# Stakeholder Convening on Disability Data Needs

September 30, 2024











## Remarks

Convening Facilitator:

Meeta Anand, The Leadership Conference Education Fund

# Executive Introductions

- Robert Santos, Director, U.S. Census Bureau
- Karin Orvis, Chief Statistician of the United States
- Brian Moyer, Director, National Center for Health Statistics
- Claudia Gordon, Chair, National Council on Disability



## Stakeholder Meeting on Disability Data Needs

# Defining Disability and Disability Identity

Marissa Ditkowsky National Partnership for Women & Families September 30, 2024

## What is a disability?

It depends who you ask, and in what context!

## **Models of Disability**

- Medical Model
  - Disability viewed as a physical condition/impairment that needs to be cured
- Charity Model
  - Disabled people as in need of help and unable to do things themselves
- Social Model
  - Disability created by the barriers that society creates
  - Limitations
- Many other models

## **Legal Definitions**

- ADA/civil rights:
  - a person who has a physical or mental impairment that substantially limits one or more major life activity
- Social Security:
  - inability to engage in any substantial gainful activity (SGA) by reason of any medically determinable physical or mental impairment(s) which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months

## **Legal Definitions Cont'd**

- Vocational rehab
  - physical or mental impairment that constitutes or results in a "substantial impediment" to employment for the applicant
- Many definitions used for public benefit/support programs
- Other definitions used for education (i.e. IDEA)

### Other Definitions

- World Health Organization's International Classification of Functioning, Disability and Health (impairment/functional limitation focus)
- Self-ID and community
  - Failing to fall under legal definitions does not necessarily mean someone does not have a disability
  - Someone may fall under the legal definition and not ID as having a disability

## Measurements of disability

- These definitions of disability are used to serve various purposes (not just measuring prevalence)
- ACS 6
  - Y/N to functional limitation questions
    - Are you deaf, or do you have serious difficulty hearing?
    - Are you blind, or do you have serious difficulty seeing, even when wearing glasses?
    - Because of a physical, mental, or emotional condition, do you have serious difficulty concentrating, remembering, or making decisions?
    - Do you have serious difficulty walking or climbing stairs?
    - Do you have difficulty dressing or bathing?
    - Because of a physical, mental, or emotional condition, do you have difficulty doing errands alone such as visiting a doctor's office or shopping?

## Measurements of disability

- WG-SS
  - Scaled response to different functional limitation questions
    - Do you have difficulty seeing, even if wearing glasses?
    - Do you have difficulty hearing, even if using a hearing aid(s)?
    - Do you have difficulty walking or climbing steps?
    - Do you have difficulty remembering or concentrating?
    - Do you have difficulty with self-care, such as washing all over or dressing?
    - Using your usual language, do you have difficulty communicating, for example understanding or being understood?
- Annual Social and Economic Supplement (ASEC) "Work Disability"

## Measurements of disability

- Self-categorized primary disability type
  - Asking people directly to describe their self-identified disability through open-ended questions as well as selecting from the following list to characterize their primary condition: intellectual or cognitive, mental illness or psychiatric, physical or mobility, chronic illness or disease, sensory, developmental, and neurological
  - https://www.healthaffairs.org/doi/full/10.1377/hlthaff.20
     22.00395

## Disability Identity and Measurements

- All current measures fall short when it comes to collecting accurate and inclusive disability data, especially among children
- Measurements of functional limitation alone are limiting and conflict with social model, self-ID, and modern conceptions/ideas of disability
  - Example
- ACS, WG-SS, and other measurements of disability may miss those with chronic illnesses/pain, mental illness, speech and communication-related disabilities, Long-COVID, autism and more, even if they meet the legal definition of disability or identify as disabled

## Disability Identity and Measurements

- WG-SS question, "Do you have difficulty hearing, even if using a hearing aid(s)?" conflicts with ADAAA definition of disability that is supposed to be considered "without regard to the ameliorative effects of mitigating measures" (except for regular glasses/lenses
- Disabled folks' experiences are shaped by the intersections of their identities—we need better data on LGBTQI+ disabled folks, disabled people of color, etc. to support the whole disabled community

## A Painful History

- History of eugenics
  - From ugly laws (1860s to 1970s) to institutionalization
    - Out of sight, out of mind
  - Homelessness (more likely to be in poverty/unhoused)
    - Criminalization of homelessness
  - Incarceration
    - Disabled people (particularly disabled people of color) more likely to be incarcerated
  - Forced sterilization
    - Buck v. Bell (1927): Three generations of imbeciles are enough.
  - o COVID-19

## Addressing this History

- Severely undercounting disabled people feeds into this history
- Disabled people must be counted—we exist
- We cannot be pushed out of sight/out of mind
- We must work toward more accurate and inclusive measurements to count all disabled people—whether they live in their homes and communities or are in institutions of any kind (i.e. nursing homes, group homes, prisons and jails, etc.)

