

Disability Survey Research— Building evidence-based policy on a slippery foundation

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Outline

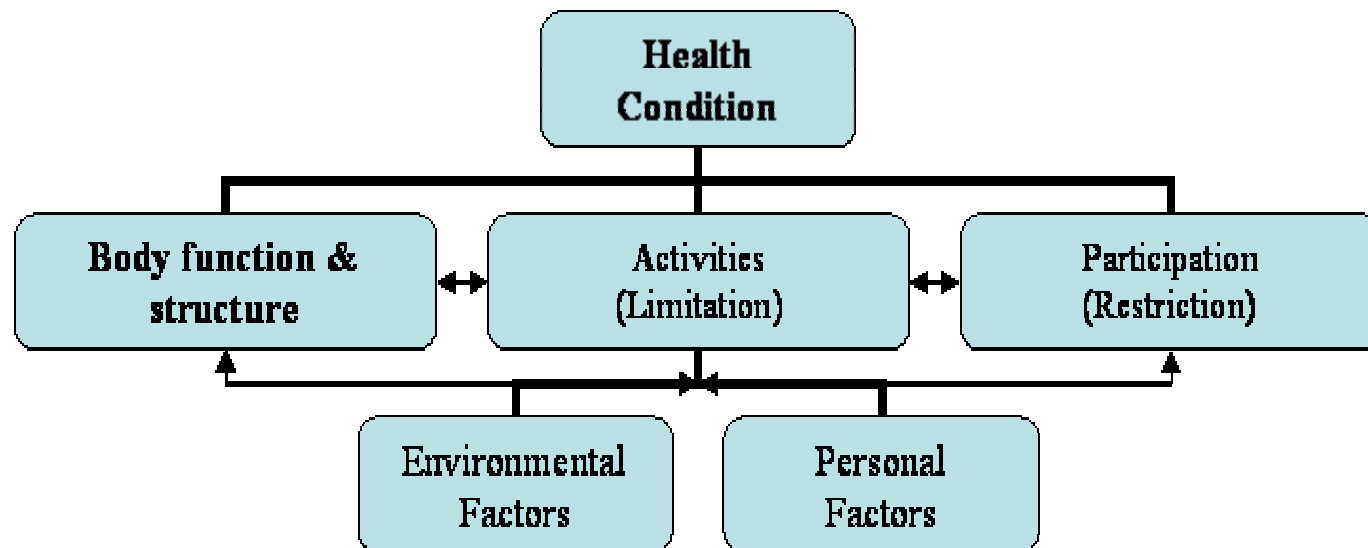
- Defining disability
- Canada's disability survey strategy
- Variations in Canadian national survey results
- Policy issues--examples
- Considerations and possible future directions

Defining disability—the first
step

Beliefs about disability have varied historically

- Punishment from God, a curse, a seer or enigmatic person (traditional beliefs)
- Impairment/chronic condition (bio-medical models)
- Activity limitation / handicap (rehab-functional models)
- Participation restriction (social, rights-based models)
 - Due to discrimination, environmental barriers
- Normal human variation (post-modern, cultural models)

The International Classification of Functioning, Disability and Health (ICF) provides a standardized framework for conceptualising disability



Several factors influence survey-based prevalence estimates

- Definition of disability
- Sampling strategy
- Number and type of questions
- Question wording
- Cultural factors (e.g. stigma)
- Rates vary from 0.2% in India and Peru to 20% in New Zealand (UN DISTAT-2 as reported by Mbogoni 2003)

Using ICF is recommended to improve consistency of surveys

- UN and WHO encourage states to adopt ICIDH (1981) / ICF (2002) for national surveys
- ICIDH / ICF has guided Canadian disability survey research since the early 1980s
- Canada has participated actively in advancing disability survey research methods (e.g. Washington City Group)

Canada's Disability Survey Strategy

Canada's current disability survey strategy was adopted in 1999

- The Government adopted two disability filter questions to identify the population with disabilities on the 2001 Census
- Primary source of disability data is The Participation and Activity Limitation Survey (PALS)
 - PALS is a post-censal survey (every five years)
- Other surveys incorporate the filter questions
 - Builds a comprehensive inventory of disability data

There are two disability filter questions

Does this person have any difficulty hearing, seeing, communicating, walking, climbing stairs, bending, learning or doing any similar activities?

- *Answer categories:*
 - Yes, sometimes
 - Yes, often
 - No

Does a physical condition or mental condition or health problem reduce the amount or the kind of activity this person can do:

- At home?
 - At work or at school?
 - In other activities, for example, transportation or leisure?
- *Answer categories:*
 - Yes, sometimes
 - Yes, often
 - No

