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 collection\(^5\)
  - Interviewing techniques and interviewer effects
  - Proxies\(^6\)
  - 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.

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

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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.

E-mail: JMarkesich@mathematica-mpr.com  
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Publications@mathematica-mpr.com
CHAPTER II. LISTING BY SUBJECT

A. Disability/Impairment Type

1. Aging and Later-Life Disabilities


Baric, Vedrana, Maria Andreassen, Annika Øhman, and Helena Hemmingsson. “Using an Interactive Digital Calendar with Mobile Phone Reminders by Senior People – A Focus Group Study.” *BMC Geriatrics*, vol. 19, no. 116, 2019, online only.


Buz, José, and María Cortés-Rodríguez. “Measurement of the Severity of Disability in Community-Dwelling Adults and Older Adults: Interval-Level Measures for Accurate Comparisons in Large Survey Data Sets.” BMJ Open, vol. 6, no. 9, 2016, online only.


II. Listing by Subject: Disability/Impairment Type

Mathematica


Ding, Yunlong, Jiali Niu, Yanrong Zhang, Wenpeng Liu, Yan Zhou, Can Wei, and Yan Liu. “Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE) for Assessing the Severity of Dementia in Patients with Alzheimer’s Disease.” BMC Geriatrics, vol. 18, no. 146, 2018, online only.


Kinosian, Bruce, Darryl Wieland, Xiliang Gu, Eric Stallard, Ciaran S. Phibbs, and Orna Intrator. Validation of the JEN Frailty Index in the National Long-Term Care Survey Community Population: Identifying Functionally Impaired Older Adults aims Data. BMC Health Services Research, vol. 18, no. 1, 2018, online only.


Kutschar, Patrick, Martin Weichbold, and Jürgen Osterbrink. Effects of Age and Cognitive Function on Data Quality of Standardized Surveys in Nursing Home Populations. BMC Geriatrics, vol. 19, no. 244, 2019, online only.

Li, Minghui, Ilene Harris, and Z. Kevin Lu. “Differences in Proxy-Reported and Patient-Reported Outcomes: Assessing Health and Functional Status Among Medicare Beneficiaries.” *BMC Medical Research Methodology*, vol. 15, 2015, online only.


Scheffelaar, Aukelien, Nanne Bos, Mattanja Triemstra, Marjan de Jong, Katrien Luijkx, and Sandra van Dulmen. “Qualitative Instruments Involving Clients as Co-Researchers to Assess and Improve the Quality of Care Relationships in Long-Term Care: An Evaluation of Instruments to Enhance Client Participation in Quality Research.” BMJ Open, vol. 10, no. 2, 2020, online only.

Scheffelaar, Aukelien, Michelle Hendriks, Nanne Bos, Katrien Luijkx, and Sandra van Dulmen. “Protocol for a Participatory Study for Developing Qualitative Instruments Measuring the Quality of Long-Term Care Relationships.” BMJ Open, vol. 8, 2018, online only.

Scott, Jason, Emily Heavey, Justin Waring, Aoife De Brun, and Pamela Dawson. “Implementing a Survey for Patients to Provide Safety Experience Feedback Following a Care Transition: A Feasibility Study.” BMC Health Services Research, vol. 19, no. 613, 2019, online only.


2. Developmental, Intellectual, and Other Cognitive Impairments

a. Developmental and Intellectual Disabilities


Beetham, Kassia S., Anita C. Bundy, Shirley Wyver, Jo Ragen, Michelle Villeneuve, Paul Tranter, and Geraldine Naughton. “Construct Validity and Test-Retest Reliability of the Coping Inventory (CI) for Children with Developmental Disabilities.” *The American Journal of Occupational Therapy*, vol. 73, no. 4, 2019.


