

# Measuring Disability: Considerations and Challenges

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# Objectives

- Review key conceptual information related to measuring disability
- Highlight challenges with studying/surveying people with disabilities
- Share promising practices needed to improve surveillance for people with disabilities

# Health outcomes for people with disabilities

- Mortality (premature and disproportionate mortality among people with severe to profound intellectual disabilities)
- Morbidity (associated conditions, co-morbidities, secondary conditions)
- Quality of life (independence, inclusion in programs, poverty, employment)

# Public health surveillance: purpose

- Determine health status of PWDs
- Identify priorities for intervention
- Identify patterns of comorbidity
- Plan for program and policy intervention
- Evaluate programs and policies for effectiveness
- Extend knowledge base through research

# Prevalence of disability

Data System	Year	Age	Prevalence
BRFSS	2008	18+ years	≈ 22%
NHIS	2008	17+ years	33.3%
SIPP	2005	All ages	18.7%
ACS	2008	All ages	12.1%

BRFSS: Behavioral Risk Factor Surveillance System

NHIS: National Health Interview Survey

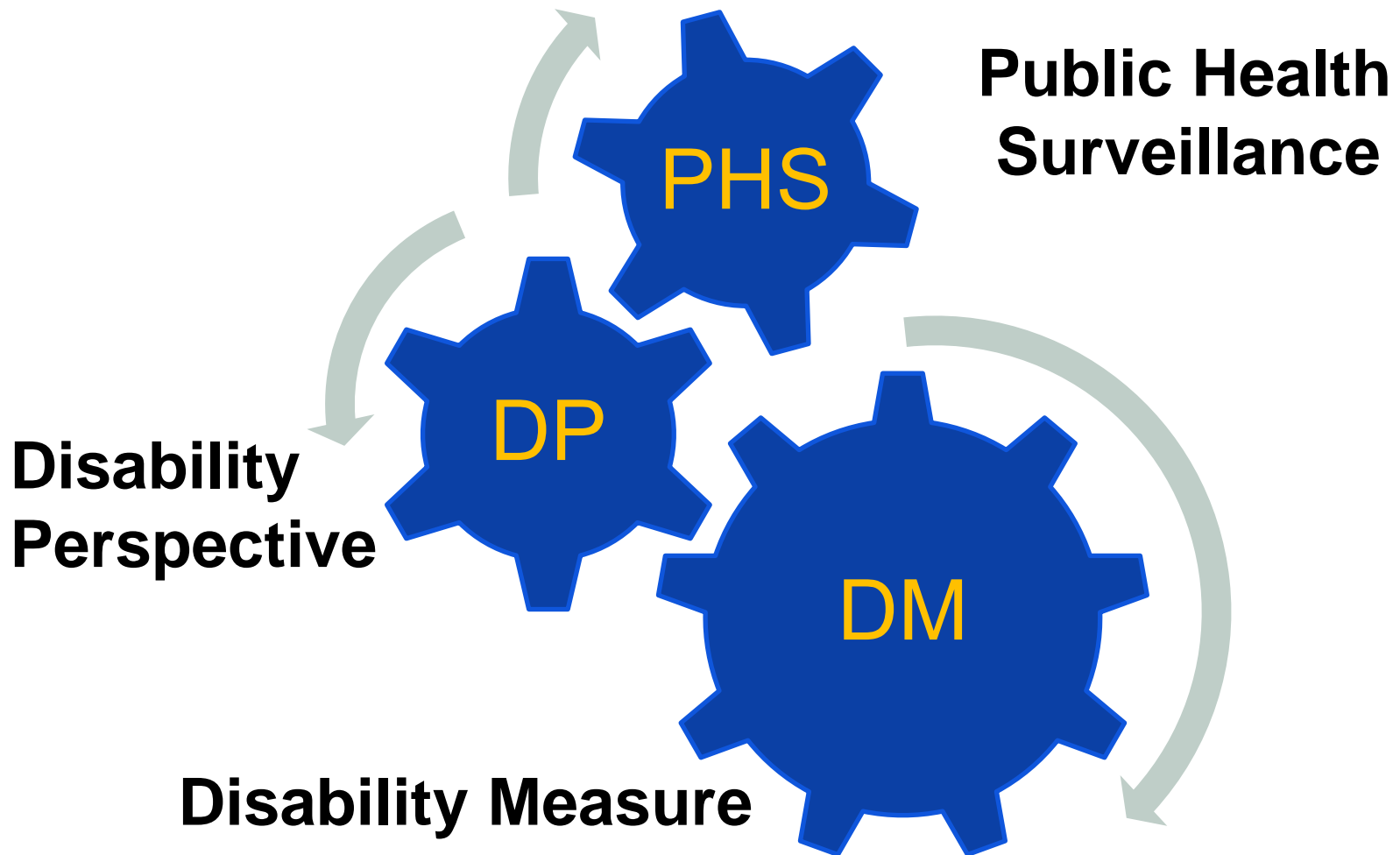
SIPP: Survey of Income and Program Participation

ACS: American Community Survey

# Overarching factors impacting disability measures

- Varying definition of disability
- Varying perspective on the concept of disability
  - Models and paradigms
- Varying methods and methodologies used for data collection
  - Homogeneity of PWDs

# Connecting disability to public health surveillance



# What is surveillance?

“*Public health surveillance* is the **ongoing**, systematic collection, analysis, and interpretation of data essential to the planning, implementation, and evaluation of public health practice.....dissemination of these data to those responsible for prevention and control.”