## The Importance of Counting the Disabled Community

- The disabled community deserves to be recognized and counted
- We are a large demographic group (about 1 in 4 people have a disability)
- Inclusive and accurate data helps us understand the community's needs
- Data helps determine funding for critical services and programs many disabled people rely on

### Conclusion

- Data measurements must reflect the needs of the community and modern conceptions/ideas of disability
- While there is no one way to define disability, we can use these definitions to create measurements for different purposes (i.e. data Social Security needs may be different from data EEOC needs)
- Can take lessons from SOGI data process—still have a lot of work to do, but significant improvements across government after working with the LGBTQI+ community
- Federal government and disability community/researchers must work together to create more accurate and inclusive disability measurements

## Contact Info (2)=

### Marissa Ditkowsky

Disability Economic Justice Counsel mditkowsky@nationalpartnership.org

### Find & Follow Us



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NationalPartnership.org



## Agency Needs, Procedure, and Communication

**Moderator:** Ana Torres-Davis, National Council on Disability

### **Panelists:**

- Bev Pratt, Office of Management and Budget
- Elizabeth Poehler, U.S. Census Bureau
- Karen Brummond, Equal Employment Opportunity Commission
- Stephen Blumberg, National Center for Health Statistics

# Overview of the Federal Statistical System

Stakeholder Convening on Disability Data Needs
Agency Needs, Procedure, and Communication
September 30, 2024



## Executive Office of the President and the Office of Management and Budget



#### **Executive Office of the President**

Council of Economic Advisers
Council on Environmental Quality
Domestic Policy Council
Gender Policy Council
National Economic Council
National Security Council
Climate Policy Office

Office of the Intellectual Property Enforcement Coordinator
Office of Intergovernmental Affairs

#### Office of Management and Budget

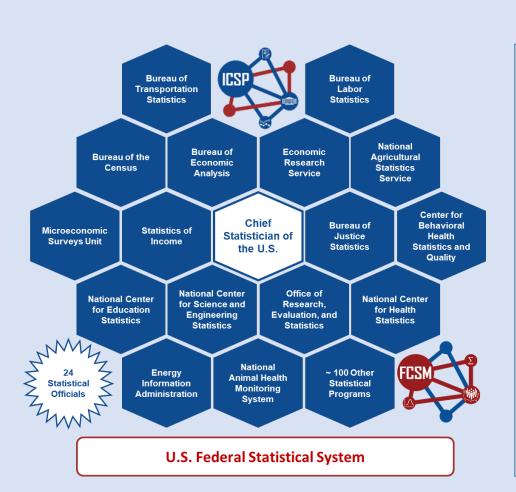
Office of National Drug Control Policy
Office of Pandemic Preparedness and Response Policy
Office of Public Engagement
Office of Science and Technology Policy
Office of the National Cyber Director
Office of the United States Trade Representative
Presidential Personnel Office
National Space Council

### Office of Management and Budget

- Budget development and execution
- Management, including oversight of agency performance, procurement, financial management, and information technology
- Coordination and Regulatory Affairs
  Coordination and review of all significant
  Federal regulations from executive
  agencies, privacy policy, information policy,
  and review and assessment of information
  collection requests
- Clearance and coordination of legislative and other materials
- Clearance of Presidential Executive Orders and memoranda to agency heads prior to their issuance

## Visit StatsPolicy.gov for more information





#### INTERAGENCY COUNCIL ON STATISTICAL POLICY

#### **30 Unique Members**

- Chief Statistician of the United States
- 24 Statistical Officials
- 16 heads\* of OMB Recognized Statistical Agencies and Units

#### Helps the U.S. Federal statistical system

- Operate as a seamless system
- Work together to provide strategic vision and robust implementation in support of the its critical longstanding – and expanding – role for supporting evidence-informed decision-making

\* 11 RSAUs heads are also Statistical Officials







Click Here to Download a PDF (with Hyperlinks) of This Image with Additional Information

