

# **Improving Data Collection for People with Disabilities**

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Bob Sivinski

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# Challenge of Defining Disability

- Medical diagnosis
- **Functional limitation**
- Self-identification
- Accessibility needs
- Program eligibility
- Statistical measures
- Statutory framework





# Background: Proposed ACS Questions

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**Response Options = No difficulty, Some difficulty, A lot of difficulty, or Cannot do at all**

- Does this person have difficulty hearing, even if using a hearing aid?
- Does this person have difficulty seeing, even when wearing glasses?
- Does this person have difficulty remembering or concentrating?
- Does this person have difficulty walking or climbing steps?
- Does this person have difficulty with self-care, such as washing all over or dressing?
- Using his or her usual language, does this person have difficulty communicating with others, for example understanding or being understood?
- 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?

# Background: Disability Data IWG (DDIWG)

## SED Action Item for Disability Data: Creation of the DDIWG

- “Disaggregated data—data about groups separated out by race/ethnicity, gender identity, veteran status, geography, sexual orientation, income level, **disability status**, rural/urban location, and other factors—are essential for identifying and remediating disparities in how the government serves American communities, particularly those that have historically been overburdened and underserved.”
- “...the federal government is making progress establishing evidence agendas and promising practices for collecting, protecting, and using data about sexual orientation and gender identity(SOGI)...The SED will begin building comparable best practices for other high-priority under-collected demographic variables, including **disability** and rural location status...As the work matures, the SED will likely **create additional IWGs** and assign specific deliverables to advance equitable data for other populations under-represented in federal datasets”

# DDIWG Purpose and Scope

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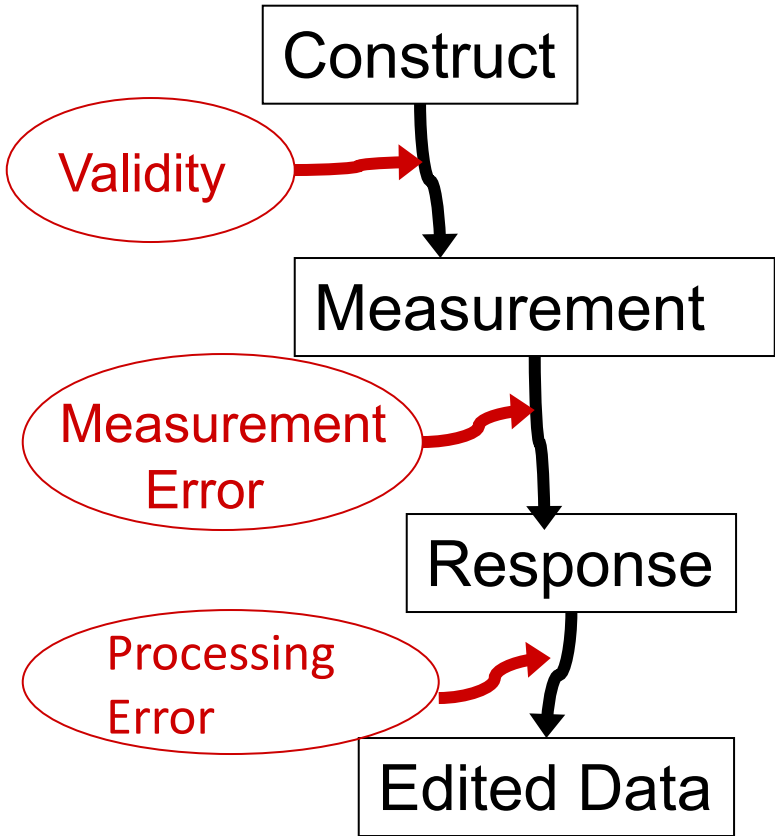
To coordinate activities to strengthen the federal government's use of disability data to advance equity for people with disabilities.