Caiels, James, Stacey Rand, Tanya Crowther, Grace Collins, and Julien Forder. “Exploring the Views of being a Proxy from the Perspective of Unpaid Carers and Paid Carers: Developing a Proxy Version of the Adult Social Care Outcomes Toolkit (ASCOT).” *BMC Health Services Research*, vol. 19, no. 201, 2019, online only.


Fellinger, Johannes, Magdalena Dall, Joachim Gerich, Maria Fellinger, Katharina Schossleitner, William J. Barbaresi, and Daniel Holzinger. “Is it Feasible to Assess Self-Reported Quality of Life in Individuals Who are Deaf and have Intellectual Disabilities?” *Social Psychiatry & Psychiatric Epidemiology*, vol. 56, no. 10, 2021, pp. 1881–1890.


II. Listing by Subject: Disability/Impairment Type


Pérez-Cruzado, David, and Antonio I. Cuesta-Vargas. “Improving Adherence Physical Activity with a Smartphone Application Based on Adults with Intellectual Disabilities (APPCOID).” *BMC Public Health*, vol. 13, no. 1, 2013, online only.


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Scheffelaar, Aukelien, Nanne Bos, Marjan de Jong, Mattanja Triemstra, Sandra van Dulmen, and Katrien Luijkx. “Lessons Learned from Participatory Research to Enhance Client Participation in Long-Term Care Research: A Multiple Case Study.” *Research Involvement and Engagement*, vol. 6, no. 1, 2020.

Scheffelaar, Aukelien, Nanne Bos, Mattanja Triemstra, Marjan de Jong, Katrien Luijkx, and Sandra van Dulmen. “Qualitative Instruments Involving Clients as Co-Researchers to Assess and Improve the Quality of Care Relationships in Long-Term Care: An Evaluation of Instruments to Enhance Client Participation in Quality Research.” *BMJ Open*, vol. 10, no. 2, 2020, online only.


II. Listing by Subject: Disability/Impairment Type


II. Listing by Subject: Disability/Impairment Type

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b. Dementia


Aguilar-Navarro, Sara, Alberto Mimenza-Alvarado, Rafael Martínez-Sánchez, Silvia Mejía-Arango, Lidia Gutiérrez-Gutiérrez, and José Alberto Ávila-Funes. “Spanish Validation and Cultural Adaptation of the Five-Word Test for the Detection of the Neurocognitive Disorder in Older Adults.” *Salud Mental*, vol. 42, no. 6, 2019, pp. 281–287.


Collins, Rachel, Anna Hunt, Catherine Quinn, Anthony Martyr, Claire Pentecost, and Linda Clare. “Methods and Approaches for Enhancing Communication with People with Moderate-to-Severe Dementia that can Facilitate their Inclusion in Research and Service Evaluation: Findings from the IDEAL Programme.” Dementia, vol. 21, no. 4, 2022, pp. 1135–1153.


Ding, Yunlong, Jiali Niu, Yanrong Zhang, Wenpeng Liu, Yan Zhou, Can Wei, and Yan Liu. “Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE) for Assessing the Severity of Dementia in Patients with Alzheimer’s Disease.” *BMC Geriatrics*, vol. 18, no. 146, 2018, online only.


Hartmann, Julia, Carola Roßmeier, Lina Riedl, Bianca Dorn, Julia Fischer, Till Slawik, Mareike Fleischhaker, Florentine Hartmann, Silvia Egert-Schwender, Victoria Kehl, Bernhard Haller, Helga Schneider-Schelte, Andreas Dinkel, Ralf J. Jox, and Janine Diehl-Schmid. “Quality of Life in Advanced Dementia with Late Onset, Young Onset, and very Young Onset.” *Journal of Alzheimer’s Disease*, vol. 80, no. 1, 2021, pp. 283–297.


Kutschar, Patrick, Martin Weichbold, and Jürgen Osterbrink. “Effects of Age and Cognitive Function on Data Quality of Standardized Surveys in Nursing Home Populations.” *BMC Geriatrics*, vol. 19, no. 244, 2019, online only.