### **EXAMPLE GROUPS**

Cybersecurity Working Group

Expanding Secure Access Working Group

Federal Statistical Research Data Centers Executive Committee

National Secure Data Service Subcommittee

Standard Application Process
Governance Board

Subcommittee on Statistical Official Roles and Responsibilities

Subcommittee on the American Community Survey





### Members

- Co-Chaired by U.S. Chief Statistician at OMB and Director of U.S. Census Bureau
- Three ICSP members

### **Mission**

- Advises U.S. Chief Statistician and Census Bureau Director on how the ACS can best
  - Fulfill its role in the portfolio of Federal household surveys
  - Provide the most useful information with the least amount of burden
- Advising is consistent with the policies and practices that govern the ACS and the Federal statistical system

## Public Outreach and Engagement

"Seek the involvement of those intended to benefit or expected to be burdened"

 Executive Order 12866 on Regulatory Planning and Review

- to ensure policies have validity and integrity.
- to ensure policies reflect the best available evidence.
- to inform and prepare the public.





Data
Collection
Principles

**Utility and Quality** 

**Minimization** 

Inclusivity and Sensitivity

**Privacy Protection** 

Consistency

Compliance

## American Community Survey Content Process

Stakeholder Meeting on Disability Data Needs 9/30/2024

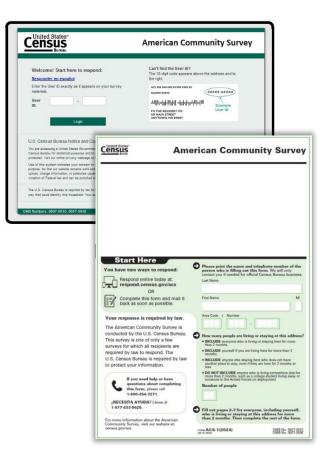
Elizabeth Poehler, U.S. Census Bureau



## The American Community Survey The Foundation

- The American Community Survey (ACS) is the premier source of detailed information about the nation's people and housing.
- Surveys 3.5 million addresses to produce annual social, economic, housing, and demographic estimates for communities throughout the U.S. and Puerto Rico
- Covers 40+ topics Collects detailed information previously collected by the decennial census each decade
- Helps inform how trillions of dollars in federal funds are distributed each year, supports over 300 evidence-based federal government uses
- Data released the year after collection as 1-year and 5-year estimates





## ACS Content Oversight

- Interagency Council on Statistical Policy: Subcommittee on the ACS (ICSP SACS) advises the Census Bureau and OMB on the ACS
- This committee includes the Chief Statistician of the U.S., the director of the Census Bureau, and 3 other statistical agency leads who serve on a rotating basis
- The committee advises on:
  - How the ACS can best fulfill its role in the portfolio of federal household surveys
  - How the ACS can provide the most useful information with the least amount of burden

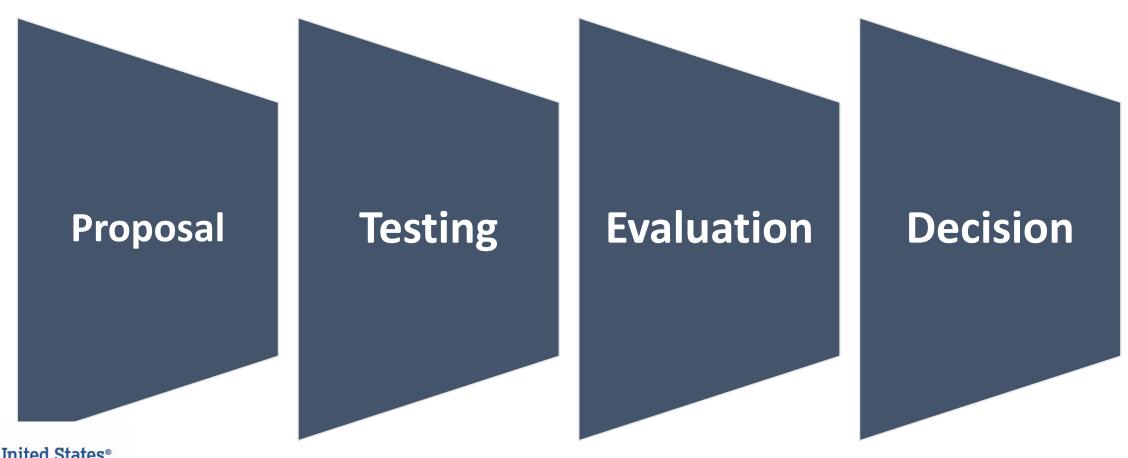


## ACS Content Requirements

- The content of the ACS is designed to meet the needs of federal government agencies. Questions on the ACS are sponsored by these agencies.
- A question can be proposed for inclusion if:
  - A federal law explicitly states that the data for a topic must come from the ACS and is needed for small populations or low-levels of geography
  - A federal law or regulation requires use of specific data
  - Used for operational needs (i.e., telephone number)