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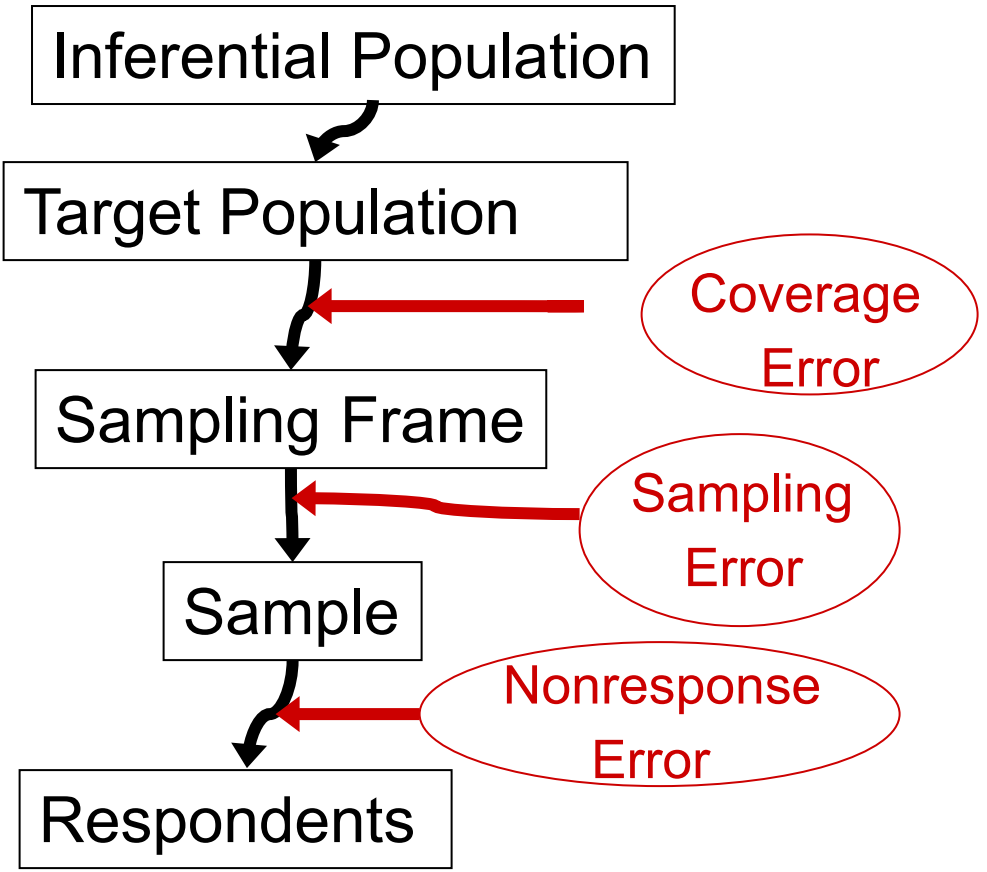
Within the broader scope of equitable data, this work will allow for rigorous assessment of the extent to which government programs and policies yield consistently fair, just, and impartial treatment of people with disabilities.

# The Total Survey Error Perspective

## Measurement



## Representation



Survey Statistic



# Coverage Error

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Frame source / linked records /  
admin data

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What's your sampling unit?

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Who responds on behalf of the  
household?

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Does your frame include group  
quarters?



Sampling  
Error

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Sample size

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Power analysis

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Targeted screening and  
oversampling

# Nonresponse Error

## Accessibility

- Plain language, large print, TTY, etc.

## Mode

- Offering a variety of modes can help reach people with a variety of disabilities.
- In person interview is best, but expensive.

Non-response follow-up: just more of the same?

