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## CONTENTS

### CHAPTER I. INTRODUCTION

- A. Overview ........................................... 1
- B. Development of the compendium ........... 3
- C. Contact information .............................. 4

### CHAPTER II. LISTING BY SUBJECT

- A. Disability/Impairment Type ................. 5
  1. Aging and Later-Life Disabilities ............... 5
  2. Developmental, Intellectual, and Other Cognitive Impairments ................. 9
  3. Sensory and Communication Impairments ....... 21
  4. Physical Impairments ............................. 25
  5. Psychiatric Impairments and Mental Health .... 31
- B. Data Collection .................................. 35
  1. Data Collection Mode and Adaptive Technologies ......................... 35
  2. Interviewing Techniques and Interviewer Effects ......................... 42
  3. Proxies ............................................. 43
  4. Inclusive Strategies and Participatory Action Research .................. 46
  5. Qualitative Methods ................................ 52
- C. Questionnaire Design and Measurement ........ 57
  1. Developing and Validating Measures and Instruments .................. 57
  2. Measuring Satisfaction and Quality of Life .............................. 69
- D. Sampling and Nonresponse ..................... 74
- E. Special Populations .............................. 76
  1. Children and Youth with Disabilities ......................... 76
  2. Veterans Populations ................................ 82
- F. Ongoing National Surveys ......................... 83
  1. American Community Survey (ACS) ......................... 83
  2. Current Population Survey (CPS) ......................... 84
  3. National Health Interview Survey (NHIS) ......................... 84

### CHAPTER III. LISTING BY AUTHOR

- ................................................................. 85
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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, in 2019 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 2019 compendium, an indexed reference list, contains 220 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

After the publication of the 2019 version of the compendium, we have continued to gather references and articles across the topics listed above. In addition, we expanded the list of subjects by including references pertaining to three ongoing national surveys: the American Community Survey (ACS), the Current Population Survey (CPS), and the National Health Interview Survey (NHIS). The current version includes 113 new references, most of which were published in 2018 and 2019. In total, the 2020 Compendium on Disability Data Collection Method contains 333 references.

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

\(^1\) 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.
the references have been placed in all applicable categories, many of the sources are indexed under more than one subject.

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, Academic Search Premier in EBSCO and PsycINFO, and MEDLINE in ProQuest
- 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

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independent reviewer validated the decisions made by the team member who indexed the articles.

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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         SFeldman@mathematica-mpr.com
         Publications@mathematica-mpr.com
CHAPTER II. LISTING BY SUBJECT

A. Disability/Impairment Type

1. Aging and Later-Life Disabilities


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.


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.


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, 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.


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, online ahead of print.


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.


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.


II. Listing by Subject: Disability/Impairment Type


b. Dementia


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.


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.


c. Learning Disabilities


II. Listing by Subject: Disability/Impairment Type


d. Traumatic Brain Injury


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


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.


b. Epilepsy


c. Muscular Dystrophy and Multiple Sclerosis


d. Other Physical Disabilities


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


a. Anxiety Disorders and Post-Traumatic Stress Disorder

Axelsson, Erland, Elin Lindsäters, 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.


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


B. **Data Collection**

1. **Data Collection Mode and Adaptive Technologies**

   a. **Interviewer-Administered Surveys**


II. Listing by Subject: Data Collection

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.


b. Self-Administered Surveys

Axelsson, Erland, Elin Lindsätter, 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


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.


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.


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


II. Listing by Subject: Data Collection


3. Proxies


II. Listing by Subject: Data Collection


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, no. 62, 2015, online only.


4. Inclusive Strategies and Participatory Action Research


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.

Vlot-van Anrooij, Kristel, Hilde Tobi, Thessa I.M. Hilgenkamp, Geraline L. Leusink, and Jenneneke 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.


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.


II. Listing by Subject: Data Collection


C. Questionnaire Design and Measurement

1. Developing and Validating Measures and Instruments


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, online ahead of print.


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II. Listing by Subject: Questionnaire Design and Management

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II. Listing by Subject: Questionnaire Design and Management


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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: Questionnaire Design and Management


II. Listing by Subject: Questionnaire Design and Management


II. Listing by Subject: Questionnaire Design and Management


II. Listing by Subject: Questionnaire Design and Management


2. Measuring Satisfaction and Quality of Life


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.


II. Listing by Subject: Questionnaire Design and Management


Jespersen, Louise N., Susan I. Michelsen, Bjørn E. Holstein, Tine Tjørnhøj-Thomsen, and Pernille Due. “Conceptualization, Operationalization, and Content Validity of the EQOL-Questionnaire Measuring Quality of Life and Participation for Persons with Disabilities.” *Health and Quality of Life Outcomes*, vol. 16, no. 199, 2018, online only.


D. Sampling and Nonresponse


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.


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E. Special Populations

1. Children and Youth with 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, online ahead of print.


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II. Listing by Subject: Special Populations


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.


2. Veterans Populations


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.


F. Ongoing National Surveys

1. American Community Survey (ACS)


II. Listing by Subject: Special Populations

2. **Current Population Survey (CPS)**


3. **National Health Interview Survey (NHIS)**


CHAPTER III. LISTING BY AUTHOR


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.


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III. Listing by Author


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 from Claims Data.” BMC Health Services Research, vol. 18, no. 1, 2018, online only.


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III. Listing by Author

Mathematica


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