

Disability Statistics at NCHS: A Changing Landscape

Julie D. Weeks, Ph.D.

National Center for Health Statistics

2015 Annual Disability Statistics Compendium
The Washington Center, Washington, DC
February 4, 2016

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

ACS Set: ACA Section 4302

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 |
| 9. Dar es Salaam, Tanzania | October 2009 |
| 10. Luxembourg | November 2010 |
| 11. Southampton, Bermuda | November 2011 |
| 12. Bangkok, Thailand | October 2012 |
| 13. Amman, Jordan | October 2013 |
| 14. Buenos Aires, Argentina | October 2014 |
| 15. Copenhagen, Denmark | October 2015 |
| 16. South Africa | December 2016 |

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

b) Yes – some difficulty

c) Yes – a lot of 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^

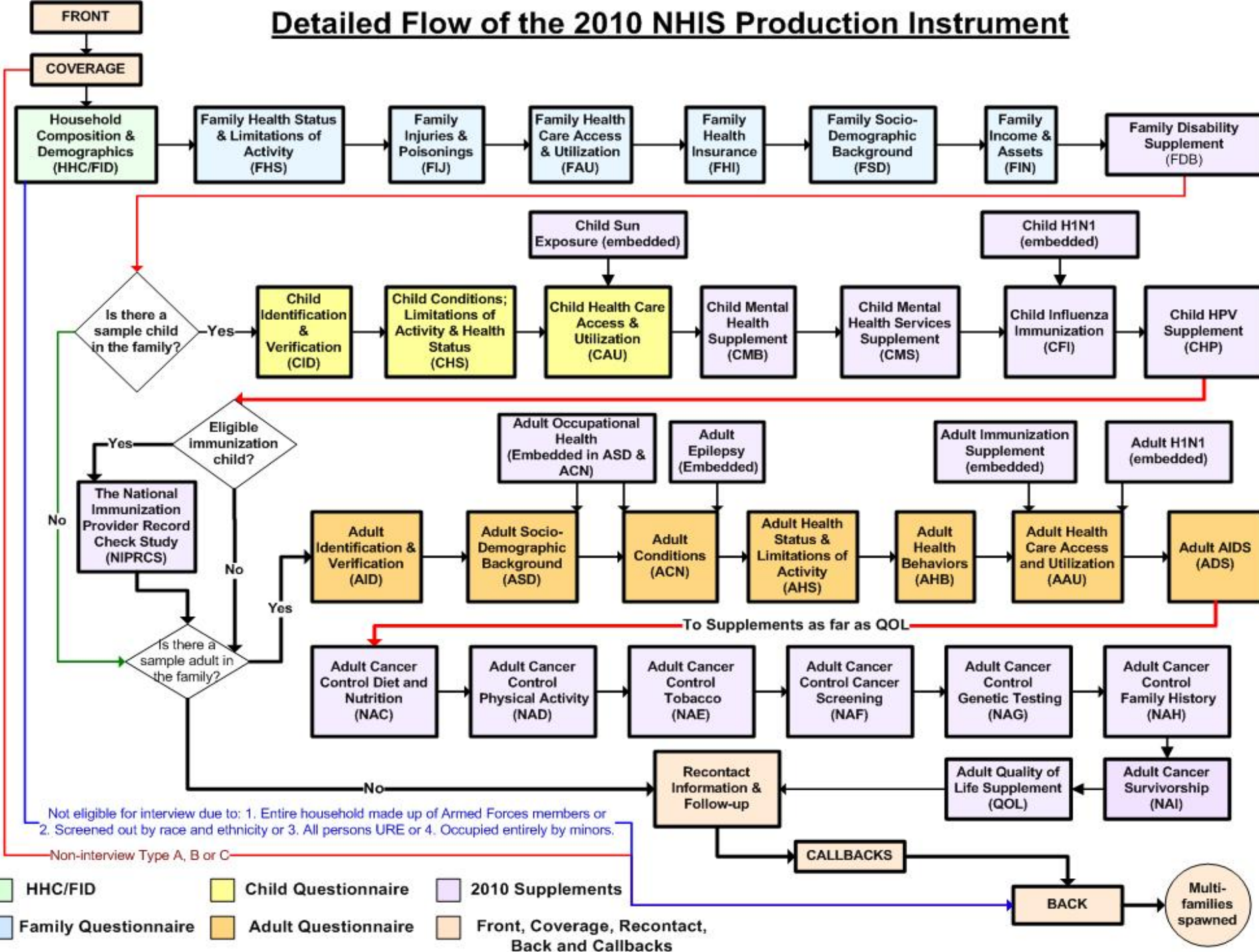
Child section^

Supplements (one-time and periodic)

*asked of a household member

^person-specific

Detailed Flow of the 2010 NHIS Production Instrument



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

Julie Weeks

jweeks@cdc.gov

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