PALS is the principal source for detailed information about disability

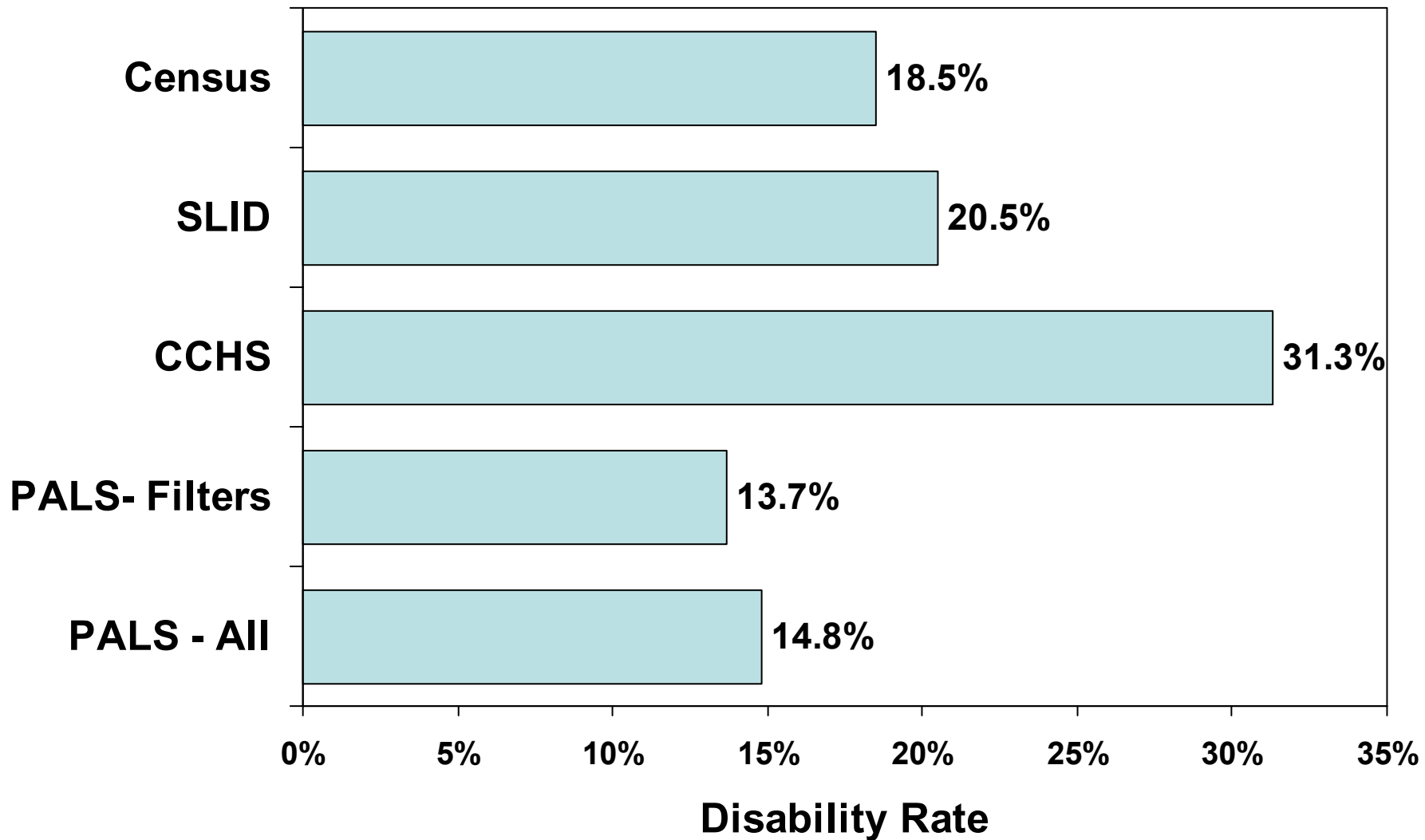
- Sample taken from positive responses to Census filter questions
- Presence of “disability” is defined by positive response to the filter questions or any of 30 screening questions
 - Screening questions correspond to elements of ICF activity areas (6), body function (pain), or certain diagnosed disorders (developmental, psychiatric) resulting in a reduction in amount or kind of activity that can be done
- Disability is categorized by severity and type
 - Severity is based on number and degree of activity limitations
 - Types correspond to areas covered by screening questions
- Extensive information is gathered about participation in particular life areas as well as environment factors of interest

Other major surveys provide disability information

- The Census (long form)
- Survey of Labour and Income Dynamics (SLID)
- Canadian Community Health Survey (CCHS)
- National Population Health Survey (NPHS)
- General Social Survey (GSS)
- National Longitudinal Survey of Children and Youth (NLSCY)