II. Listing by Subject: Disability/Impairment Type


II. Listing by Subject: Disability/Impairment Type


c. Learning Disabilities


II. Listing by Subject: Disability/Impairment Type


d. Traumatic Brain Injury


e. Other Cognitive Disabilities


II. Listing by Subject: Disability/Impairment Type


3. Sensory and Communication Impairments


a. Blindness and Low Vision


Elsman, Ellen Bernadette Maria, Gerardus Hermanus Maria Bartholomeus van Rens, and Ruth Marie Antoinette van Nispen. “Psychometric Properties of a New Intake Questionnaire for Visually Impaired Young Adults: The Participation and Activity Inventory for Young Adults (PAI-YA).” PLoS ONE, vol. 13, no. 8, 2018, online only.


b. Hearing Loss and Deafness


c. Autism Spectrum Disorder


d. Communication and Speech Impairments

Anglade, Carole, Michel Tousignant, and Isabelle Gaboury. “Rigorous Qualitative Research Involving Data Collected Remotely from People with Communication Disorders: Experience from a Telerehabilitation Trial.” *Neurorehabilitation and Neural Repair*, vol. 36, no. 8, 2022, pp. 557–564.


II. Listing by Subject: Disability/Impairment Type


4. Physical Impairments

a. Musculoskeletal Conditions


Fekete, Christine, Wolfgang Segerer, Armin Gemperli, and Martin W.G. Brinkhof. “Participation Rates, Response Bias and Response Behaviours in the Community Survey of the Swiss Spinal Cord Injury Cohort Study (SwiSCI).” *BMC Medical Research Methodology*, vol. 15, 2015, online only.


O’Halloran, Paul D., Jason Holden, Jeff Breckon, Megan Davidson, Wenny Rahayu, Melissa Monfries, and Nicholas F. Taylor. “Embedded Motivational Interviewing Combined with a Smartphone App to Increase Physical Activity in People with Sub-Acute Low Back Pain: Study Protocol of a Cluster Randomised Control Trial.” *Contemporary Clinical Trials Communications*, vol. 17, 2020, article no. 100511.


II. Listing by Subject: Disability/Impairment Type


b. Epilepsy

Egger-Rainer, Andrea, Stefan Lorenzl, and Eugen Trinka. “Considerations in Preparing a Multicenter Study: Lessons Learned from the Epilepsy Monitoring Unit Comfort Questionnaire (EMUCQ) Validation Feasibility Study.” *Epilepsy & Behavior*, vol. 98, 2019, pp. 53–58.


c. Muscular Dystrophy and Multiple Sclerosis


d. Other Physical Disabilities


Chen, Szu-Wei, Megen Devine, Marian Keglovits, and Susan Stark. “Phone Or Email Survey: How do Demographics of People Aging with Long-Term Physical Disability Associate with Survey Format Choice?” *Archives of Physical Medicine and Rehabilitation*, vol. 102, no. 10, 2021, p. e42.


Olsen, Sara H., Sandra L. Saperstein, and Robert S. Gold. “Content and Feature Preferences for a Physical Activity App for Adults with Physical Disabilities: Focus Group Study.” *JMIR mHealth and uHealth*, vol. 7, no. 10, 2019, online only.


Vasudevan, Vijay, James H. Rimmer, and Frederick Kviz. “Development of the Barriers to Physical Activity Questionnaire for People with Mobility Impairments.” *Disability and Health Journal*, vol. 8, no. 4, 2015, pp. 547–556.


5. Psychiatric Impairments and Mental Health


II. Listing by Subject: Disability/Impairment Type


Scheffelaar, Aukelien, Nanne Bos, Marjan de Jong, Mattanja Triemstra, Sandra van Dulmen, and Katrien Luijkx. “Lessons Learned from Participatory Research to Enhance Client Participation in Long-Term Care Research: A Multiple Case Study.” *Research Involvement and Engagement*, vol. 6, no. 27, 2020, online only.