*(Institute of Medicine, 2003)*



# What is disability?

“*Disability* is an umbrella term for impairments, activity limitations and participation restrictions. It denotes the negative aspects of the interaction between an individual (with a health condition) and that individual’s contextual factors (environmental and personal factors).”

(WHO, 2001)

# Disability models and paradigms

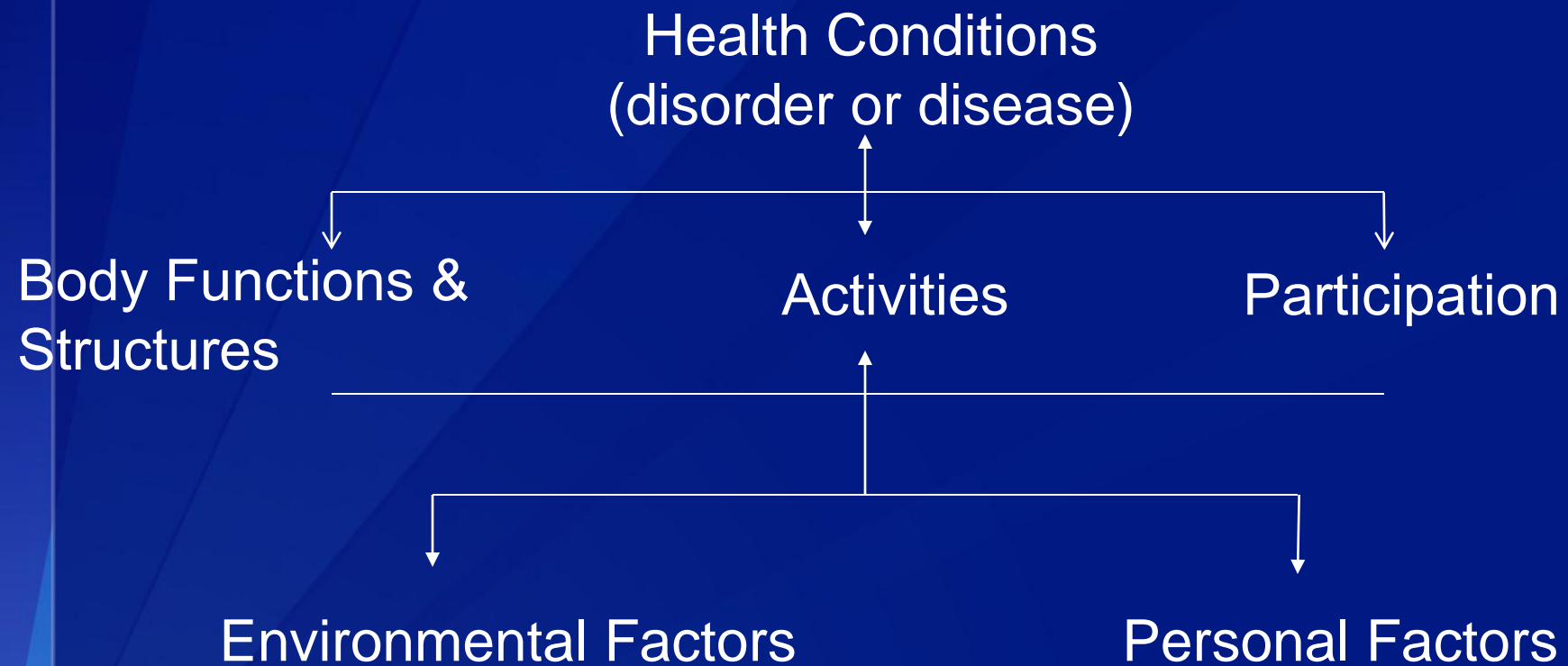
## Medical Model

- Disability is an **individual** condition
- Disability due to individual **impairment**
- Perceived to be **less inclusive**
- Fix the **person**

## Social Model

- Disability seen as a **societal** problem
- Disability is a product of the **environment**
- Perceived to be **more inclusive**
- Fix the **environment**