Variations in Canadian survey results

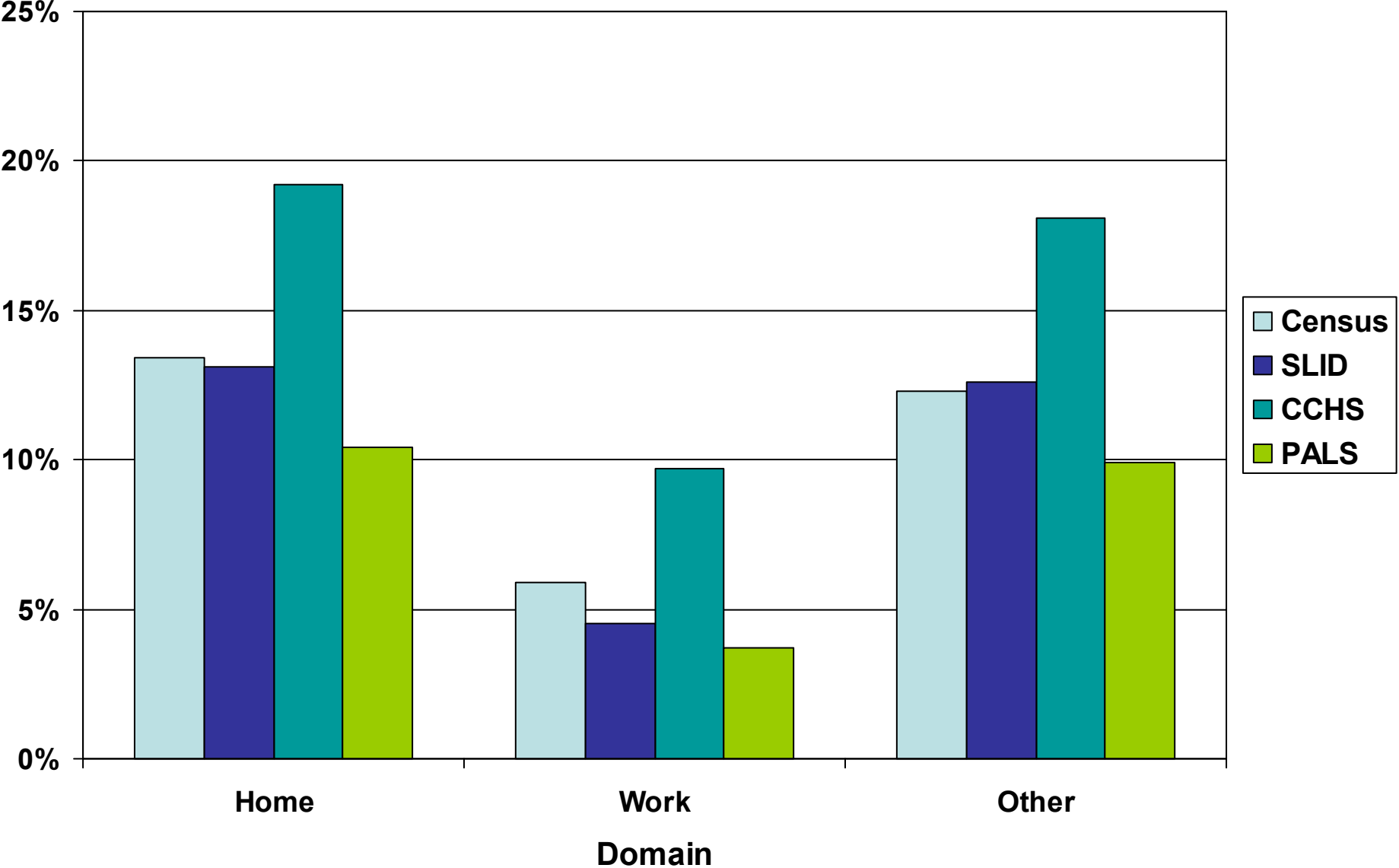
Disability Rates for Major Surveys, Ages 16-102, 2001