Scheffelaar, Aukelien, Nanne Bos, Mattanja Triemstra, Marjan de Jong, Katrien Luijkx, and Sandra van Dulmen. “Qualitative Instruments Involving Clients as Co-Researchers to Assess and Improve the Quality of Care Relationships in Long-Term Care: An Evaluation of Instruments to Enhance Client Participation in Quality Research.” *BMJ Open*, vol. 10, no. 2, 2020, online only.


a. Anxiety Disorders and Post-Traumatic Stress Disorder


Axelsson, Erland, Elin Lindsäter, Brjánn Ljótsson, Erik Andersson, and Erik Hedman-Lagerlöf. “The 12-Item Self-Report World Health Organization Disability Assessment Schedule (WHODAS) 2.0 Administered Via the Internet to Individuals with Anxiety and Stress Disorders: A Psychometric Investigation Based on Data from Two Clinical Trials.” *JMIR Mental Health*, vol. 4, no. 4, 2017, online only.


II. Listing by Subject: Disability/Impairment Type


Scheffelaar, Aukelien, Michelle Hendriks, Nanne Bos, Katrien Luijkx, and Sandra van Dulmen. “Protocol for a Participatory Study for Developing Qualitative Instruments Measuring the Quality of Long-Term Care Relationships.” *BMJ Open*, vol. 8, 2018, online only.

b. Psychotic Disorders

Chia-Ting Su, Hong-Son Ng, Ai-Lun Yang, and Chung-Ying Lin. “Psychometric Evaluation of the Short Form 36 Health Survey (SF-36) and the World Health Organization Quality of Life Scale Brief Version (WHOQOL-BREF) for Patients with Schizophrenia.” *Psychological Assessment*, vol. 26, no. 3, 2014, pp. 980–989.


Scheffelaar, Aukelien, Michelle Hendriks, Nanne Bos, Katrien Luijkx, and Sandra van Dulmen. “Protocol for a Participatory Study for Developing Qualitative Instruments Measuring the Quality of Long-Term Care Relationships.” BMJ Open, vol. 8, 2018, online only.

c. Mood Disorders


II. Listing by Subject: Disability/Impairment Type


B. Data Collection

1. Data Collection Mode and Adaptive Technologies

a. Interviewer-Administered Surveys


Pugliese, Christopher Cornelius, Tandrea Hilliard, Coretta Mallery, Elizabeth Frentzel, Susan Raetzman and Beth Jackson. “Evaluating Survey Administration Mode in Individuals with Physical and Mental Challenges: Results from the Home and Community Based Services Experience of Care Survey Field Test.” Presented at the American Association for Public Opinion Research conference, Austin, TX, May 2016.


II. Listing by Subject: Data Collection


b. Self-Administered Surveys

Axelsson, Erland, Elin Lindsäter, Brjánn Ljótsson, Erik Andersson, and Erik Hedman-Lagerlöf. “The 12-Item Self-Report World Health Organization Disability Assessment Schedule (WHODAS) 2.0 Administered Via the Internet to Individuals with Anxiety and Stress Disorders: A Psychometric Investigation Based on Data from Two Clinical Trials.” *JMIR Mental Health*, vol. 4, no. 4, 2017, online only.


II. Listing by Subject: Data Collection


Fekete, Christine, Wolfgang Segerer, Armin Gemperli, and Martin W.G. Brinkhof. “Participation Rates, Response Bias and Response Behaviours in the Community Survey of the Swiss Spinal Cord Injury Cohort Study (SwiSCI).” BMC Medical Research Methodology, vol. 15, no. 80, 2015, online only.


