ACS Questions

Is this person deaf or does he/she have serious difficulty hearing?
Is this person blind or does he/she have serious difficulty seeing even when wearing glasses?
Because of a physical, mental, or emotional condition, does this person have serious difficulty concentrating, remembering, or making decisions?
Does this person have serious difficulty walking or climbing stairs?
Does this person have difficulty dressing or bathing?
Because of a physical, mental, or emotional condition, does this person have difficulty doing errands alone such as visiting a doctor's office or shopping?

Response: Yes / No
The Washington Group on Disability Statistics

Purpose: The promotion and coordination of international cooperation in the area of health statistics by focusing on disability measures suitable for censuses and national surveys which will provide basic necessary disability information throughout the world.

Measures must be developed within the framework of a model, culturally comparable, and accepted for use across many countries.

Development of the international standard for disability measurement.

Annual meetings with membership and participation from over 130 national statistical offices, NGOs, DPOs and other international organizations.
WG: Summary of Annual Meetings

1. Washington, DC  February 2002
2. Ottawa, Canada    January 2003
3. Brussels, Belgium February 2004
4. Bangkok, Thailand September 2004
5. Rio de Janeiro, Brazil September 2005
6. Kampala, Uganda   October 2006
7. Dublin, Ireland   September 2007
8. Manila, Philippines October 2008
10. Luxembourg       November 2010
11. Southampton, Bermuda November 2011
13. Amman, Jordan    October 2013
15. Copenhagen, Denmark October 2015
WG Question Sets Milestones

Short Set on Functioning (6 questions):
• Adopted in 2006
• Adopted as the standard for the 2020 Round of Censuses by UN and UNECE
• Implemented in surveys and censuses internationally
• Added to 2009 NHIS
• 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 with UNICEF, field testing complete, release shortly

Module on Inclusive Education
• Under development
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          c) Yes – a lot of difficulty
b) Yes – some difficulty      d) Cannot do at all
WG Extended Set on Functioning

Additional questions in these domains:

- Hearing
- Cognition
- Mobility

Additional functional domains:

- Upper body
- Affect (anxiety and depression)
- Pain
- Fatigue
The National Health Interview Survey
2018 Content Redesign
NHIS History

• Established by the 1956 National Health Survey Act, Public Law 652, 84th Congress
• Authorized as the National Health Survey
• First fielded in July 1957 and continuously ever since
• Collect and disseminate data on the health status and health care access of the U.S. non-institutionalized population
• Last redesign was in 1997
Uses of the NHIS Data

- Annual report to Congress
- Address specific issues of ongoing and emergent public health concern
- Provide estimates for monitoring (Health United States, Healthy People program)
  - 69 Healthy People 2020 Objectives
  - 71 Healthy People 2010 Objectives
  - Dashboards and indicators
- Research
- Policy and program evaluation
- Benchmark
National Health Interview Survey
Disability Content

Limitation of Activity
ADLs
IADLs
Basic Actions Difficulties
Complex Activity Limitations
Social Activity Limitations
Personal Care
Child Mental Health Services
ACS Set
WG Short Set
WG Extended Set
Participation Limitation
NHIS Format

Core Module:
Household composition*
Family questions*
Recontact information*
Adult section^
Child section^

Supplements (one-time and periodic)

*asked of a household member
^person-specific
2018 Content Redesign Goals

- Shorten the questionnaire
- Improve the flow
- Make more current
- Synch content with other HHS surveys
- Eliminate repetition
- Avoid rare event content
- Streamline for faster release (less coding)
- Improve response rates
- Include biomeasures
Redesign Timeline

2014 – 2015: Stakeholder engagement, outreach

2015 – 2016: Qualitative and quantitative assessment of new or revised questions

Summer 2016 – Spring 2017: OMB review and public comment

Late Spring 2017: Revised questionnaire programmed

January 2018: Revised questionnaire fielded
Gathering Input

Public comment
  • Federal register notice
  • NCHS website

Contacting stakeholders

Reviewing other survey content

Work groups
What we need to know...

- How are NHIS data currently being used?
- What is considered to be the most critical content on the survey?
- What content is assumed will always be there (or should always be there) regardless of how short the questionnaire gets?
- What periodicity is acceptable for other content?
- What are we doing or collecting that is not useful?
- What limitations have been encountered when using NHIS data?
- How could NHIS data be more useful?
Contact Us

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The Washington Group on Disability Statistics

http://www.cdc.gov/nchs/washington_group.htm

NHIS Web Page

http://www.cdc.gov/nchs/nhis.htm

NHIS Listserv

http://www.cdc.gov/nchs/products/nchs_listservs.htm