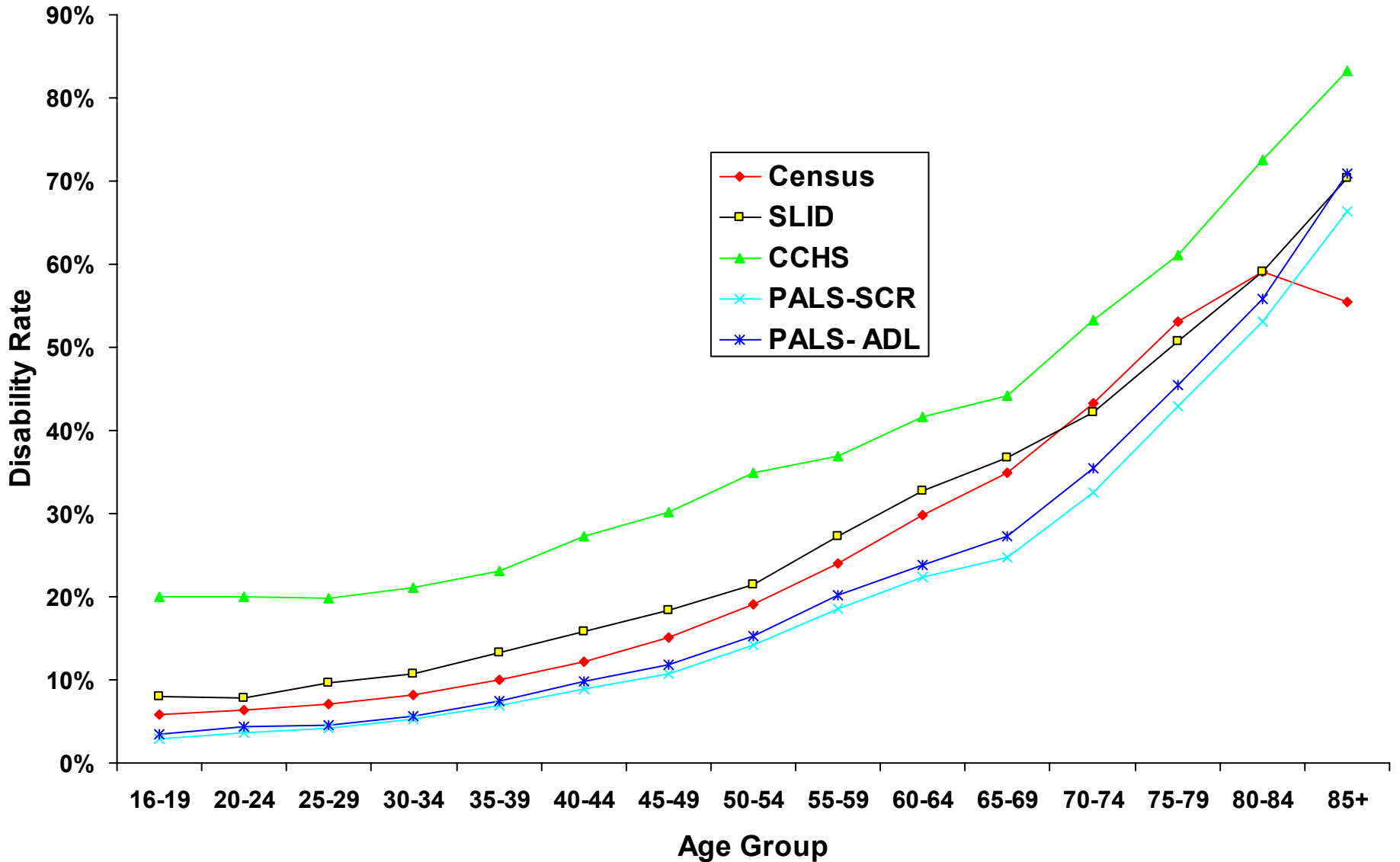
Possible sources of differences

- Sampling (PALS)
- Survey context
- Proxy responses
- Placement of disability questions
- Language/culture

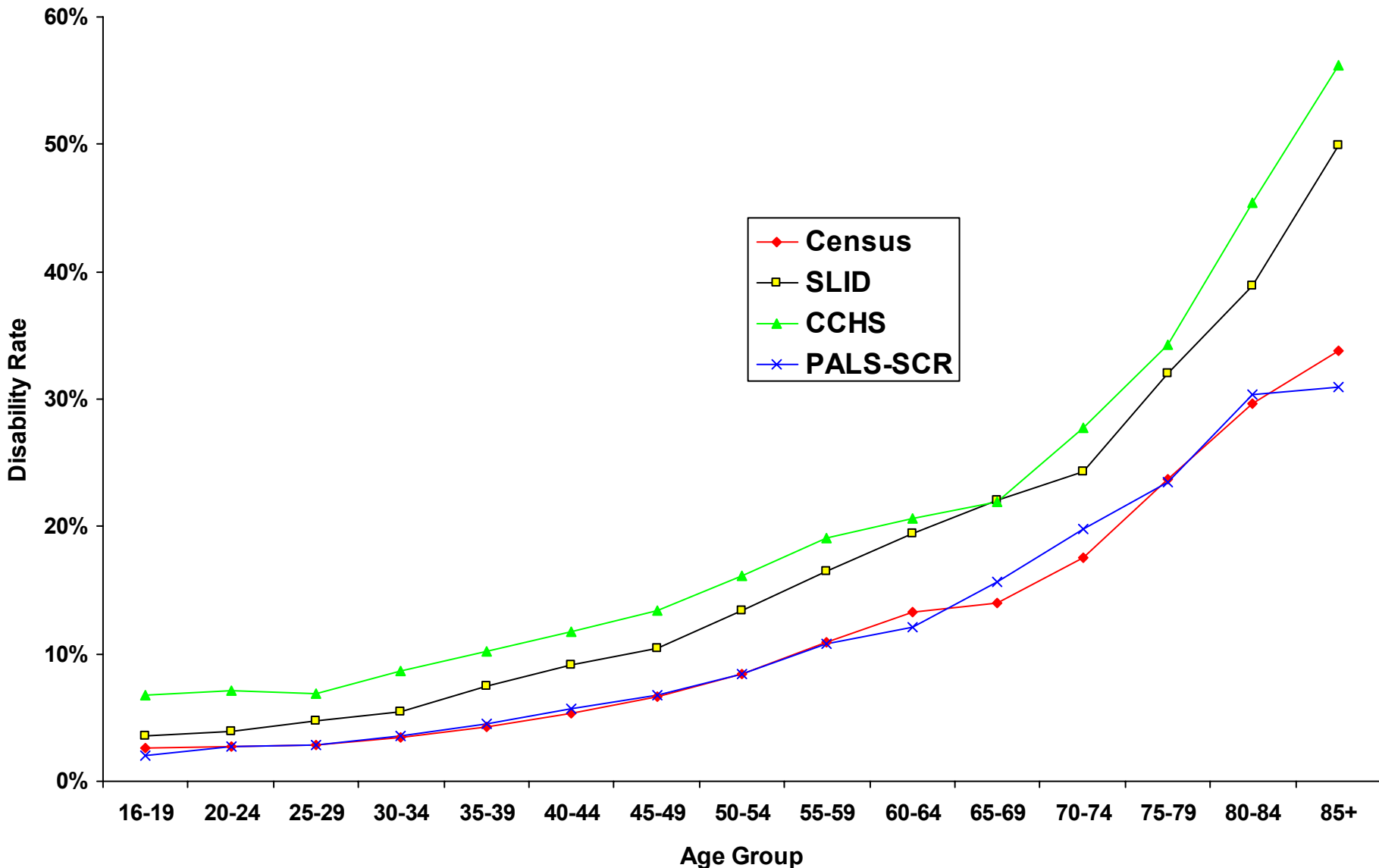
Disability Rate by Survey and Domain, 2001