### How a Question Becomes Part of the ACS





## Phase 1. Proposal

- A federal agency can propose a new or changed question at any time
  - Rationale for the change
  - The federal law associated with the request
  - Initial ideas for the question change
  - Impact on respondents because of the change
- The Census Bureau and OMB co-chair a committee of over 25 federal agencies that sponsor ACS questions and use ACS data
- Proposals undergo legal, technical, and policy review
- The ICSP SACS advises whether the proposal moves forward for testing



## Phase 2. Testing

- 1. Form topical subcommittee & develop wording options
- 2. Conduct Cognitive testing
  - 1:1 interviews to evaluate how well a person understands and answers survey questions
- 3. Field Test
  - A Federal Register Notice is published soliciting input on test plans
  - New question wording is tested against existing question wording
  - All ACS data collection modes are tested
    - follow-up reinterview is conducted to assess response reliability

### Phase 3. Evaluation

- Census Bureau staff conduct statistical analysis of the field test
  - Analysis Plans developed in the testing phase guide this analysis
  - Analysis typically includes comparisons of:
    - Benchmarks
    - Item nonresponse
    - Response distribution
    - Response reliability
    - Other topic specific analysis
- Federal agencies are also part of this evaluation process



### Phase 4. Decision

- Recommendations are presented to the ICSP Subcommittee for the ACS for input
- Federal Register Notices are published about the proposal to change questions on the ACS
- OMB reviews the request
- Census Bureau implements approved changes



## Content Process Changes

- The Census Bureau learned many valuable lessons from the 2022
   Content Test and is working to make improvements to the process
- The Census Bureau recommended that the ICSP SACS strengthen the ACS Content Process so that federal agencies requesting changes engage with stakeholders and data users throughout the testing phases
- The Census Bureau anticipates that the proposal phase for the next content test will start later this fall or early next year



# Federal Workforce Disability Data

Karen M. Brummond, Ph.D.

Social Science Research Analyst

Federal Sector Programs

Office of Federal Operations

U.S. Equal Employment Opportunity Commission



### Overview

- The Rehabilitation Act of 1973
- ADA Amendments Act (ADAAA) Definition of Disability
- Collecting and Using Federal Workforce Disability Data
- Challenges in Finding Comparable Nationwide Data

# The Rehabilitation Act of 1973 (The Rehab Act)

- The Rehab Act prohibits disability-based discrimination in Federal employment
- The Rehab Act requires affirmative action in employment by Federal agencies for persons with disabilities.
- Uses the Americans with Disabilities Act Amendments Act (ADAAA) definition of disability.

## The Definition of Disability in the ADAAA

- "The term 'disability' means, with respect to an individual—
  - (A) a physical or mental impairment that substantially limits one or more major life activities of such individual;
  - (B) a record of such an impairment; or
  - (C) being regarded as having such an impairment."
- Working is specified as a major life activity.

## What Does "Substantially Limits" Mean?

- "The term 'substantially limits' shall be construed broadly [...]"
- The determination of a substantial limitation shall be made without regard to the ameliorative effects of mitigating measures.

## Federal Workforce Data Collection: Self-Identification of Disability – Standard Form 256

- Voluntary and confidential form for new hires
- Employees select only one option from
  - 12 types of "Targeted Disabilities or Serious Health Conditions"
  - 20 types of "Other Disabilities or Serious Health Conditions"
  - "I have a disability or serious health condition, but it is not listed on this form."
  - "I do not wish to identify my disability or serious health condition."
  - "I do not have a disability or serious health condition."
- Very specific, but no room for reporting multiple disabilities
- Data is aggregated by agencies and reported to the EEOC on MD-715 Reports

## EEOC Management Directive (MD) 715 Reports

- MD-715 establishes Federal agencies' responsibilities under Section 501 of the Rehab Act.
- Federal agencies must have goals:
  - 12% individuals with disabilities
  - 2% individuals with targeted disabilities
  - These goals are analyzed separately for lower- and higher-ranking employees.
- Agencies use these data to conduct barrier analysis.

