

2023 Compendium of Disability Data Collection Methods

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CHAPTER I. INTRODUCTION

A. Overview

In 2018, the Administration for Community Living's National Institute on Disability, Independent Living, and Rehabilitation Research, within the U.S. Department of Health and Human Services, funded a Rehabilitation Research and Training Center on Disability Demographics and Statistics (StatsRRTC). The goal of this center, which is housed at the University of New Hampshire's Institute on Disability, is to bridge the divide between the producers and end users of disability statistics, thereby supporting better data collection, more accurate information, better decisions, more effective programs, and improved lives for people with disabilities. As a collaborator with the StatsRRTC, Mathematica is working on several integrated research and dissemination projects designed to improve existing methods of collecting disability data and to identify innovative ways to collect data on the experiences of people with disabilities.

Entities involved in quantitative and qualitative data collection—such as federal agencies, university survey centers, and private polling firms—should (and sometimes by law must) consider the extent to which their methods create barriers to participation for people with disabilities. Yet few resources are available to address this problem. To fill this knowledge gap, we created the Compendium of Disability Data Collection Methods, an easily accessible source of research on the methodological issues associated with collecting data from or about people with disabilities. The 2023 version of the compendium, an indexed reference list, contains 615 references on the following subjects:

- Disability/impairment type
 - Aging and later-life disability
 - Developmental, intellectual, and cognitive impairments, including dementia, traumatic brain injury, and learning disabilities
 - Sensory and communication impairments, including blindness and low vision, hearing loss and deafness, autism spectrum disorder, and speech impairments
 - Physical impairments, including musculoskeletal conditions, epilepsy, muscular dystrophy, multiple sclerosis, and other disabilities
 - Psychiatric impairments and mental health, including anxiety disorders, post-traumatic stress disorder, psychotic disorders, and mood disorders

- Data collection
 - Data collection mode and adaptive technologies,¹ including interviewer-administered surveys,² self-administered surveys,³ ecological momentary assessments,⁴ and mobile-device-based data collection⁵
 - Interviewing techniques and interviewer effects
 - Proxies⁶
 - Inclusive strategies and participatory action research
 - Qualitative methods
- Questionnaire design and measurement
 - Developing and validating measures and instruments
 - Measuring satisfaction and quality of life
- Sampling and nonresponse
- Special populations
 - Children and youth with disabilities
 - Veterans' populations
- Ongoing national surveys
 - American Community Survey (ACS)
 - Current Population Survey (CPS)
 - National Health Interview Survey (NHIS)
 - National Health and Nutrition Examination Survey (NHANES)

Chapter II of the compendium is an indexed reference list. The entries are ordered alphabetically within each subject, and most include a URL so that users can retrieve the publication. Because the references have been placed in all applicable categories, many of the sources are indexed under more than one subject.

¹ Includes articles that discuss American Sign Language-based surveys and the use of Braille devices as a adaptive technologies.

² Includes computer-assisted telephone interviewing, computer-assisted personal interviewing, and other in-person survey administrations.

³ Includes web-administered surveys, audio computer-assisted self-interviewing, and mail and other paper-and-pencil survey administrations.

⁴ Ecological momentary assessments are methods for collecting data in real time and in everyday contexts to minimize recall bias. Examples include asking study participants to provide in-the-moment reports of their behaviors, experiences, and opinions by completing a daily hard-copy, video, or audio diary; using a wearable device such as an accelerometer; or sharing photos and videos to add context to survey findings.

⁵ Includes data collection efforts that rely on smartphones, texting, wearable devices, and GPS-enabled devices.

⁶ Includes proxy bias and the comparison of proxy and self-reported data.

Chapter III is a list of references ordered alphabetically by the first author's last name.

B. Development of the compendium

To create the compendium, we conducted a literature search on the topics listed in Section A, focusing on articles and references published since 2012.⁷ We obtained references from many diverse sources, including the following:

- Online journal articles and social science resources, such as SocINDEX and Academic Search Premier on EBSCO, APA PsycInfo on ProQuest, and MEDLINE on OVID
- Conference presentations, papers, and summaries
- Citations from articles and books
- Internet search engines, such as Google Scholar
- Working papers and dissertations

After completing the literature search, we applied eligibility criteria to further specify which references to include in, or exclude from, the compendium. We included all resources that discuss, examine, or test methods used to collect data from people with disabilities. For example, we included articles that summarized analyses of methodological experiments, papers and presentations that discussed challenges and best practices for collecting data from people with disabilities, and systematic reviews of various screening and measurement tools. We considered publications and presentations from all geographic regions in the world for inclusion. For the excluded references, we screened out any articles for which the full text was not available or accessible, or for which the full text was published in a language other than English. Due to time and budget constraints, we did not evaluate the methodological quality of the articles selected for inclusion.

To ensure that all relevant references are included in the compendium, two screeners independently reviewed each article's title, abstract, and/or full text. After the first screener applied the eligibility criteria to the articles generated from the literature search, a second screener reviewed the inclusion and exclusion decisions made by the first screener. Wherever the two screeners disagreed, an additional screener reviewed the titles, abstracts, or full text to help reach consensus.

After screening was complete, we created the reference list by indexing articles under all relevant topic areas. To ensure that the articles appeared in the appropriate topic areas, an independent reviewer validated the decisions made by the team member who indexed the articles.

⁷ Mathematica has published three versions of the compendium (titled *Surveying Persons with Disabilities: A Source Guide*) under prior StatsRRTC contracts. The first version, published in 2006, includes references from 1974 through 2005. The second version, published in 2008, includes references from 2005 through 2007, and the third version, published in 2013, includes references from 2007 through 2012.

C. Contact information

Readers who wish to contribute to future updates of the Compendium of Disability Data Collection Methods should send copies of relevant literature to Jason Markesich, Stacie Feldman, or Mathematica's publications mailbox.

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CHAPTER II. LISTING BY SUBJECT

A. Disability/Impairment Type

1. Aging and Later-Life Disabilities

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b. Dementia

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B. Data Collection

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C. Questionnaire Design and Measurement

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E. Special Populations

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