Pugliese, Christopher Cornelius, Tandrea Hilliard, Coretta Mallery, Elizabeth Frentzel, Susan Raetzman and Beth Jackson. “Evaluating Survey Administration Mode in Individuals with Physical and Mental Challenges: Results from the Home and Community Based Services Experience of Care Survey Field Test.” Presented at the American Association for Public Opinion Research conference, Austin, TX, May 2016.
II. Listing by Subject: Data Collection


c. Ecological Momentary Assessments


II. Listing by Subject: Data Collection

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d. Mobile Device-Based Data Collection

Baric, Vedrana, Maria Andreassen, Annika Öhman, and Helena Hemmingsson. “Using an Interactive Digital Calendar with Mobile Phone Reminders by Senior People – A Focus Group Study.” *BMC Geriatrics*, vol. 19, no. 116, 2019, online only.


Pérez-Cruzado, David, and Antonio I. Cuesta-Vargas. “Improving Adherence Physical Activity with a Smartphone Application Based on Adults with Intellectual Disabilities (APPCOID).” *BMC Public Health*, vol. 13, no. 1173, 2013, online only.


e. Assistive Technologies


II. Listing by Subject: Data Collection


2 Interviewing Techniques and Interviewer Effects


### 3. Proxies


4. Inclusive Strategies and Participatory Action Research


Burch, Leah. “‘We Shouldn’t be Told to Shut Up, We Should be Told We Can Speak Out’: Reflections on Using Arts-Based Methods to Research Disability Hate Crime.” *Qualitative Social Work*, 2021.


Collins, Rachel, Anna Hunt, Catherine Quinn, Anthony Martyr, Claire Pentecost, and Linda Clare. “Methods and Approaches for Enhancing Communication with People with Moderate-to-Severe Dementia that can Facilitate their Inclusion in Research and Service Evaluation: Findings from the IDEAL Programme.” *Dementia*, vol. 21, no. 4, 2022, pp. 1135–1153.


II. Listing by Subject: Data Collection

Mathematica


Scheffelaar, Aukelien, Nanne Bos, Mattanja Triemstra, Marjan de Jong, Katrien Luijkx, and Sandra van Dulmen. “Qualitative Instruments Involving Clients as Co-Researchers to Assess and Improve the Quality of Care Relationships in Long-Term Care: An Evaluation of Instruments to Enhance Client Participation in Quality Research.” BMJ Open, vol. 10, no. 2, 2020, online only.


Underwood, Kathryn, Cherry Chan, Donna Koller, and Angela Valeo. “Understanding Young Children’s Capabilities: Approaches to Interviews with Young Children Experiencing Disability.” *Child Care in Practice*, vol. 21, no. 3, 2015, pp. 220–237.


Van Schelven, Femke, Hennie Boeije, Maj-Britt Inhulsen, Jane Sattoe, and Jany Rademakers. “‘We Know What We Are Talking About’: Experiences of Young People with a Chronic Condition Involved in a Participatory Youth Panel and Their Perceived Impact.” *Child Care in Practice*, vol. 27, issue 2, 2021, pp. 191-207.

Vlot-van Anrooij, Kristel, Hilde Tobi, Thessa I.M. Hilgenkamp, Geraline L. Leusink, and Jennene Naaldenberg. “Self-Reported Measures in Health Research for People with Intellectual Disabilities: An Inclusive Pilot Study on Suitability and Reliability.” *BMC Medical Research Methodology*, vol. 18, no. 80, 2018, online only.


5. Qualitative Methods


Baric, Vedrana, Maria Andreassen, Annika Öhman, and Helena Hemmingsson. “Using an Interactive Digital Calendar with Mobile Phone Reminders by Senior People – A Focus Group Study.” BMC Geriatrics, vol. 19, no. 116, 2019, online only.


Fales, April S., Yasmin S. Cypel, Marsha E. Dunn, Ann L. Truelove, Erick K. Ishii, Aaron I. Schneiderman, and Victoria J. Davey. “Qualitative Interviewing: Testing Health Surveys Among Vietnam War Veterans at the Age of 70 Years.” *SAGE Open*, vol. 9, no. 1, 2019, online only.