## Agency-Level Barrier Analysis

- MD-715 requires that agencies conduct barrier analysis:
  - Identify "triggers": Inequalities by demographic group
  - Identify the barriers (root causes) causing these triggers
  - Where a barrier exists, make a corrective action plan
- Use detailed Federal workforce data by demographic group
  - Overall representation
  - Hiring
  - Separations
  - Occupations
  - Salary bands
  - And more

# EEOC Reports on Individuals with Disabilities in the Federal Workforce Using MD-715 Data

- Annual Report on the Federal Workforce
- The EEO Status of Workers with Disabilities in the Federal Sector
- Retaining Persons with Disabilities in the Federal Workforce

 Available on the EEOC's Federal Sector Reports webpage at <u>https://www.eeoc.gov/federal-sector/reports</u>

# Challenges in Finding Comparable Nationwide Disability Data

- Large nationwide surveys' disability questions do not match the Rehab Act/ADAAA definition of disability.
  - E.g., American Community Survey, Current Population Survey.
- The Survey of Income and Program Participation (SIPP) added questions in 2021 that come closer.
  - Still doesn't match Rehab Act/ADAAA definition.
  - The smaller sample size makes it a less ideal data source.
- If you know of comparable data, please let us know!

## Summary and Conclusion

- Defining Disability Under the Rehab Act and ADAAA
- Collecting Federal Workforce Disability Data
- How These Data Are Used in Barrier Analysis and EEOC Reports
- Challenges in Finding Comparable Nationwide Data

## Thank you!

karen.brummond@eeoc.gov



# Measuring Disability with the National Health Interview Survey

Panel on Agency Needs, Procedure, and Communication

Stephen J. Blumberg, PhD
Director, Division of Health Interview Statistics

September 30, 2024

## **National Health Interview Survey**

- Purpose: To monitor the health of the US population through the collection and analysis of data on a broad range of health topics
- Sample: Address-based, clustered sample of housing units from every state, to be representative of the civilian noninstitutionalized US population
- Mode: In-person interviews by Census interviewers, with follow-up by telephone if needed
- Questionnaire: Includes sample adult and sample child sections
- Data collection: Continuous, with quarterly and annual data files
- Sample size: Complete interviews for 27,000+ sample adults and 7,000+ sample children annually

National

## **History and Purpose of the NHIS**

#### History

- Established by the National Health Survey Act in 1956
- Continuously in the field since July 1957

#### Established to provide data for:

- Appraising the true state of health of our population
- Adequate planning of any programs to improve their health
- Research in the field of chronic diseases
- Measurement of the numbers of persons in the working ages so disabled as to be unable to perform gainful work

NATIONAL CENTER Series 10
For HEALTH STATISTICS Number 1

#### VITAL and HEALTH STATISTICS

DATA FROM THE NATIONAL HEALTH SURVEY

#### Acute Conditions

incidence and associated disability

United States - July 1961 - June 1962

Statistics on the incidence of acute conditions and the associated days of restricted activity, bed disability, and time lost from work and school, by age, sex, calendar quarter, residence, and geographic region. Based on data collected in household interviews during the period July 1961-June 1962

Washington, D.C.

May 1963

U.S. DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE Anthony J. Celebrezze Secretary

Public Health Service Luther L. Terry Surgeon General

## **Statutory Obligations for NHIS**

- NCHS mandate (excerpted from Public Health Service Act, 42 USC 242k)
  - Shall collect statistics on the **extent and nature of illness and disability** of the population of the United States . . . [and] the **impact of illness and disability** of the population on the economy of the United States and on other aspects of the well-being of its population
- NHIS mandate (Public Health Service Act, 42 USC 242k)
  - There shall be an **annual collection of data** from a statistically valid sample concerning the general health, illness, and **disability status** of the civilian noninstitutionalized population
  - Specific topics to be addressed shall include:
    - The incidence of illness and accidental injuries
    - Prevalence of chronic diseases and impairments
    - Disability
    - Physician visits
    - Hospitalizations
    - The relationship between demographic and socioeconomic characteristics and health characteristics