# After the Survey...

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Provide  
accessible results  
and products

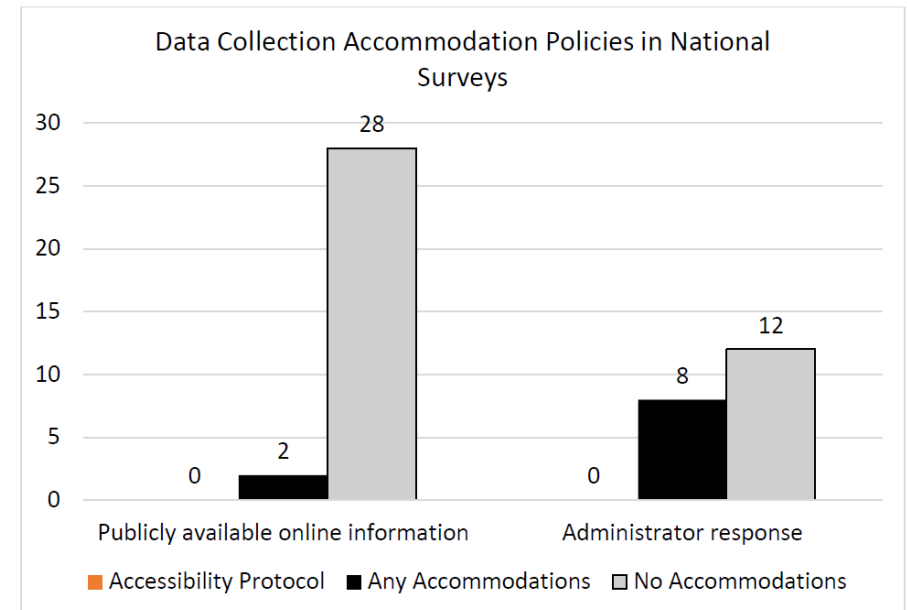
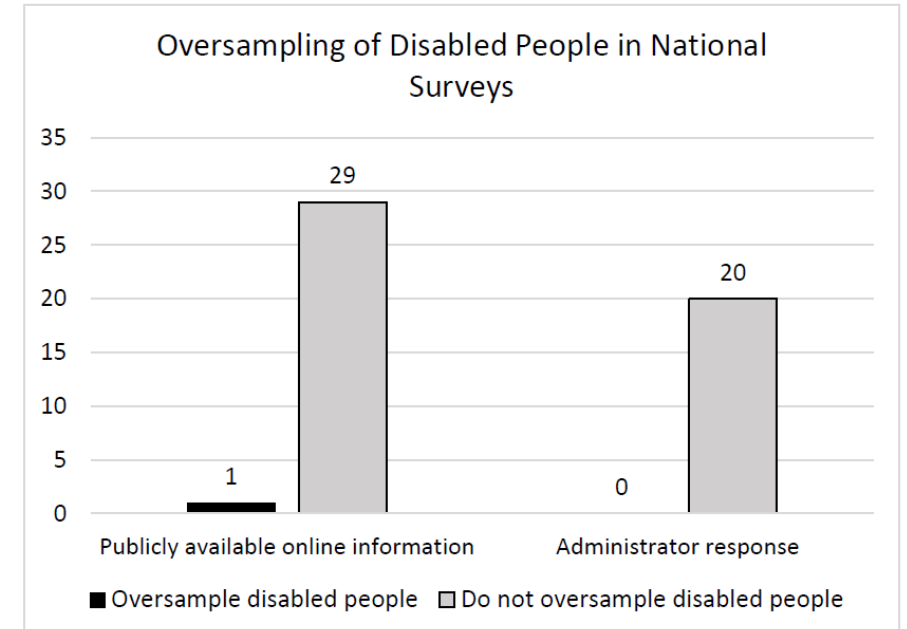
Check against  
benchmarks

Non-response  
Bias analysis and  
adjustment

# How are we doing right now?

Caroline Cerilli et. al., *Disability Inclusion in Federally Funded Surveys*, 2024

- Looked at 30 health and demographic surveys.
- Used online info and sent questions to survey administrators.



# Thank you!



HAVE ANY QUESTIONS? ASK  
ADAM!



ADAM.POLITIS@OSTP.EOP.GOV