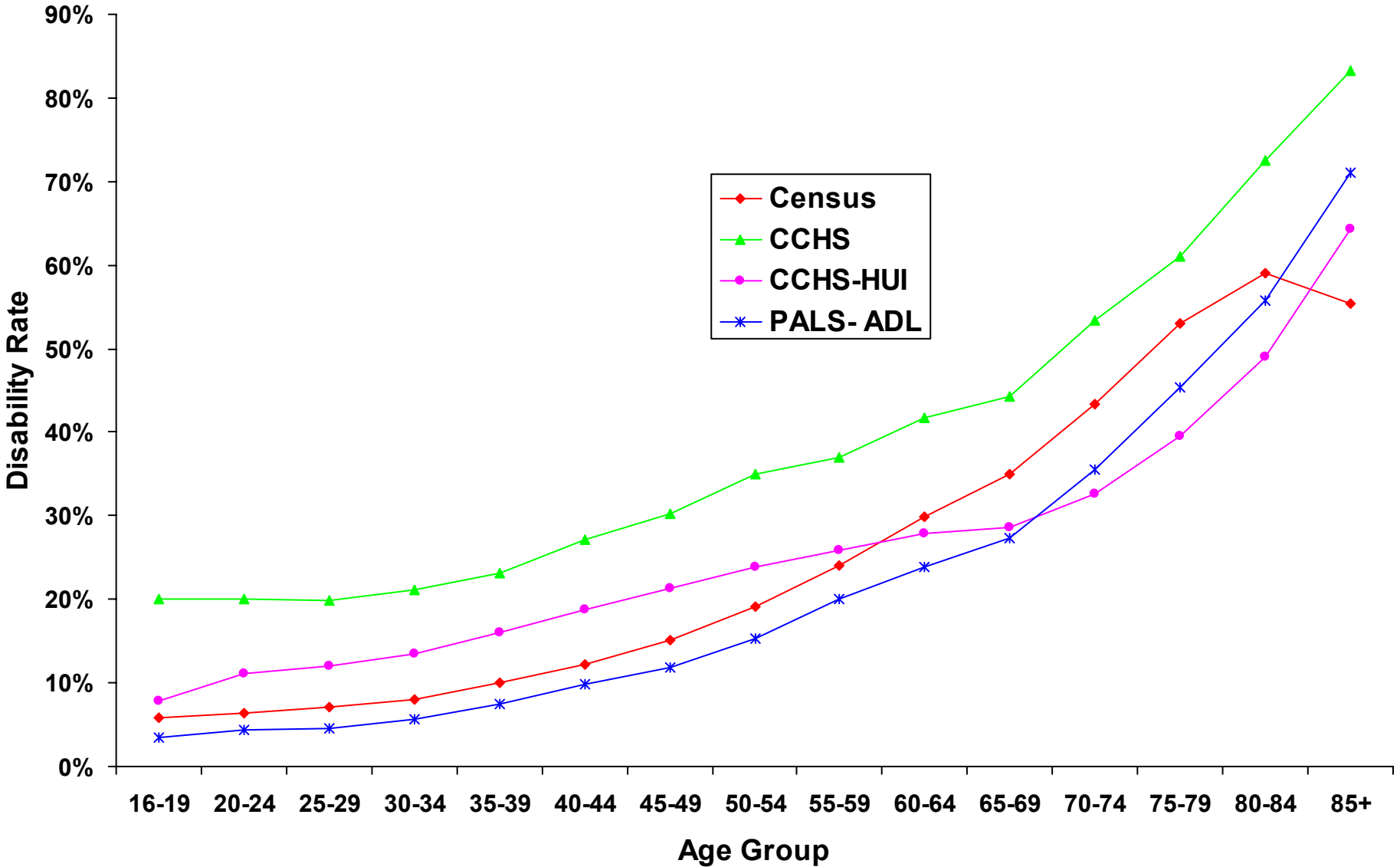
Disability Rate by Survey, 2001 (16-102)