## **History of Selected Disability-Related Measures**

- 1957-1996
  - Restricted activity days
    - Bed disability days, work-loss days, school-loss days, cut-down days
- **1980-2018** 
  - Limitation of activity due to chronic conditions
- **1983-1996** 
  - Impairments checklists
- **1997-2018** 
  - Activities of daily living and instrumental activities of daily living
    - First included in NHIS follow-up surveys, such as
       1984 Supplement on Aging and 1994-1995 NHIS-D, Disability Followback Survey

## **2019 NHIS Content Redesign**

#### Why redesign?

- Most recent major content redesign was 1997
- Respondent burden increasing and response rates decreasing

#### Goals of the Redesign

- Improve the relevance of covered health topics
- Harmonize overlapping content with other federal heath surveys
- Reduce respondent burden and improve data quality
- Shorten questionnaire and reduce variation in interview times
- Eliminate or reduce content better covered by other methods
- Establish a long-term structure for periodic topics

## Input to Guide Decision Making

#### Engaged with stakeholders

- CDC centers, agency partners, Healthy People federal interagency working group, professional associations, conference presentations
- Public solicitation of input: Oct. 2015, Feb. 2016, June 2016
- Federal Register notices: Oct. 2016, Aug. 2017, two in 2018
- Consulted with technical experts
- Worked closely with leadership and advisors
  - From NCHS, CDC, HHS/Assistant Secretary for Planning and Evaluation as well as NCHS Board of Scientific Counselors and OMB
- Conducted cognitive testing and field tests

## Washington Group Extended Set on Functioning

- Designed to provide comparable data for populations living in a variety of cultures with varying economic resources
- Includes 34 questions, with more than one question for most of the 11 domains
- Includes psychosocial domains, mental health, pain, and fatigue
- Includes questions on use of equipment and aids, and medication for anxiety and depression
- Captures functioning in some domains both with and without the use of equipment to better understand the residual functional difficulties

#### Added to NHIS annual core in 2019

• First field-tested in NHIS in 2010 as supplemental content

## Washington Group Short Set (WG-SS)

- Do you have difficulty seeing, even if wearing glasses?
- Do you have difficulty hearing, even if using a hearing aid?
- Do you have difficulty walking or climbing steps?
- Do you have difficulty remembering or concentrating?
- Do you have difficulty with self-care, such as washing all over or dressing?
- Using your usual language, do you have difficulty communicating, for example understanding or being understood?

## **Comparing WG-SS with ACS-6: Domains**

#### **Washington Group Short Set**

- Do you have <u>difficulty seeing</u>, even if wearing glasses?
- Do you have <u>difficulty hearing</u>, even if using a hearing aid?
- Do you have <u>difficulty walking or climbing steps?</u>
- Do you have <u>difficulty remembering or concentrating?</u>
- Do you have difficulty with self-care, such as washing all over or dressing?
- Using your usual language, do you have difficulty communicating, for example understanding or being understood?

#### **American Community Survey**

- Are you blind, or do you have serious difficulty seeing, even when wearing glasses?
- Are you deaf, or do you have serious difficulty hearing?
- Do you have serious <u>difficulty walking or</u> climbing stairs?
- Because of a physical, mental, or emotional condition, do you have serious <u>difficulty</u> <u>concentrating</u>, remembering, or making <u>decisions?</u>
- Do you have difficulty <u>dressing or bathing?</u>
- Because of a physical, mental, or emotional condition, do you have difficulty doing errands alone such as visiting a doctor's office or shopping?

## **Comparing WG-SS with ACS-6: Answer Choices**

#### **Washington Group Short Set**

- No difficulty
- Some difficulty
- A lot of difficulty
- Cannot do at all

#### **American Community Survey**

- Yes
- No

## Comparing WG-SS with ACS-6: Disability Identifiers

#### **Washington Group Short Set**

- At least 1 domain is coded SOME DIFFICULTY or A LOT OF DIFFICULTY or CANNOT DO AT ALL
- At least 2 domains are coded SOME DIFFICULTY, or at least 1 domain is coded A LOT OF DIFFICULTY or CANNOT DO AT ALL
- At least 1 domain is coded A LOT OF DIFFICULTY or CANNOT DO AT ALL
  - > This is the international standard for WG-SS
- At least 1 domain is coded CANNOT DO AT ALL