Lindsay, Sally. “A Comparative Analysis of Data Quality in Online Zoom Versus Phone Interviews: An Example of Youth with and without Disabilities.” *SAGE Open*, vol. 12, no. 4, 2022.


Olsen, Sara H., Sandra L. Saperstein, and Robert S. Gold. “Content and Feature Preferences for a Physical Activity App for Adults with Physical Disabilities: Focus Group Study.” *JMIR mHealth and uHealth*, vol. 7, no. 10, 2019, online only.


Scheffelaar, Aukelien, Michelle Hendriks, Nanne Bos, Katrien Luijkx, and Sandra van Dulmen. “Protocol for a Participatory Study for Developing Qualitative Instruments Measuring the Quality of Long-Term Care Relationships.” *BMJ Open*, vol. 8, 2018, online only.


C. Questionnaire Design and Measurement

1. Developing and Validating Measures and Instruments

Aguilar-Navarro, Sara, Alberto Mimenza-Alvarado, Rafael Martínez-Sánchez, Silvia Mejía-Arango, Lidia Gutiérrez-Gutiérrez, and José Alberto Ávila-Funes. “Spanish Validation and Cultural Adaptation of the Five-Word Test for the Detection of the Neurocognitive Disorder in Older Adults.” *Salud Mental*, vol. 42, no. 6, 2019, pp. 281–287.


II. Listing by Subject: Questionnaire Design and Management


Axelsson, Erland, Elin Lindsäter, Brjánn Ljótsson, Erik Andersson, and Erik Hedman-Lagerlöf. “The 12-Item Self-Report World Health Organization Disability Assessment Schedule (WHODAS) 2.0 Administered Via the Internet to Individuals with Anxiety and Stress Disorders: A Psychometric Investigation Based on Data from Two Clinical Trials.” *JMIR Mental Health*, vol. 4, no. 4, 2017, online only.


II. Listing by Subject: Questionnaire Design and Management

Beetham, Kassia S., Anita C. Bundy, Shirley Wyver, Jo Ragen, Michelle Villeneuve, Paul Tranter, and Geraldine Naughton. “Construct Validity and Test-Retest Reliability of the Coping Inventory (CI) for Children with Developmental Disabilities.” *The American Journal of Occupational Therapy*, vol. 73, no. 4, 2019.


Buz, José, and María Cortés-Rodríguez. “Measurement of the Severity of Disability in Community-Dwelling Adults and Older Adults: Interval-Level Measures for Accurate Comparisons in Large Survey Data Sets.” *BMJ Open*, vol. 6, no. 9, 2016, online only.


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Fales, April S., Yasmin S. Cypel, Marsha E. Dunn, Ann L. Truelove, Erick K. Ishii, Aaron I. Schneiderman, and Victoria J. Davey. “Qualitative Interviewing: Testing Health Surveys Among Vietnam War Veterans at the Age of 70 Years.” *SAGE Open*, vol. 9, no. 1, 2019, online only.


Fekete, Christine, Wolfgang Segerer, Armin Gemperli, and Martin W.G. Brinkhof. “Participation Rates, Response Bias and Response Behaviours in the Community Survey of the Swiss Spinal Cord Injury Cohort Study (SwiSCI).” BMC Medical Research Methodology, vol. 15, no. 80, 2015, online only.


II. Listing by Subject: Questionnaire Design and Management


II. Listing by Subject: Questionnaire Design and Management

Mathematica


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F. Ongoing National Surveys

1. American Community Survey (ACS)


II. Listing by Subject: Ongoing National Surveys


3. National Health Interview Survey (NHIS)


II. Listing by Subject: Ongoing National Surveys


4. National Health and Nutrition Examination Survey (NHANES)


5. Survey of Income and Program Participation (SIPP)

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