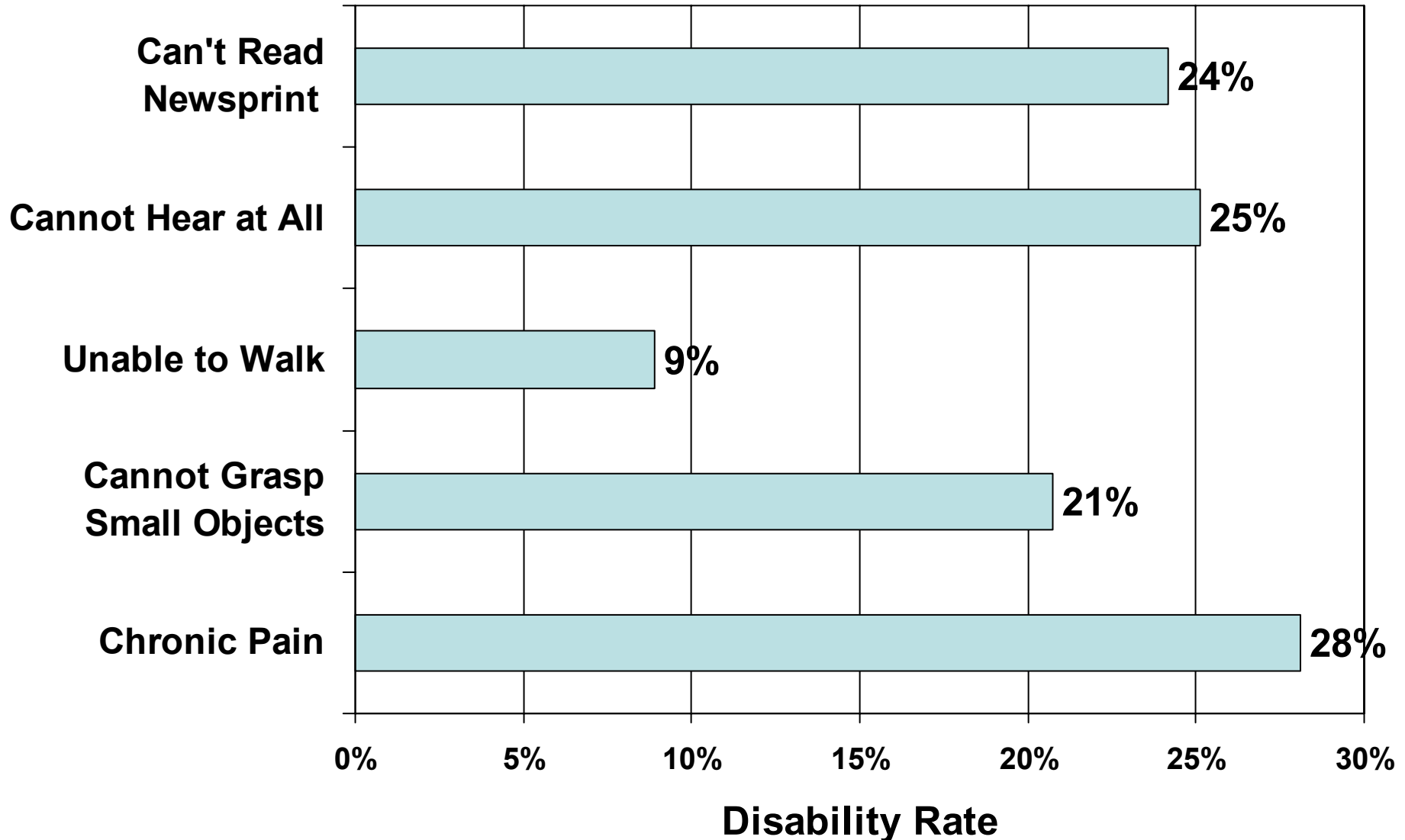
Disability Rate by Survey, Yes Often, 2001 (16-102)



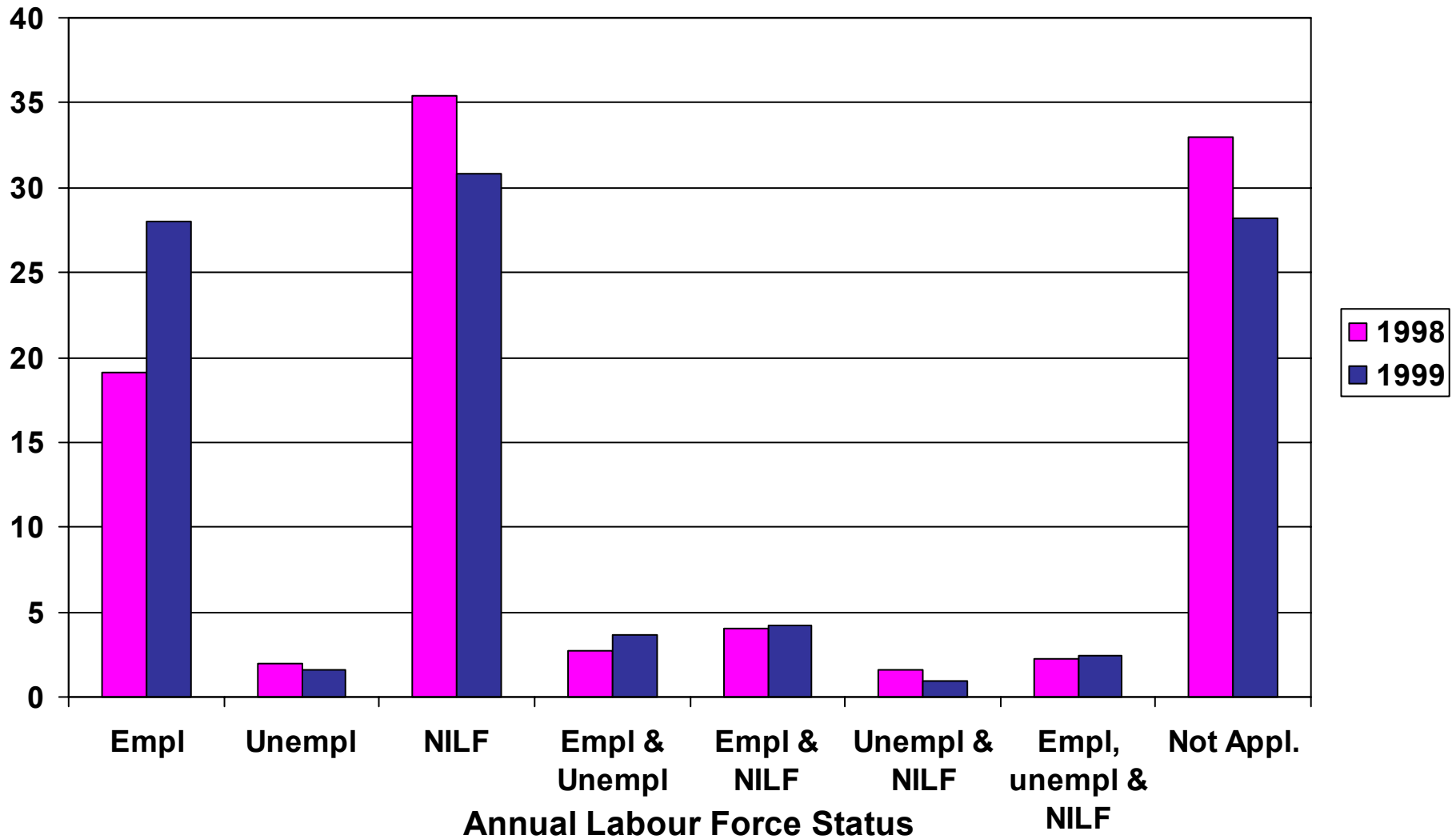
Disability Rate by Survey, 2001 (16-102)