#### **American Community Survey**

At least one domain is coded YES

## **Comparing WG-SS with ACS-6: Adult Prevalence**

#### **Washington Group Short Set**

- At least 1 domain is coded SOME DIFFICULTY or A LOT OF DIFFICULTY or CANNOT DO AT ALL
  - > 45.2% (NHIS 2023)
- At least 2 domains are coded SOME DIFFICULTY, or at least 1 domain is coded A LOT OF DIFFICULTY or CANNOT DO AT ALL
  - > 23.7% (NHIS 2023)
- At least 1 domain is coded A LOT OF DIFFICULTY or CANNOT DO AT ALL
  - 9.3% (NHIS 2023) International standard
- At least 1 domain is coded CANNOT DO AT ALL
  - > 1.5% (NHIS 2023)

#### **American Community Survey**

- At least one domain is coded YES
  - > 15.9% (ACS 2022)

#### **National Health Statistics Reports**

Number 161 
August 9, 2021

Measuring Disability: An Examination of Differences Between the Washington Group Short Set on Functioning and the American Community Survey Disability Questions

by Julie D. Weeks, Ph.D., James M. Dahlhamer, Ph.D., Jennifer H. Madans, Ph.D., and Aaron Mailland, Ph.

#### Abstrac

Objective—This report examines differences in survey reports of disability between two sets of disability questions, the 8bort Set on Fantscinning (WO-SS) developed by the Wahnington (Found on Disability Statistics (WO) and a set of disability questions developed for the American Community Survey (ACS). Method—Data from the 2011–2012 Teatornal Health Interview Survey we used to containing agreement between the WV-SS and ACS measures. One differ between the agention net is the ACS questions have develorations—"set" or "Found production and the ACS of the three acts of the ACS o

understand the level of agreement and investigate differences between the two.

Restaller—Approximately twice an amy suids were adminded a thorough called by the ACS measure compared with the WO-US measure. This result holds across the contract of the co

Conclusion—The ACS disability measure identifies a higher percentage of version in the two ensearces in julin. The VG-SC enterous—The ACS disability measure identifies a higher percentage of version in the two ensearces in julin. The VG-SC enterous, version is considered to the version and the version enterous indication of disability severity, which is useful in describing the full centimate of disability severity, which is useful in describing the full centimate of disability severity, which is useful in describing the full centimate of disability severity.

tional Health Interview Survey (NHIS)

#### Introduction

The health status of a population is obtom reported in stress of the prevalence of diseases or risk, factors for the contract of the prevalence of diseases or risk, factors for the status of the prevalence of the contract of the contract



U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES Centers for Disease Control and Prevention National Center for Health Statistics

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## **NCHS Benefits from Washington Group Questions**

- Rigorous, standards-based approach, aligned with ICF framework
- Includes communication difficulty, capturing psychosocial and cognitive disability in addition to problems with speech
- Graded response categories permit NCHS to:
  - Meet its mandate to "collect statistics on the extent and nature of disability"
  - Assess differing levels of functional limitation
  - Identify differences in outcomes for people with differing levels of functional limitation
  - Provide data for adequate planning of programs to improve health of people with specific levels of functional limitation
- Meets NCHS's international reporting obligations and facilitates crossnational comparisons

For more information, contact CDC 1-800-CDC-INFO (232-4636)

TTY: 1-888-232-6348 www.cdc.gov

The findings and conclusions in this presentation are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.



# Update on Disability Data Interagency Working Group

Adam Politis, Office of Science and Technology Policy

## Lunch

12:35 PM - 1:30 PM

A Path Toward Meaningful Engagement with the Disability Community

Moderator: Tho Vinh Banh, Disability Rights California

#### Panelists:

- Kate Caldwell, Center for Racial and Disability Justice
- Sheryl Emery, National Black Deaf Advocates
- Marlene Sallo, National Disability Rights Network
- Maria Town, American Association of People with Disabilities
- Silvia Yee, Disability Rights Education and Defense Fund

## Break

2:30 PM - 2:45 PM

Reimagining Disability Data: Disability Researcher Perspectives on Gaps, Uses, and Promising Practices

Moderator: Jean Hall, University of Kansas

#### **Panelists:**

- Anjali Forber-Pratt, American Association on Health & Disability
- Scott Landes, Syracuse University
- Marjorie McGee, Oregon Health Authority
- Daniel Mont, Center for Inclusive Policy
- Bonnielin Swenor, Johns Hopkins University

# Opportunity for Comments

## Remarks

Claudia Gordon, Chair, National Council on Disability

# Closing Remarks

Robert Santos, Director, U.S. Census Bureau

# Thank you!