The Importance and Feasibility of Disaggregating by Disability Status – the U.S. Experience

Jennifer H. Madans

Associate Director for Science,

National Center for Health Statistics, USA

and

Chair, Washington Group on Disability Statistics

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Lessons Learned

- It is possible and useful to include a short set of disability questions – for the purpose of disaggregation – in major national data systems.

- There will be some small differences in prevalence – but the differentials are consistent.

Design Requirements for Disability Questions

Work was subject to several strict guidelines and requirements. In particular, the revised questions:

- could not exceed the space limitations in the American Community Survey;
- must perform equally well across a number of administration modes (mail, telephone, in-person);
- must be appropriate for the greatest proportion of individuals as possible, including young children;
- provide a valid, reliable and understandable general measure of disability; and
- would be fielded, without changes, for a 5-year period beginning with 2008 in order to generate 2010 Census estimates comparable in quality to the 2000 Census long form estimates.

Measurement Objectives

- Based on the legislative review (18 agencies had legislative mandates and the conceptual framework), "equalization of opportunity" was selected as the key policy question in areas such as housing, employment, communications, income and other areas of participation in society.

- To accomplish this objective, the question set must identify persons who, because of their limitations in functioning, are at risk for discrimination or lack appropriate opportunity for participation.

- To meet legislative and programmatic requirements for services and other forms of support, a measure of severe disability identifying those in need of assistance to maintain independence should be included.

Measurement of Equalization of Opportunities

- Locate the definition of disability at the most basic level of activity/participation.

- This level is associated with the ability or inability to carry out basic activities at the level of the whole person (i.e., walking, climbing stairs, lifting packages, seeing a friend across the room).

- Development of a demographic means of understanding disability (can compare persons with and without disability).
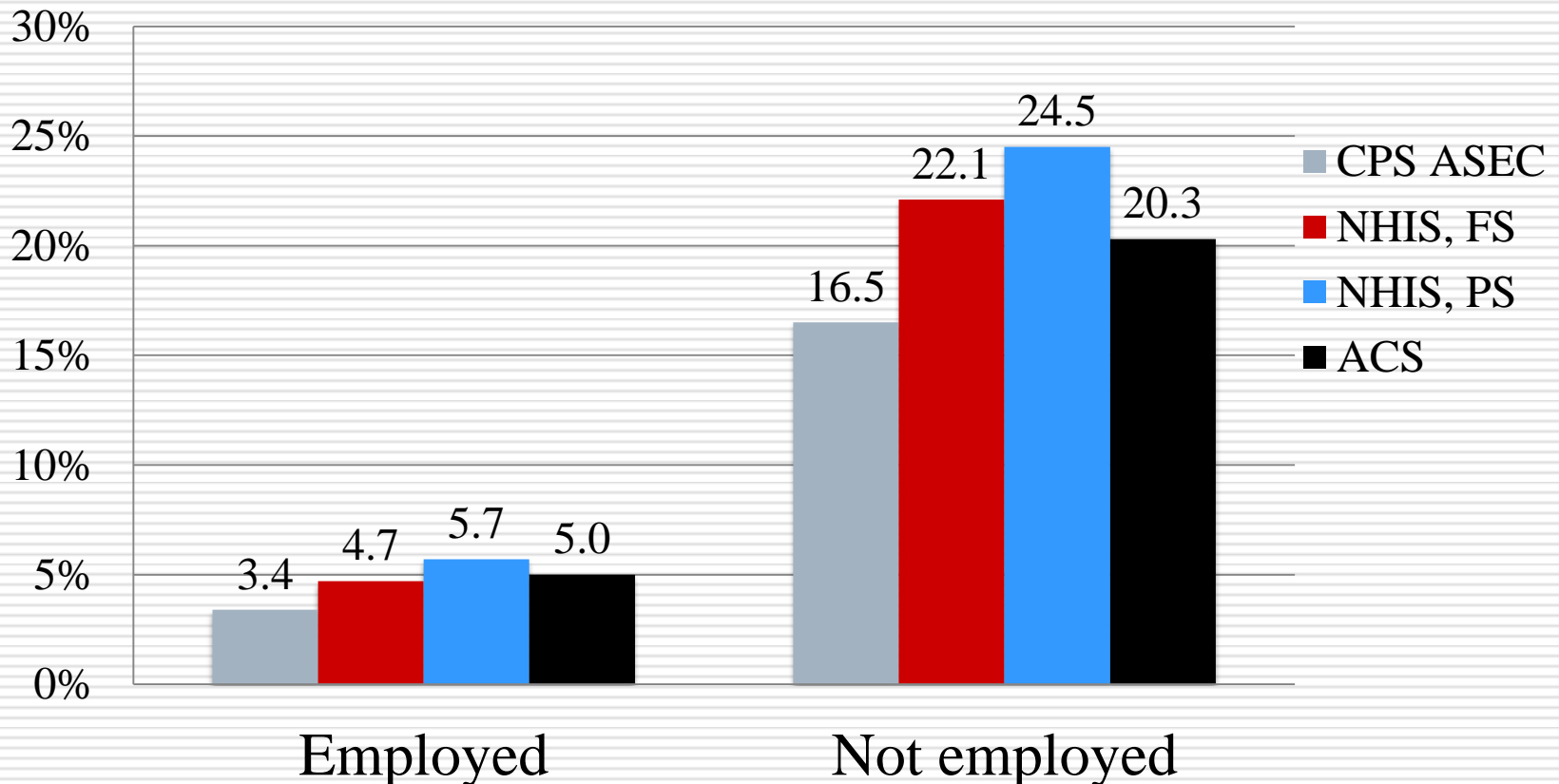
Comparisons across Surveys