# International Classification of Functioning, Disability and Health (ICF Model)

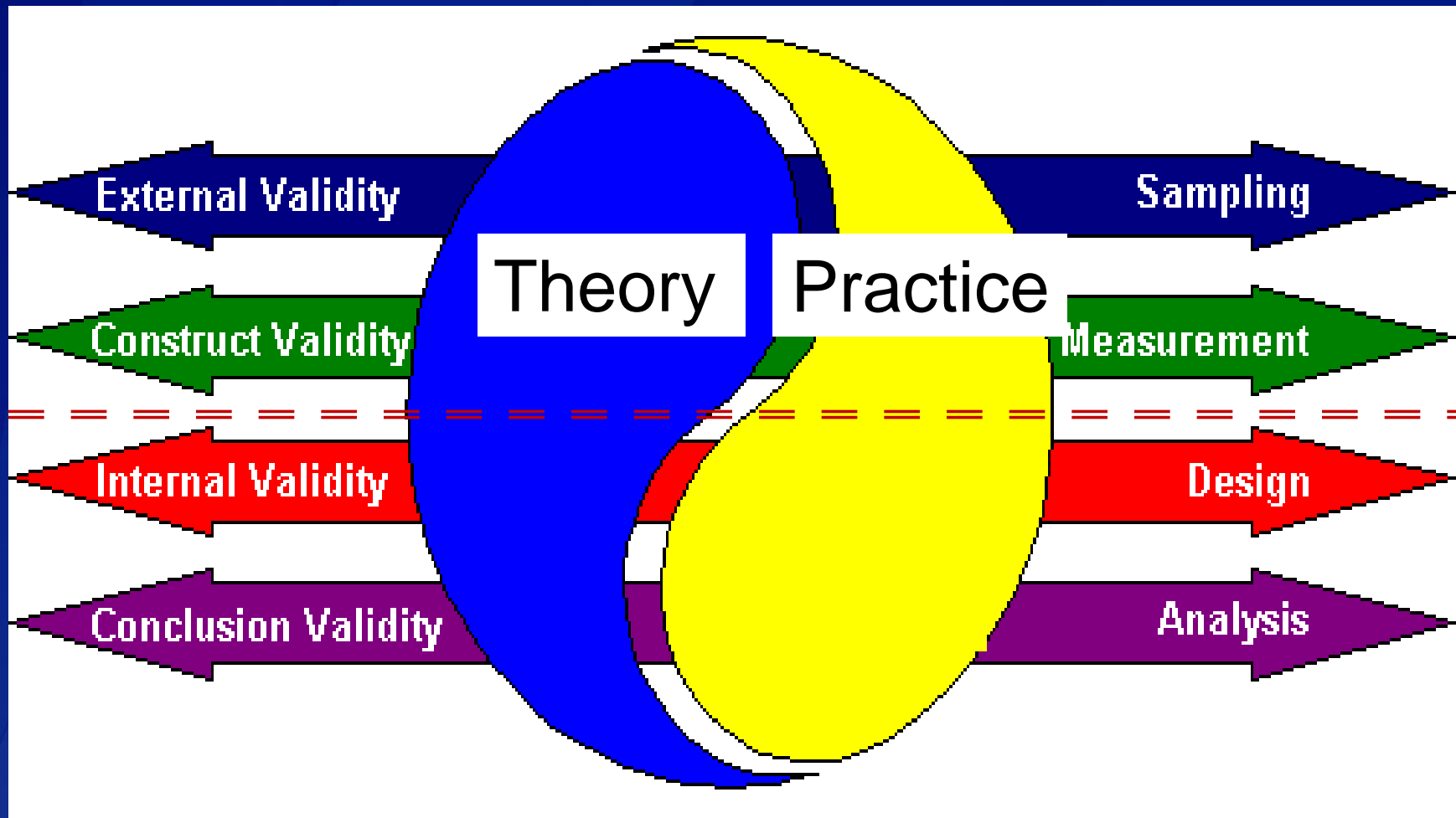


*(World Health Organization, 2001)*

# Methodological issues related to studying and measuring PWDs

- Cognitive abilities
- Proxies
- Sampling bias
- Response bias
- Non-response
- Interviewer training
- Under-representation in clinical trials

# Evaluating the quality of research & surveillance



*(Illustration adapted from Trochim, 2006)*

# Validity of disability measures in public health surveillance/research

## Sampling (External validity)

- Representativeness
  - Types of disability
  - Institutional/Non-institutional

## Measurement (Construct validity)

- Instrumentation
- Self vs. Proxy
- Cognitive/Stamina
- Questionnaire/  
Interviewer training

# Applying sampling methods in disability surveillance/research

## Probability sampling

- Random sampling (simple, stratified, systematic)
- Cluster sampling
- Multi-stage sampling

## Non-probability sampling

- Convenience/ Accidental sampling
- Purposive sampling

## Using proxies in disability surveillance/research activities

- Useful for increasing response rate
- May also be subjective rather than objective
- May be ineffective for data on psychological functioning/status
- More than 30% of respondents in NHIS and SIPP use proxies



# Cognitive abilities

- Cognitive barriers:
  - People with profound intellectual disabilities have limited ability to respond to interviews
- Communication challenges:
  - Recall bias is likely to be higher for people severe or profound disabilities
- Stamina
  - The endurance of those with severe disabilities may affect participation
- Consent

# Recommendations

## - Sampling -

- Proactively engage survey designers from the beginning
- Pay attention to subgroups with a high propensity for non-response
- Deploy devices to increase response rate (advance letters, incentives, etc)

# Recommendations - measurement -

- Use decomposition techniques in questionnaire design
  - Spatial cues
  - Temporal cues
- Interviewer training

# Thank you!

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**For more information please contact Centers for Disease Control and Prevention**

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

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