Disability Types Found by the HUI Following Negative Responses to Filter Questions

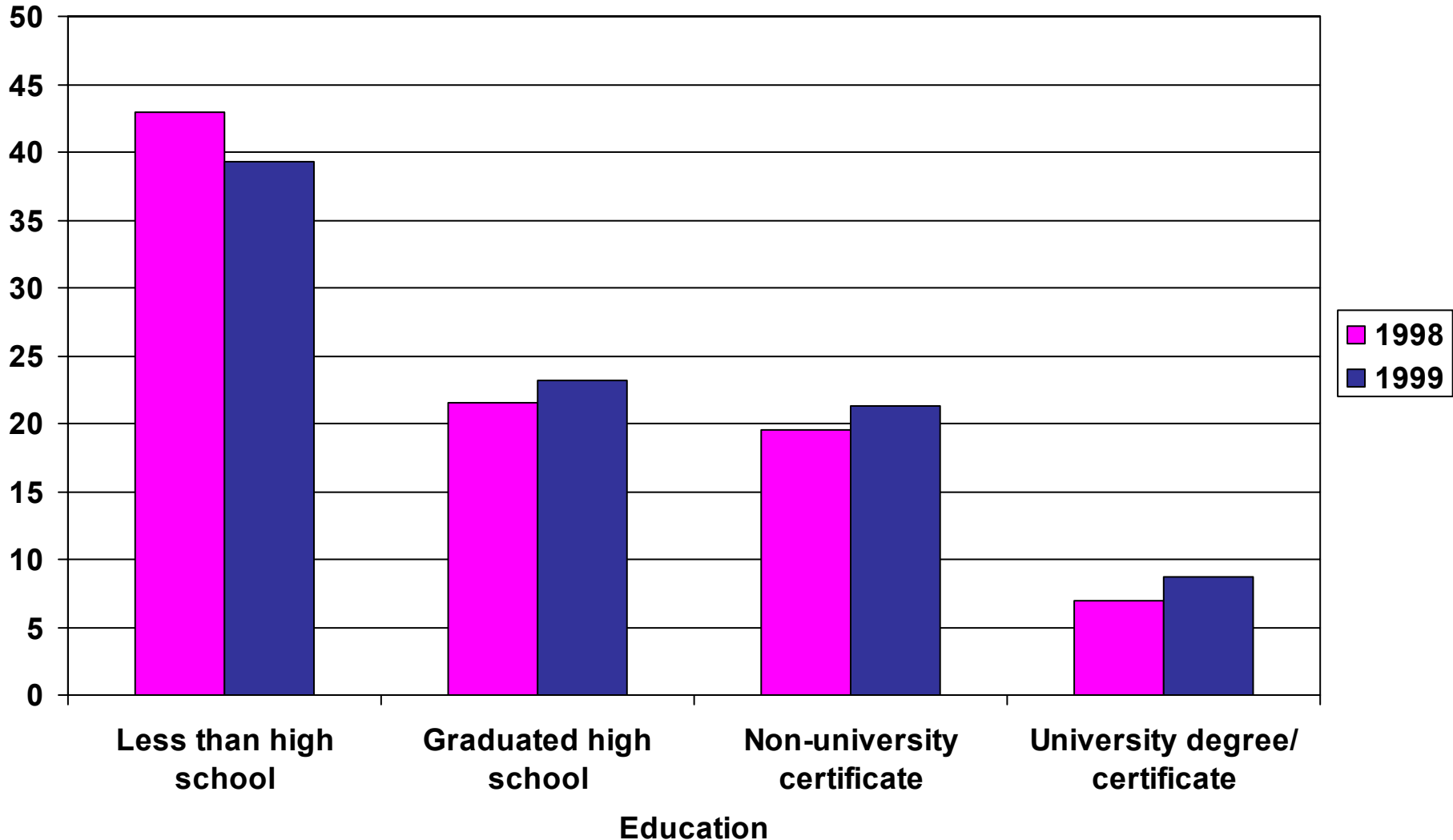


Disability Rate by Annual Labour Force Status 1998 & 1999 SLID Panel #2

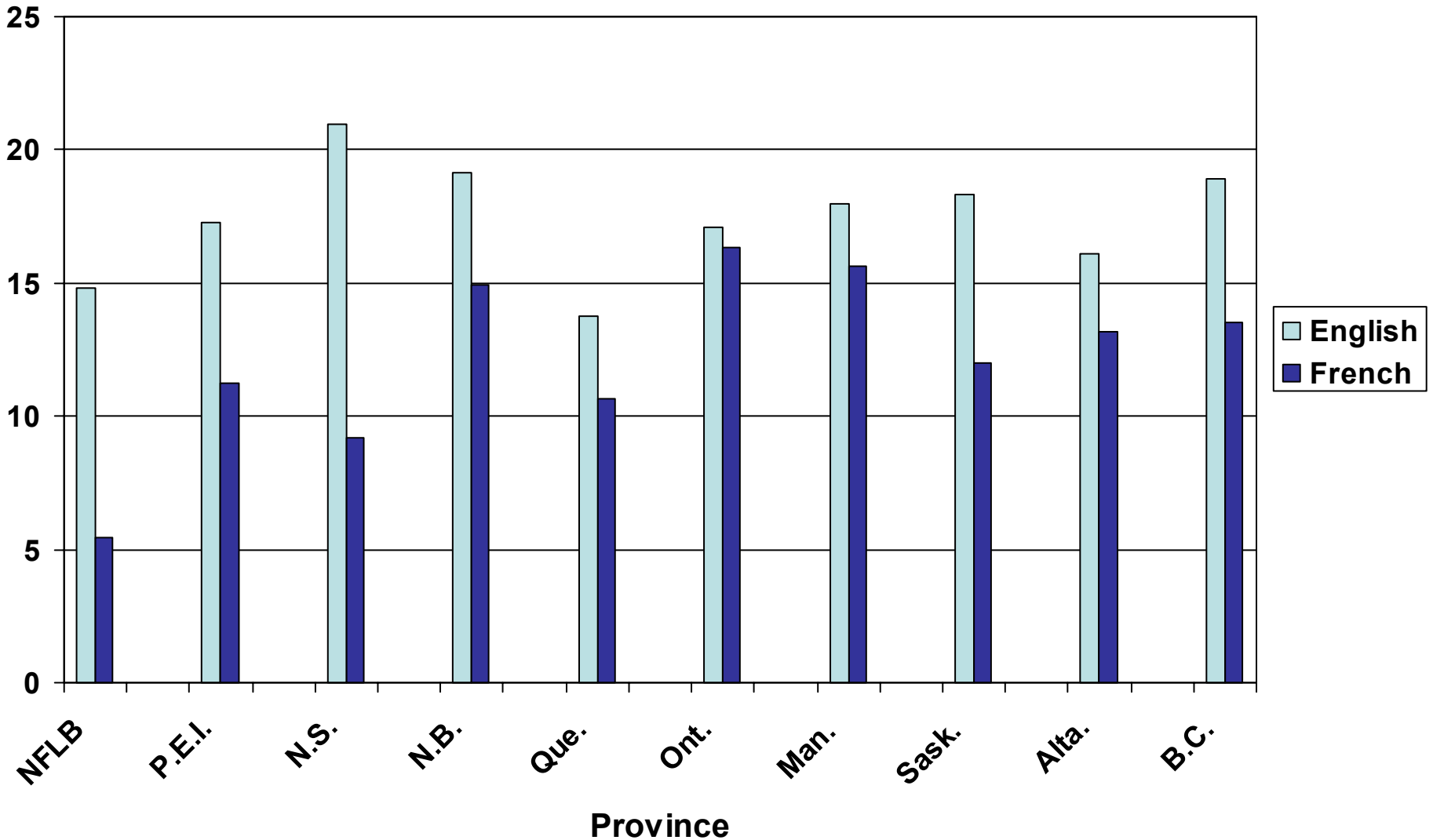


Disability Rate by Highest Level of Schooling

1998 & 1999 SLID Panel #2



Disability Rate by Questionnaire Language and Province, 2001 Census



Survey results and policy

What do we need to know from a disability policy perspective?

- Since 1996, Canadian governments have accepted “full inclusion” of persons with disabilities as a policy goal
 - Inclusion—can persons with disabilities participate equally as others? (equal opportunities)
 - Inclusion—do persons with disabilities have equality with others in the goods of society (equal outcomes)
- Composition/size of the population with disability
 - 3.6 million Canadians have a disability
 - Subsets for particular policy initiatives

We need information in order to address specific issues

- Some key dimensions of inclusion
 - Disability supports, skills development and , employment, income, community capacity, health and well-being
- Tracking and reporting progress
 - Accountability frameworks and reporting
 - *Advancing the Inclusion of Persons with Disabilities*
- We need both general population (societal) as well as specific (program-level) measures

A number of recent policy examples illustrate challenges arising from “slippery” disability survey results

- Multilateral framework for Labour Market agreements for persons with disabilities
- Disability tax credit evaluation
- Employment equity reporting
- Reporting progress—
 - the federal report on disability
 - long-term trends
- International comparative analyses

Questions and possible next
steps

Should we use the same definition of disability for every policy question?

- McColl and Bickenbach (2003, 1998) argue that different policy issues require different definitions of disability

	Biomedical	Economic
Health services		
Income replacement		
Human rights		

How much emphasis should be placed on “the” rate?

- Is the expectation that there should be a single rate based on a biomedical definition or (possibly) activity limitation approach?
- When using a participation restriction approach, should we expect similar rates:
 - Across surveys?
 - Across participation domains?
 - Across cultural groups?

If different rates are inevitable then what does this mean for policy?

- To what extent can we control for methodological differences? (e.g. can we imagine a comparison of HALS and PALS?)
- What are the issues in combining survey results to produce a profile of disability?
- How to communicate with policy makers? (as if disability weren't complicated enough already!)

Possible next steps

- Continued research agenda to better understand sources of differences in disability rates in various surveys
- Continue to apply ICF framework to survey research and (possibly) to program data collection to improve conceptual consistency
- Develop improved approaches for “combining” survey results
- PALS 2006 could produce multiple disability estimates (e.g. for different participation domains)

Building disability policy on a slippery foundation

Thank you