Prevalence of Disability by Survey: 2009

Disability Item	Ages	CPS ASEC† (%)	NHIS		ACS (%)
			Family-Style (%)	Person-Style (%)	
Vision difficulty	1+	1.7	2.1	2.4	2.2
Hearing difficulty	1+	3.1	3.9	4.1	3.4
Mobility difficulty	5+	6.9	6.6	7.2	6.9
Cognitive difficulty	5+	3.5	3.9	4.7	4.8
Self-care difficulty	5+	2.0	1.8	2.2	2.6
Independent living diff	15+	4.0	4.7	5.1	5.4
Any disability	1+	11.6	12.0	13.1	12.1

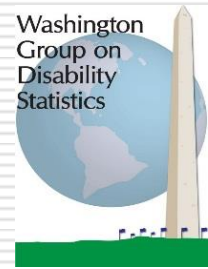†NOTE: CPS data are for population 16 years and over.

Prevalence of Any Disability by Survey and Employment Status*: 2009

* CPS and ACS cover persons 16-64; NHIS covers persons 18-64.
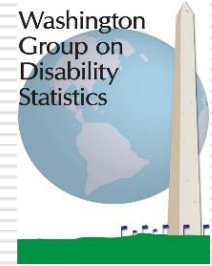
The National Health Interview Survey

- The American Community Survey questions were added to the NHIS in 2008.

- The Washington Group Short Set (WG-SS) was added in 2008 and the Extended Set were added in 2010.

- The WG-SS are the improved version of the ACS – expanded response categories.

- The NHIS 2018 redesign will include the WG Extended Set (which includes the Short Set) and the Child Functioning Module.

- A proposal has been made to use the WG-SS for the ACS.

Disability Prevalence USA
(n=16,777; ages 18+) (NHIS: 2013)

Person with disability has:	n	%
at least 1 Domain is 'some difficulty'	7511	41.9
at least 2 Domains are 'some difficulty'	3672	19.6
at least 1 Domain is 'a lot of difficulty'	1872	9.5
at least 1 Domain is 'unable to do it'	465	2.2

Disaggregation in U.S. NHIS Data

NHIS 2013 18-64 years of age Weighted %	**Disability Status**: WG Short Set Cut-off = *a lot of difficulty* in at least 1 domain	
	Without Disability	With Disability
Employment Status Last Week = Working	73.5	30.8
Current Every Day Smoker	14.5	27.8
Health Insurance Coverage (yes)	79.5	81.0

Standardized Approach to Monitoring

- By standardizing disability data collection instruments it will be possible to provide comparable data within countries and cross-nationally for populations living in a variety of cultures.

- Data can be used to assess:

  - a country's compliance with national legal requirements, development goals and the UN Convention on the Rights of Persons with Disabilities and, over time,

  - improvement in meeting these goals.

Mainstreaming Disability Statistics

- As the U.S. experience shows, questions can be added to any on-going data collections;
  - Can be used in any national or subnational survey (health, labor force, income & expenditure, DHS, MICS etc.).
- Once the questions become integrated into core statistical systems (e.g., the systems used to produce the SDG indicators and other reporting requirements) – disaggregating outcomes (education, employment etc.) by disability status becomes routine.
- Challenge – once questions are included in ongoing surveys it is hard to change them to meet evolving standards and improved methods.